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The pendulum time of life. The experience of time, when living with severe incurable disease – a phenomenological study

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THE PENDULUM TIME OF LIFE

The experience of time, when living with severe incurable disease - a phenomenological and philosophical study

Abstract

The aim of this study was to gain a deeper understanding of the experience of time when living with severe incurable disease. A phenomenological and philosophical approach of description and deciphering were used. In our modern health care system there is an on-going focus on utilizing and recording the use of time, but less focus on the patient's experience of time, which highlights the need to explore the patients' experiences, particularly when life is vulnerable and time is limited. The empirical data consisted of 26 open-ended interviews with 23 participants receiving palliative care at home, in hospital or in a nursing home in Norway. The theoretical frameworks used are mainly based upon K. E. Løgstrup and K. Martinsens phenomenological philosophy in addition to C. Saunders' hospice philosophy, L. Feigenberg's thanatology and U. Qvarnström's research exploring patient's reactions to impending death. Experience of time is described as being a *movement that moves the individual towards death in the field of opposites*, and deciphered to be a universal, but a typical and unique experience emerging through three integrated levels: *Sense of time*; where time is described as a movement that is proceeding at varying speeds. *Relate to time*; where the awareness of limited life changes the understanding of time to be more existential. *Being in time*; where limited time seems to clarify the basic living conditions and phenomena of life. The existence of life when the prospect of death is present is characterized by emotional swings that move within polarizing dimensions which is reflected in the experience of time illustrated as the moves of the pendulum in a grandfather clock. The diversity of the experience of time is oscillating between going fast or slow, being busy or calm, being unpredictable but predictable, safe or unsafe and between being good or bad, depending on the embodied situation of the individual.

Keywords: experience of time, end of life, palliative care, phenomenology, philosophy, phenomena of life, polarizing dimensions.

INTRODUCTION

It is a common observation that the most elementary phenomena of existence are the ones we are least aware of (Løgstrup 1997, p16). Researchers at Oxford University Press have found that the word "time" is the most commonly used noun in the English language (BBC News 2006), daily we use the word but with different meanings. Even if we all talk about time and relate to time defining time in a non-controversial manner consistently has challenged even the greatest of scholars. Still today it seems like St. Augustine's (354-430) famous quotation "I do know what time is, but do not know how to put what I know into words", are relevant (cited in Ellingsen et al 2013a).

Although we cannot see time we see and hear everything that happens in time, all that which is created, changed, annihilated becoming nothing as a consequence of the passage of time (Martinsen, 2012, p.117-23). Time affects our life, illustrated by the lyrics in "Time Waits for No One" by the Rolling Stones:

"Time can tear down a building or destroy a woman's face. Hours are like diamonds, don't let them waste. And time waits for no one, and it won't wait for me..." (Jagger and Richards, 1974)

In palliative care there can be moments that can shine like diamonds while simultaneously there are ever present the destructive effect of the passage of time. According to Cicely Saunders (2003), the founder of the modern hospice movement, facing death is an individual journey but takes place across a similar map, stating that what is learned from patients facing death can have impact on ordinary living (p.9, 19). In our modern healthcare there has been a rather unilateral focus on how to utilize and record use of time (Martinsen 2002 p. 250-71). The purpose of this phenomenological and philosophical study is to explore the diversity of time as it is experienced when time is limited.

BACKGROUND

Entering palliative care is often associated with an expectancy that the patient may die within the next months or weeks (Slatten et al., 2010). Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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, both physical, psychosocial and spiritual (World Health Organization, 2013). In palliative care the quality of time is of great interest, illustrated by Cicely Saunders often quoted statement:

“You matter to the last moment of your life. We will do all we can not only to help you to die peacefully, but also to live until you die“ (Saunders, & Clark, 2006,,p.137).

Saunders work in palliative care is pioneering (Clark, 2007). Through engagement and a systematic approach she developed knowledge about how to relieve painful symptoms, stressing the need for a multidisciplinary approach because of the complexity of being in this situation. She also emphasized the importance of maintaining a sentient presence and to add feelings and intuitive thinking to the discourse of palliative care in order to fully comprehend the reality of another person in need. It involves looking continuously at the patients, not at their need but at their courage; not at their dependence but at their dignity. It includes the family, the mind, and the spirit as well as the care of the body, being so interwoven that it is hard to consider them separately (Saunders 1978, p.194). She applied the phrase “*Watch with me*” to the philosophy of palliative care making reference to the Gospel and the Garden scene at Gethsemane (Matthew 26, 36-45). Real watching means to be looking at the patient with compassion, learning what this kind of pain is like, what these symptoms are like, and from this knowledge finding out how to relieve them. But the phrase also means a lot more that cannot be directly understood; those words did not mean understanding everything that is happening, explaining or taking away when they were first spoken, but to be present, even if we feel that there is nothing to do (Saunders 2003, p.1,2,4). However, palliative care, like

curative therapy, demands much activity where the opportunity to be present is challenged and the quietness of “presence” seems to have been over-ridden (Saunders, 2003, Saunders and Clark, 2006). The science of palliative care has undergone rapid developments, particularly in relieving of distressing symptoms (Borreani et al., 2004, Clark, 2007, Sigurdardottir et al., 2012), yet, there is less research focusing on the lived experience of time when death is expected. According to Rasmussen & Elverdam (2007), the experience of time is under-researched and theoretically underdeveloped in nursing and by nurses.

Theoretical perspective

Time is of great interest in phenomenological philosophy. The founder of modern phenomenology Edmund Husserl claims that analysis of pure subjective time-consciousness is extraordinarily difficult and open to contradictions, particularly when it comes to exclude the notion of objective time (Husserl, 1965, p.21-7). While Husserl analyzed how time appeared in our consciousness, Martin Heidegger explored the phenomenon of time in relation to our being in the world. Our being cannot be separated or seen independently of the world. This relationship is so fundamental that Heidegger put a hyphen between the words. Being is being-in-the-world and being is time itself; we are temporally being –in-the-world, moving towards death (Heidegger, 1992, p.1E-18E). In his masterpiece `Being and Time`, he wants to show that being in time not only is a prerequisite for all understanding, but also constitutes the basis for human existence (Holm-Hansen, 2007, s.16). In daily life, we are prospective or `futural` in our way of being-in-the-world, preoccupied and concerned about our doings, and what to do, often to such an extent that we do not reflect on our being-in-the-world. “By the term `futural`, we do not have in view a `` now``, but what next to happen. In the face of our own death, when the future becomes absent, the `` now`` is extended, giving our being-in-the-world the ultimate possibility to authentically encounter with itself (Heidegger, 1962, p.370-80).

This study is mainly influenced by the phenomenological work to the Danish theologian and philosopher Knud Eiler Løgstrup (1905 – 1981) and the Norwegian nurse and philosopher Kari Martinsen who relates Løgstrup`s theory to nursing (Alvsvåg, 2010, p.165-187). Løgstrup refers to among others Husserl (1964) and Heidegger (1962), but adds a new and original perspective by claiming that our experience of time has its origin in what is independent of us and is created in a resistance or revolt against the linear irreversibility of time that moves us towards annihilation (Løgstrup, 1978, p.11-44). According to Løgstrup space and time are the external universal conditions of our existence, which make everything in our existence contradictory and in opposition. Time is irreversible and linear while we are embedded with our respiration and metabolism in the circadian cycle of the earth (Løgstrup, 1984, p.11, 15. 1987, p. 19, 28-43). Without change, there is no time, but without the seeming stability of the universe we would have no sense of time (Løgstrup, 1978, p.37). Life comes alive when opposing tendencies collide and influence one another, and in this tension the different phenomena of life, such as time, become apparent (Løgstrup, 1978, p.124). Løgstrup distinguishes between unified and disjointed opposites; the unified oppositions are phenomena that are distinct but interdependent by mutually reinforcing each other in their diversity, while the disjointed opposites suppress or expel its opponent out (Martinsen, 2012, p37-8). There are some universal situations in life, where some general emotions appear such as hope and grief in the face of death. The feelings are at once universal but individual: universal in what it reveals, individual in what the occasion concerns because of the irreversibility of time (Løgstrup, 1983,p. 63-4).

According Løgstrup we are sentient receiving. Sensing and understanding are unified opposites that are so closely connected that it is difficult to separate them. The sense impression that moves the mind occurs in an embodied fictitious space where the impression

is formed into an understanding that wants to be expressed (Løgstrup, 1978, p.33-45, 1983, p.9,10, 1984, p.11,19).

According to Martinsen (2012) philosophy can help to illuminate the fields that have been in the dark by questioning what is taken for granted. Then we can move closer to what is most important within existence (p.18-20). Martinsen`s phenomenological and philosophical work deals with care, focusing on the patients` vulnerability. She describes care as a trinity:

relational, practical and moral, and a fundamental precondition for life and stresses that time, care and vulnerability are all interrelated (Alvsvåg 2010, 173-4, Martinsen, 2003b, p.14-21).

Our relationship to time determines and marks the atmosphere at the place and impacts upon our openness to the world. Today, health care and hospitals are affected by a constant bustle and an ever increasing demand for fast throughput of patients, which can lead to over activity even in the encounter between the health worker and the patient (Martinsen,2002, p. 250-71),.

Martinsen outlines two types of bustle which impact on how we act towards the other in need: being busy, preoccupied doing a task in relation to a time-schedule, and being sentient present and busy alleviating the patients` suffering (Kjær and Martinsen, 2012, p.8).

According to Martinsen (2012) it is an illusion to think that we can master time. In revolting against the time that passes independently of us, we experience the condition which time allows us to live within, with its life-giving powers, which we sense and which we nourish our lives on, gaining some time off from the annihilation of time (2012, p 121-3). We are not objectively present in the world, but always tuned in a mood or a spirit where the sense impressions can cheer us up but also make us feel downcast (Martinsen, 2012, p.48). We are touched and moved through sensing; sensing provides an independent access to the world regardless of our understanding. While sensing is related to presence in the situation, our understanding of a situation may be at a distance and are linked to our preconceptions in

which cultures and knowledge are embedded (Martinsen, 2006, p.67-8, Kjær and Martinsen, 2012, p.12-13).

Literature research

Since life is finite, temporality as opposed to objective time or clock time, has been offered as a concept more appropriate to describing the lived experience of time (Caldas and Bertero, 2012). According to the Swedish doctor Loma Feigenberg (1980, p. 11-32) the very thought of death presupposes time. In his thanatology he presents 12 polarizing dimensions where the dimension of time is the first and the most important. In the face of death time becomes increasingly disconnected from chronological time, which loses its significance. The habitual and conventional idea of chronological time as a linear, everlasting process is now broken up by the patient and the medical staff into sections or intervals between meals, nursing shifts, visits or painkilling drugs. All that is left to the dying person is the situation of dying and their existential time. Existential time is the expression of the personal meaning of what happens to a human being in the present.

The Swedish nurse Ulla Qvarnström used Feigenbergs thanatology as a model, emphasizing that our reactions to impending death move in a field of seven different dichotomous dimensions. These are: rebellion and submission, acceptance and protest, hope and despair, identity and resolution, dignity and humiliation, regeneration and regression, security and insecurity. In this interaction of opposites, the emotions change depending on where the pendulum swings, the feeling may not only be either one or the other but may be influenced by both dimensions simultaneously; the patient may want to die but may also want to live, feel hope but also resignation (Qvarnstrom, 1979, p.71-91, 1982). To be moved in a tension between opposites is also highlighted in recent research. Sand et al., (2009), describes the coping strategies in the presence of one's own impending death from cancer as a cognitive and emotional pendulum, swinging between the extremes of life and death. Dalgaard (2007) emphasizes that in the scenario of death the individual and the family moves between loss and

self-expression, predictability and unpredictability, between life-facilitating and life-limited phenomena. Saeteren et al (2011) highlights how people living with serious cancer disease may try to hold on to life while living in the tension between the possibility of life and the necessity of death. La Cour et al, (2007, 2009 a, b, 2011) describe how humans strive for an authentic being toward death, through engagement in daily living, while living in a dialectic oscillation between health and suffering.

Nurminen (2009) emphasizes how the multidimensional nature of time provide us with interpretations of dimensions, layers and levels, where the existential level emerges in a dialogical movement between health and suffering elucidating the double nature of time through the shaped movement of outer time and the hidden movement of inner time.

Time is also emphasized as an important contextual factor in palliative care. When the structural frame of clock time and personal time co-exist harmoniously, nurse and patient may meet in a shared reality in which the professionals presence is characterized by a flexibility that encourages a contextualized and individualized care in which the nurses doing and being represent states of open attentiveness (Dalgaard and Delmar, 2008). According to Thorsen et al (2011) the change from hospice to palliative care and medicine has implied much more than just a new name. Improved medical knowledge means improved symptomatic palliation, but time and resources are spent in other ways than before. Observations from a Nordic hospice ward indicate that seriously ill and dying persons spend much time on their own. Better symptomatic treatment is valuable and needed, but extended medicalization takes a lot of time and attention. It was rarely observed that nurse attending a patient`s room without carrying medicine or objects relating to treatment. The nurses spending time with the patient without a goal or purpose was rare. Ellingsen et al (2013 a,b), emphasizes the impact of the health workers' relation to time on the atmosphere of the place. The place is in various ways marked by time that either can promote or restrict the opportunity for self-expression.

According to Delmar (2006a) life phenomena are fundamental experiences in life understood as generalized labels for the various ethical and existential phenomena which are given with life itself distinguishing between life-facilitating phenomena, where life flourishes and life-limiting phenomena that break life down, such as loneliness, homelessness, fatigue and pain (Delmar, 2006a). There is a duality in situations; a situation is typical because in relationships there will always be some typical features which are recognizable from previous situations, but also unique, because of the irreversibility of time (Delmar, 2006b, p.25). To recognize the difference between being and doing is emphasized by Toombs (1988, 1990, 2004) as an important step in preserving self-worth when illness strikes at the fundamental features of embodiment that transform the nature of being, representing dis-ability and a dis-ease to engage in the world in a habitual way.

STUDY AIM, DESIGN AND METHOD

The aim of this study was to describe and decipher the embodied experience of time when living with severe incurable disease, using a phenomenological philosophical approach of wondering over the immediate expression of time experience that manifests itself in diversity and nuances. A qualitative interview is considered a suitable method for patient receiving palliative care (Gysels et al., 2008). By using unstructured in depth interviews it was assumed that it was possible to gain access to the patient's lived experience of time.

Sample and interview

Data consisted of 26 tape recorded interviews from 23 respondents, 9 men and 14 women, receiving palliative care in western Norway. Three of the participants were interviewed twice because they wanted to talk more about the subject. All but one was diagnosed with severe incurable cancer. The physical appearance of the disease varied; most respondents were

clearly marked by their illness and mostly confined to their beds, while some were more able and mobile. The number of interviews conducted was determined by the amount, variation and saturation of information received. The interviews were carried out from April 2009 to February 2010.

Inclusion Criteria

Participants were selected on the basis of meeting the following inclusion criteria:

- Having a severe incurable disease, receiving palliative care.
- Over 18 years of age.
- Participants had mental capacity.
- Able to manage an interview.
- Able to speak and understand Norwegian.
- Participants were receiving care in any of the following settings; palliative daycare units, In-patient hospital palliative care units, palliative nursing home units, and private homes.

Table 1 (see last page)

The nurse and doctor in charge of the ward organized and selected the sample on the basis of the inclusion criteria, distributed written information and gained initial consent. The first contact the researcher made with respondents was when they had agreed to participate, liaising directly with the participants to arrange a suitable 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 also conducted in accordance with the guidelines issued by these institutions and with the World Medical Association (WMA) declaration of Helsinki (2013).

The Interview

The interview was carried out face to face in the respondent's home or in a palliative care unit. Respondents from the Palliative day-care unit were interviewed in a private room allocated for interviewing; the other respondents from Palliative care bedded units were interviewed in the patient's room, while respondents at home were interviewed in their living room. Except for one interview, where the spouse was present, participant 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 self-reported diagnosis were recorded. The issue of time was raised in an open-ended initial question: *Can you in your own words tell me what you are thinking when you hear the word time?* This open ended question and the subsequent responses led to further questions. A number of themes or prompts were used. These included the exploration of duration, rhythm, quantity and quality of time and the impact of time in connection to context, care, attitude and progression of disease. These general prompts were used as necessary to maintain the focus on the topic of interest. During the interview there was a need to be aware and sensitive to the physical limitations of participant such as breathlessness when answering questions and exhaustion or ability to complete the interview.

A phenomenological philosophical approach of describing and deciphering

The interviews were analyzed through the method of phenomenological describing and deciphering which is using a philosophical wondering approach to the lived experience of time. Decipher means to move between sensing and understanding, where the understanding is subject to sensing (Martinsen, 2012, p.14). According to Martinsen (2006) the tone of voice is in itself an utterance. The voice may have a distressed, depressed, ironic, happy or excited

tone that gives the spoken word emphasis. The tone expresses and conveys feelings, attitudes and a mood providing a sense of what is essential to the individual (p.60). To decipher is to follow the words into their many twists and to explore different levels of importance to get the impression clarified. It is to discover the unexpected in the familiar and to understand the one in terms of the other to clarify differences (Martinsen, 2003a, p.114). This is a slow process remaining close to the lived experience allowing the researchers to remain in indefiniteness for as long as possible trying to capture and understand the impression as it presents itself (Dahlberg and Dahlberg, 2003). Løgstrup (1987) emphasizes that the movement of mind is full of dormant realization, having a sense of something is the beginning of insight.

Concentration has to be maintained by an incessant desire to allow the adequate expression to unfold by giving oneself enough time, not rushing to the conclusion. If one hurries too quickly to the conclusion the movement of mind stops, the sense of something shrinks and the insight may disappear before it has unfolded (p.128).

The analyzing process of deciphering has been a movement back and forth between the followings:

1. During the interview maintaining sensory awareness not only to the meaning of the words, but also of the tone conveying the words, since the tone may express something of importance.
2. Transcribe the interviews verbatim, noting down the impression of the tone of voice, and the immediate thoughts that arise.
3. Read the interviews with a wondering and open attitude to what presents itself.
4. Discuss the content of the transcribed interviews within the research group.
5. Read relevant theory and research, write and reflect, read more, rewrite and reflect over and over again.

6. Discuss reflections within the research group and with other colleagues, health professionals, friends and patients. Note if the deciphering gives a phenomenological nod of recognition.

In what follows, some selected quotes that have touched and made impression on the researchers will be described. Pseudonym names have been given to each participant.

The quotes are deciphered and discussed in light of Løgstrup`s (1987) and Martinsen`s (2003a) phenomenological philosophical perspective in addition to Saunders` hospice philosophy, Feigenberg`s (1980) thanatology and Qvarnström`s (1979,1982) research into patient`s reactions to impending death.

THE TUNED VOICE OF THE RESPONDENTS

In a wondering approach to the respondents' descriptions the experience of time appeared as; a movement that moves the individual towards death where the quality of the time emerges in a field of opposites. This was revealed through three coinciding aspects: Time as a movement. Time moves the individual towards death. The quality of time becomes apparent in a field of opposite phenomenon of life.

Time as a movement

The description of time was immediately recognizable in statements like time was 'going` or `passing` but at different speeds, as exemplified by Olav:

“It is absolutely amazing how fast time goes by. And especially after I got sick, things have gone faster, I do not know where time has gone this year.”

The description of time as a movement was ambiguous as it referred to both external and internal conditions. The description of time as `going` was related to external conditions, while the sense of speed in this passage was bodily connected to being sick, and given a meaning in relation to the opposite experience of a slow time, but also to what one was doing, what was happening and to life being limited. Anna described the following:

“And even if I lie like this, time passes quickly. Even if I lie, it's very strange, because there are many who wonder if I am bored. So I say, no, not at all. I need time to sleep, or to browse in a newspaper or to do some very simple things. For the great things I cannot do anymore. Yet I do not feel that time is wasted.”

When embodied, living with severe illness it was prominent to the patient that time moved quickly, but the opposite was evident: the movement of time was also described as slow and boring, when seen in the context of the tuned mood of having little to do, expressed by Svein in a puzzled tone:

“And I am bored, and when I am bored, time passes slowly, but it is when I am bored I feel that I am alive. When I am bored, lying here doing nothing, time becomes meaningful in a way because boredom makes time stretch and makes me feel that I live. But when I introduce that dimension it also loses its meaningfulness, because when I realize that I'm bored, I reveal myself in a way. I destroy some of it by discovering it, as I become more aware of the time aspect. It is very difficult because it is when I am bored that I feel that I am alive.”

Having little to do puts the mind to work; in light of having limited time boredom appeared in a paradoxical way: when life is limited it feels good that time stretches out and passes slowly, while at the same time being boring.

Time moves the individual towards death

To a person embodied with severe illness everyday living and the prospects of a future will change and also alter the relation to time as revealed by Tone:

“She (the doctor) said that I had such a bad prognosis, it was inoperable and so on and so forth, it was doubtful that I got to experience Christmas. There and then it was half a year. There and then I got really busy and I've been busy since.”

Somehow, the experience of time and life are connected. When realizing and experiencing that life is about to end, time appears limited. When it becomes clear that life is ending, it becomes very important to utilize the limited amount of time left.

“When you have a lot of lifetime it is not so important what you spend your time on, but when life is limited, it is important to spend time on things that have value” (Tone).

There is a huge difference between the general knowledge of being mortal and realizing that one's own life is about to end. To be informed that the disease is incurable and that time is limited created feelings of despair, expressed by Olav in an angry tone:

“Before I got sick then I heard about all the others and thought it was bad. But it was only when it affected me myself that I realized how small I was in this. It's like being thrown in a ditch, quite like that. You are just like a little shit, and you cannot do anything to change it.”

Being able to plan and take control of the limited time left can provide some predictability of time, but when embodied with severe illness and most things are unpredictable, it becomes very hard to remain punctual to a schedule of time. Finally holding control of time can be so overwhelming that it claims all the attention. This is described by Kari:

“I have always had control over my own life and always liked having that control, but have now reached a point where dropping the control is a release. Maintaining control finally took all my time and attention. Now, others have taken over the control and responsibility for me, which makes time open up for new opportunities to live within the present. To give up the control and feel safe is a relief which gives life new possibilities that makes it good to live.”

In this situation, giving up control can free up the attention to be present in the moment to what is of value to the individual. Gradually as the disease places constraints on normal living, the clock time loses its structural impact and appears as unsuitable for scheduling tasks despite one's noticing the structural significance of clock time for others. This is outlined by Anna:

“I'm not so concerned about the clock. I have it with me, but it doesn't govern my life. It's more for the others to come. More or less, I notice that some of them are good at putting it aside.”

Increasingly, it becomes the physical condition and not the time schedule that determines the possibility of interaction with others and of participating in activities and tasks during the day.

“I have found that there is only one thing to do and that's if I'm tired, so I sleep, if I'm hungry I eat. I am not trying to push away something; I am facing it me there and then” (Anna).

In the face of unpredictable embodied changes, one long for everyday to be the same as it used to, this was uniquely expressed by Olav in a despairing tone:

“So now I've just made it clear when I come home, when we are at home, we do not talk about disease whatsoever. We cut it out totally. It's not any discussion topic at all. We act, we act like a normal family and shall live as normal as possible. And that we have done, and it has worked fantastically well. And all of us agree, and we have talked a lot about death and all that, 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, they know he is not getting better, he is just getting worse.”

Olav wanted so desperately to live as before although life situation had changed. To carry on as before when living with severe illness is hard. Some are fighting a fierce battle to be able to do as before, although the body is becoming weaker and more deteriorated. The interconnectedness of doing and being becomes apparent when the ability to do as before is altered due to severe illness. The decline is articulated by Tone:

“I would love to be working. It kept me up. As long as I have the pressure on me that I have to get up, shower and freshen up every morning, I'm still me. Because what I see is that when I have bad days then I'll just stay in bed, or move at best onto to the couch, and then I think: I cannot have it like this, I will not have it like this. ... I have wonderful colleagues, I enjoy my job and I feel I'm doing a useful job. It has something to do with my,- what should I say, self-esteem. For me it's very important.”

To do is described as necessary so that one is not completely overwhelmed by the illness and this dominating the quality of time. In addition, doing is given a meaning associated with the role one holds, with one's self-respect and to how one would like others to perceive one to be.

This is expressed by Tone:

“I want so fervently that my relatives', children and grandchildren will remember me as a person who said and did as long as possible, that I did not change me as a person.”

The quality of time appears in a field of opposites

Time was not only described as a movement holding a variable speed but also to holding a varying quality that was associated with what happened as described by Tone:

“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.”

It seems as the quality of time is clarified and evidenced in light of the opposite quality as outlined by Kari:

“When I came in here everything was hopeless, the pain overwhelmed me and I did not want to live anymore. 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.”

The feelings are reflected in the experience of time, being overwhelmed by pain gives one a terrible time, while being relieved of pain can create a wonderful time. When one experiences that life is limited, it appears that the basic conditions of life such as feeling safe, become more prominent and elucidated as reflected by Kari:

“Feeling safe, is what determines whether the time is good or bad, as it always has been. What I want for this time 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 going to be about in the days to come.”

It seems like reduced ability to act as before in addition to an awareness of limited time sharpens the senses about the quality of time and makes one's being more prominent with all its nuances and opposites, beautifully expressed by Kari:

“Death's presence makes time very precious, intense, bright and nice, with lots of colors and sounds and smells. Time just is. The clock means nothing anymore. But sometimes when I am sad, death is not friendly anymore but heavy to carry.”

DECIPHERING AND DISCUSSION OF THE FINDINGS

According to Eriksen, (1999, p.254) it is not the clock that stops going but the heart that stops beating when time ceases to the individual. Our experience of time is embodied. In this section we present; *sense of time, relate to time and being in time* as three different but integrated levels that possess opposites and polarizing dimensions that are reflected in opposite time experiences illustrated by the pendulum move of a clock (Figure 1). The dial is an image of our time being temporal and limited. The pendulum refers to simultaneously being embedded in the circadian rhythm of repetition but the irreversible linear movement of change. The long case refers to a tuned fictitious space for wondering wherein the movement in the mind takes place and where the sensory impression of what is sensed is formed into an

understanding. The walls of the case indicate that our horizon for understanding has a limitation that is adjustable; we can be both open and narrow-minded.

The experience of time as a universal, but typical, unique and individual experience

The immediate recognition of the participants' descriptions of time as going fast or slow, having much or little time, being terrible or fantastic, gave rise to a wondering about the experience of time being simultaneously a universal, but typical and unique experience (Figure 2).

In a manner of speaking, we are like everyone, someone, and no one else at the same time.

Everyone is subject to the basic conditions of life, such as the passage of time, but we may

have a typical way of being that is recognizable in terms of culture, epoch, event and

situation. However, due to the irreversible and linear movement of time, each situation and

each of us are unique and singular like no one else, which means that we can never be sure of

what the other feels, thinks or means.

According to Løgstrup (1978) we use the words universal and general (typical)

interchangeably, this makes it possible to overlook a significant distinction. The word

'general' should be reserved for the statements that describe everyone in an open or closed

group, such as typical signs or symptoms that are recognizable when affected by severe

incurable illness. The word 'universal' should be reserved for what is the same in every

individual. 'Typical' is what can be said of all, in an open or closed group, such as typical

signs when living with incurable disease and receiving palliative care; while 'universal' is the

same for all of us (Løgstrup 1978, p. 121-154). The universal is present in individuals, but is

independent of time and place, in contrast to the unique and singular that are depended on

time and place (Løgstrup 1987 p.131). The universal is recognizable in a singular and

individual expression because it expresses something universal about being human (Løgstrup,

1997, p. 280-2). It is the universal condition of being subject to the irreversible and linear

movement of time which we recognize in the unique and singular description of time passing or going. However, the universal and singular experience of time may be typical for those who are in the same situation. This point gives meaning to the statement made by Saunders (2003, p.19) facing death is an individual journey but takes place across a similar map.

Sense of time

The basis of experience is sensing. Our access to the world, others and ourselves are based on our sensory impressions of whatever is seen, heard and felt (Toombs, 1988). According to Løgstrup (1984, p.15) senses have no distance even if we are in distance from what is sensed, we are not in distance to our eyes and ears. Although this is obvious it may be necessary to point out that sensing is embodied and always tuned, as Martinsen (2012, p.48) emphasizes we are not objectively but subjectively sentient in the world. Our participants' description of time as going refers to the universal condition of being subject to the passage of time; however, the variations of this experience are embodied and connected to the tuned life situation of the individual.

The pendulum movement between sensing and understanding

Sensing is not the same as understanding, but they are united. Sensing is related to the moment while the understanding has a time lapse. Understanding takes time, is linked to our preconceptions and knowledge and may take place at a distance from what is sensed (Kjær and Martinsen, 2012, p.12-13). We cannot see time in itself but we understand time through the sense impression of everything that is happening and unfolding in time (Martinsen, 2012, p.117-23). Time must be reflected in something concrete to be visible such as a building or a woman's face described in the text to the Rolling Stones song earlier. Without the movement of time, everything is like a fixed moment, just as in a snapshot where nothing moves or changes. Usually the pendulum moving between sensing and understanding are unnoticed, but

sometimes the sense impression can be so overwhelming that the pendulum movement between sensing and understanding halts. We can become totally caught or enclosed in a sense impression unable to make any sense of what is sensed, such as our participants` that were overwhelmed and enclosed in pain. But it can also mean the opposite; we can be so encapsulated within our understanding, so closed not to be moved by the sense impression. When this occurs our understanding will be characterized by deadlock and rigidity. However, the movement of time that creates a continuous change can restore the exchange between sensation and understanding and thus alter the experience of time.

Relate to time

To be informed about time, in the meaning of a point in time as given by a watch, is crucial to be able to function in a modern society. It is quite inconceivable to imagine employment, social life, and transportation without clock time as a structuring and synchronizing factor. The importance of clock time in our lives is so great that it dominates our understanding of time. However, time is an ambiguous term. To our participants' embodied with severe illness and gradually losing the ability to participate in normal life, the structuring and synchronizing function of clock time had lost its importance. In the face of death, time was associated with lifetime and existence. This shift in understanding of time gave everyday expressions such as; `to be busy`, and `have little time`, a significantly different meaning.

The pendulum movement between predictability and unpredictability

Our participants' highlighted *safety* as the most important element for the quality of time, wanting desperately to return to a life where every day was predictable, a longing for life as it used to be. To be simultaneously subject to the irreversible and linear passage of time and embedded in the earth's rhythm of rotation is to be caught in the tension between repetition and change. The Earth's rotation around its own axis gives us a circadian rhythm, with days that are coming but also going. Nature's cycle of repetition is embodied reflected in our

metabolism, breathing and heartbeat (Løgstrup, 1984, p11). Repetition characterizes our way of being; we sleep, eat and work over and over again. For the most part we live in a predictable manner with everyday events that repeat themselves day after day which means that we acquire routines and typical patterns of being. At the same time we are subject to the irreversible linear movement of time which means that in reality nothing that has passed can be repeated. The passage of time means a continuous change; we are all growing older with each passing day. Although the days are coming and going, yesterday will never return. Being embedded in the tension between repetition and change is to be moved within a polarizing dimension of predictability and unpredictability which is reflected in the experience of time. If life is characterized by too much predictability time may appear as safe but for some maybe a little boring. However, it can also be the opposite, if we are exposed to great changes, time can be experienced as unsafe and unpredictable.

The pendulum movement between resistance and acceptance

According Løgstrup (1978, p.28-32) we experience time or rebel against the movement of time that will inevitably lead us towards annihilation. As a paradox we want to live long, but resist aging. This resistance is evident in how we try to hide the signs of aging, a resistance that has brought the beauty industry and plastic surgery good fortune. In this resistance signs of aging are considered signs of decay. In our resistance against annihilation we try to hold back time by doing physical exercise and by creating traditions, habits, routines and rhythms where life is predictable. However, we are doomed to lose the race and battle with time. If our opposition to an avoidable change dominates, time can be saturated with a struggle against any change such as the respondents that wanted everything to be as it used to be when coming home, despite the fact of living with severe and progressive disease. In the opposite case, if the pendulum moves to the other extreme and all change are accepted, time may be colored by

discouragement, apathy and resignation where all the energy and desire to fight to sustain life may be absent.

Being in time

Our sense of time and the way we relate to time are included and reflected in our being. When time is understood as existential, the experience of time also conveys how it is to be in time, and as emphasized by both Saunders and Heidegger the significant in one's being becomes evident when time is limited (Saunders, 2003, p.9, Heidegger, 1962, p.370-80). When one's ability to do various activities are limited because of bodily weakness, one has a better opportunity to reflect on being. Our participants' descriptions of time as fast or slow, boring or meaningful, busy or quiet, terrible or fantastic, safe or unsafe, good or bad, were also descriptions of life being marked by opposites. However, this is a universal condition for all. Throughout life we are moved in a field of opposites, of polarizing or dichotomous dimensions; we are all approaching death, but as emphasized by Feigenberg (1980) and Qvarnström (1979, 1980) when approaching death and time is limited this pendulum move becomes evident.

The pendulum movement between doing and being

The participants' in this study had experienced great changes in what they could do physically and socially which was reflected in their being and experience of time. However, they wanted so desperately to be able to be active as before and struggled not to lose themselves when no longer being able to do what they used to, whether it was as an employee, family member or friend. What we have done, do and plan to do is often what we talk about with other people. Our doings position ourselves in the society and these have an impact on how we may be perceived to be. Our unique and distinctive way of being permeate our doings and what we do also characterizes our being. One can be so concerned, preoccupied and committed to doing that it overshadows our being or we can be so lost in being that one totally forgets the doing.

When we are bored, having little to do, or when we are engaged, busy or have too much to do these are reflected in our way of being and shape our experience of time. However, according to Toombs (2004) an important step in preserving self-worth in illness is to recognize the difference between being and doing.

The pendulum movement between life-facilitating and life-limiting phenomena

When time is limited, it is as if the universal phenomena of life are concentrated and clarified. It also seems like the true essence of a life`s phenomenon is revealed in its significance in the light of the opposite phenomenon. It is like the true meaning of happiness is only revealed against a backdrop of grief, as exemplified by our participant who had a terrible time being enclosed in pain, feeling that everything was hopeless, but after efficient pain relief was lying in bed smiling to herself having a wonderful time experiencing how good it was to live without pain.

CONCLUDING REMARKS

In the face of death the universal, typical, singular and unique experiences of time are revealed through a pendulum movement between opposites. How we experience time in the last phase of life is unique to each individual but reveals something of the universality of being. This may be the reason why Saunders (2003, p.9) stated that what is learned from the patients being in this situation can have impact on ordinary living.

How patients with severe incurable disease experiencing time is ambiguous and diverse as life itself, but embodied. The pendulum movement between sensing and understanding, which has its origin in the sense impression, is always contextual. The actual location where the patient is sets the tone for the sense impression and the social interaction at the place. There is a tension between the time experience of the dying person versus the time regime of the

institution, with its shifts, brakes, timekeeping and time management. While the patient is committed to being in the limited lifetime left, the healthcare worker is committed to doing in relation to the limited working hours. This is challenging for both sides as both can feel that there is not enough time either to be or to do. These tensions can make it challenging for both the patient and health worker to tune up after each other and to meet attuned in harmony in time at the place they are. The tension in this opposition can mark the encounter between patient and health worker with disharmony, but as emphasized by Dalgaard and Delmar (2008), if the structural frame of clock time and personal time co-exist harmoniously, the healthcare worker and patient may meet in a shared reality in which the professionals presence is characterized by a flexibility that encourages a contextualized and individualized care in which the healthcare workers doings and beings represent states of open attentiveness.

Limitations

Authors' background and the phenomenological philosophical perspective selected, provide a backdrop for how respondents' expressions are deciphered and described. However, the goal is that the deciphering should reveal something of the universal but also typical about the experience of time when living with severe incurable disease. The validity of the content will either be verified by the reader with a phenomenological nod of recognition or be judged as not valid in the absence of recognition (Munhall, 2012, p.523-4).

Relevance to clinical practice

In a health system with a constant demand for increased speed, it is challenging to be calm and attentive present. However, the health care worker's attitude and relation to time is reflected in the encounter with the patient, and is important for whether the patient feels seen or overlooked, heard or ignored. The task for the health care worker is to use the passage of

time to contribute to bringing life to life, when life is enclosed in painful suffering. How this can be done depends on each situation, but a good start is to dare to be attentively present even if we feel that there is nothing we can do. The simple and basic may be useful such as trying to be aware of the patient's breathing rhythm and tune oneself after this when performing care and treatment or to sit down when talking with the patient even if it is only for two minutes. The challenge for health workers is to not take for granted that the individual will experience time in a typical and traditional way. How individuals experience time even in the face of death is as diverse as life itself, but nevertheless it may be important to note that patients' understanding of time may be associated with their existence and not with a time schedule where structuring and synchronization are essential, such as in in hospitals (Ellingsen,et al 2013b) .

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Figure 1. The pendulum time of life

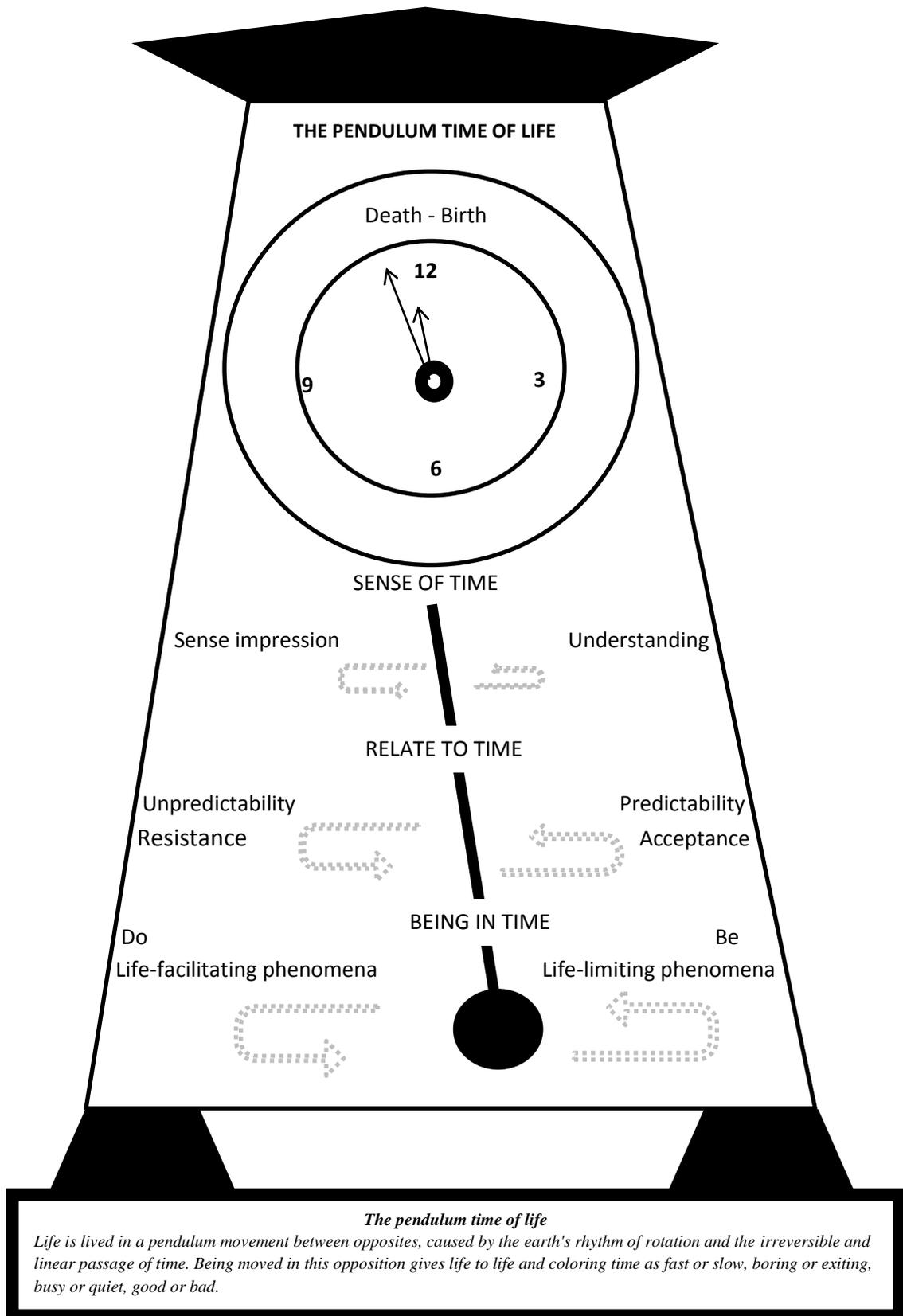


Figure 2 Relationship between the universal, typical and unique experience of time.

