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Searching for knowledge and understanding while living with impending death—a phenomenological case study

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Abstract
In this article, expression of the quest for knowledge and understanding while living with the threat of fatal cancer is explored. By means of a case study, recurrent narrative interviews and participant observations were performed with one 71-year-old man and the oncology nurse taking care of him. The data were analysed phenomenologically and the results disclose three paths during the illness trajectory at the end-of-life; the stable path, the turning point and the waiting. Existential uncertainty is managed in the stable path, while confronting existential uncertainty is characterized by the turning point, and there is a shift towards living existential certainty during the waiting. The significance of openness towards the intertwining of the experiential and existential dimensions of living in end-of-life care is emphasized. Research into patients’ multidimensional learning at the end of life is needed in order to expand knowledge of how the patient makes sense of their situation particularly in relation to the information they receive from palliative care professionals.

Key words: Palliative cancer care, making sense, patient, lifeworld, existential

Introduction
There is a considerable body of knowledge on the importance of creating appropriate palliative cancer care (e.g. Doyle, Hanks & McDonald, 2005; Payne, Seymour & Ingleton, 2004). One purpose of high-quality palliative care, concerns helping the patient to understand the changed and changing health situation and the consequences thereof. Here, we focus on how patients make sense of their situation, particularly in relation to the information they obtain from palliative care professionals. From the patients’ perspective, we intend to explore the appropriate-ness of conceptualizing this in terms of patient learning.

Over the past decades this area has been intensively studied in respect of aspects such as cancer patients’ level of knowledge (Gattellari, Voigt, Butow & Tattersall, 2002) and different diagnosis groups’ preferences for knowledge (Clayton, Butow, Arnold & Tattersall, 2005; Echlin & Rees, 2002; Hagerty, Butow, Ellis, Lobb, Pendlebury, Leight, Goldstein, Kai Lo & Tattersall, 2004). Sapir, Catane, Kaufman, Isacson, Segal, Wein & Cherny (2000) study on, among others, colorectal cancer patients’ information needs reveal that despite being satisfied with the clarity of information provided by the healthcare professionals about the disease, a substantial percentage of patients had an inaccurate understanding of the disease status. Even if some cancer patients felt sufficiently informed about the disease (Tattersall, Gattellari, Voigt & Butow, 2002; Voogt, van der Leeuwen, Visser, van der Heide & van der Maas, 2005) gaps were identified in the relevant prognostic information (Gattellari et al., 2002; Hagerty et al., 2004; Tattersall, Gattellari, Voigt & Butow, 2002). Some patients wanted
disclosure of prognostic information as a whole or in part, and some not at all (Butow, Dowsett, Hagerty & Tattersall, 2002; de Haes & Koedoot, 2003; Fried, Bradley & O’Leary, 2003).

In a study on cancer patients’ desire for communication of prognosis information (Kaplowitz, Campo & Chiu, 2002) there were preferences expressed as to patients requesting and physicians providing qualitative prognostic information (that the patient will die from the disease) and also as to patients’ requesting and physicians providing quantitative prognostic information (how long the patient will survive/live). Interestingly, just over 50% of the patients who wanted quantitative prognosis received one, whereas over 60% of those who declined a qualitative prognosis, did receive one. Thus, discrepancies in the communicative pattern occurred. Of significance is the involvement of the patient in the health process, such as in the vital role of taking charge and control over the situation (Carter, MacLeod, Brander & McPherson, 2004) and in decision-making related to different aspects of the disease (Clover, Browne, McErlain & Vandenberg, 2004; Jefford & Tattersall, 2002; Koedoot et al., 2003; Sanders & Skevington, 2004).

The studies reported a complex and demanding life situation where adequate communication and information processing is of ultimate importance. As Lawton (1998) states, dying is not a linear process. There is a risk of marginalizing dying patients with threatened identity and view of self (Lawton, 1998; Rozmovits & Ziebland, 2004; Sahay, Gray & Fitch, 2000). Even if considerable research activity has been conducted in the area of information provision within the cancer care context, patients continue to have unaddressed communication needs (Butow et al., 2002; Hack, Degner & Parker, 2005) and unmet information needs, with focus on prognosis (Gattellari et al., 2002; Jefford & Tattersall, 2002) and long-term management of the disease (Sahay et al., 2000) and alternatives to anti-cancer treatment (Gattellari et al., 2002; Tattersall et al., 2002). Thus, there are several reasons for deepening the understanding of cancer patients’ quest for knowledge and understanding during the palliative period. However, little research has been conducted on the process involved in the patients’ search for knowledge and understanding at the end-of-life period. To our knowledge, there are no studies from the perspective of patients with fatal colorectal cancer. Such knowledge is of significance in improving information provision, with a focus on cancer patients’ quest for knowledge and understanding in palliative care.

**Aim**

The aim was to explore the expression of the quest for knowledge and understanding while living with the threat of fatal cancer. In this way, we intend to problematize provision of information in the context of palliative care, and particularly to relate patients’ search for knowledge to patient learning.

**Methods**

**Theoretical basis**

The study is based on lifeworld phenomenology (Merleau-Ponty, 1995; Schutz, 1997; Thomas, 2005). The lifeworld is accordingly regarded as the world in which we live our daily lives; the unconscious background for our experiences and actions. This means that everyday experiences in everyday contexts are of interest in the search for knowledge and understanding. Both the individual and the surrounding world are of importance. In this study, learning is regarded as the ongoing pursuit of knowledge and understanding; a human condition in life (Dewey, 1966; Merleau-Ponty, 1995).

To capture the complexity of living with life-threatening cancer, we have turned to Ashworth’s (2003) existential-phenomenological approach; people’s experiences of events or features of their everyday world described in terms of “fractions” aimed at empirical exploration of lifeworld aspects. The lifeworld fractions described by Ashworth (2003) are:

a. Selfhood; includes various aspects of identity, questions of experienced presence, agency and voice
b. Sociality; relatedness to other people
c. Embodiment; the situation in relation to experiences of and about the body including, gender, disabilities and emotions
d. Temporality; the sense of time, duration, biography
e. Spatiality; the geography of places (including things)
f. Project; ability to carry out the activities they are committed to and which they regard as central to their life
g. Discourse; what sorts of terms are employed to describe and live the situation

We have used the fractions as an analytical tool in order to disclose significant features about the complexity of information processes in the end of life. Ashworth (2003) stresses that “fractions” should not be seen as “rationally-distinctive parts”; rather as “bits” of the lifeworld.
Case study approach

This case study is part of larger fieldwork about information provision among people receiving palliative cancer care. An oncology outpatient unit within a surgery clinic at a university hospital in an urban area of Sweden with an explicit profile emphasizing palliation was chosen. Fourteen people with colorectal cancer care were monitored by means of interviews and observations during a period of some weeks up to a year, and longer. The selection of the patient for this case study was made according to Stake's (2000) distinction between intrinsic (i.e. focusing on the case as such) and instrumental (i.e. focusing on a certain issue where a suitable case is chosen from which something can be learned about that issue) case studies. Here, an instrumental case study was chosen and one patient was selected from whom we assumed to learn about the quest for knowledge and understanding during the palliative period. The patient had a history and problems similar to the other patients in the project, which we assumed to imply some kind of general applicability for people with this illness. However, the patient was not affected by pain, which provided an avenue for needs other than alleviation of pain during the palliative phase. Having established trust with the researcher, a safe space was created for the patient to share and articulate his experiences.

The participant

The patient, here named John, was 71 years old and asked to participate by his primary nurse at the unit, two years after he was diagnosed with colitis cancer. Shortly after the diagnosis, he had gone through surgery and radiation therapy. He had lived as a single man in his city flat and had mostly continued to practice the habits he had developed since retirement including frequent gatherings with friends. He had felt quite well until six months after the surgery, when he was diagnosed with liver metastasis. After this, he regularly visited the oncology unit for chemotherapy every second week, and had done so for 15 months when he was included in the project. He was diagnosed with brain metastasis and he received radiation therapy two months after the inclusion and died another five months later (see Table I). He remained lucid with communicative capacity until his death.

Field work

The data collection was informed by Beekman (1984, 1986) who talks about “teilnehmende Erfahrung” which can be interpreted as “participating experience” (Beekman, 1984, p. 16). It means being with the participant for a period and sharing experiences of importance throughout. With the participant, interviews resembling dialogues were conducted during a period of seven months in different settings: outpatient unit, hospital ward, participant’s home, and hospice. The long data collection period and different institutional contexts paved the way for the collection of rich and diverse data. During the interviews, John was asked to

| Table I. Data collection time points. |
|--------------------------------------|
| October | November | December | January | February | March | April | May |
| Data | Interview patient (IP) | IP1 | | IP3 | | | | IP4 | Dead |
| | IP2 | | | | TCP1 | TCP2 | TCP3 |
| Telephone conversation patient (TCP) | | | | IN1 | | IN2 |
| Interview the primary nurse at the oncology unit (IN) | | | | | | |
| Field notes (FN) | FN1 | | | | | | FN2 | FN3 | FN4 |
| Significant events | Chemotherapy | Brain metastasis | No chemotherapy |
| Care settings | Radiotherapy | Hospital ward | Home |
| Illness trajectory | Stable | Turning point | | | | | | |
describe what it was like to live with life-threatening cancer with a focus on his search for knowledge and understanding (see Mishler, 1986). Field notes were taken on some occasions (oncology unit, hospital ward) and reflective notes were completed after the interviews in order to deepen the understanding of the participant’s involvement with the setting and other persons. Interviews were also conducted with the nurse responsible for John at the oncology unit. Both authors took part in the project’s major fieldwork while the data collection for this participant was conducted by the first author.

Analysis

The analysis was performed stepwise. First, all data was read repeatedly as open-mindedly as possible in order to gain understanding of the whole. Three terms with significant meanings of John’s sequential illness experience were identified in his story; “The Stable Path”, “The Turning Point” and “The Waiting”. We interpreted these three meanings as paths in his illness trajectory, and we decided to use them as a sequential frame for the analysis. Then, all data was sorted into the structure of Ashworths’ (2003) lifeworld fractions. Within the fractions, different units of meaning were identified, comprising, for example, a sentence, a few words or a whole paragraph relating to the same meaning. Thereafter, the fractions were related to the three paths to deepen the understanding of the illness trajectory. Finally, an interpretation was performed pertaining to that which characterizes the three paths during the illness trajectory according to the quest for knowledge and understanding in the end of life. In doing this we had a particular focus on existential meaning, knowledge search foci, own knowledge seeking, and significant learning; all from the perspective of the person living with the illness.

Ethical considerations

Approval for the study was obtained from the Ethics Committee at Gothenburg University (Ö 437–02). Informed consent was obtained from the patient before participation in the study. Special attention was given to the possibility that the patient might discontinue participation if there was a change for the worse. On every occasion for data collection, the patient was asked to reassure the researchers that he wanted to continue, thus informed consent was asked for repeatedly (Seymour & Ingleton, 1999). Further, there was an assurance that confidentiality would be respected during the entire period of data collection. We have tried to achieve balance in telling Johns’ story and conducting a neutral and not too personal text. However, John emphasized that he wanted his story to go down to posterity and gave the following reason for participating: “You are interested in the other things, not the disease itself”.

Results

The results are structured on the basis of the three paths of the participant’s illness trajectory expressed explicitly himself in order to re-contextualise the analysis from the story. On each of these paths, specified meanings of the patient’s knowledge search foci and significance of own knowledge seeking, as well as significant learning experienced were interpreted (see Table II). The phenomenological lifeworld fractions (Ashworth, 2003) used in the analysis are interwoven and marked in bold type. Quotations are used to increase comprehensiveness. “I” stands for interviewer and “J” stands for John and “N” for nurse. When a part of a quote is omitted, it is marked with ellipses.

The Stable Path

The stable path was characterised by managing existential uncertainty. During this stage of his illness trajectory, John strived for normalcy in the shadow of the effects of the chemotherapy with a focus on trying to continue social life habits from earlier life. The view of self as being “the usual John” and at the same time “a seriously ill cancer patient” was strongly influenced by the uncertainty as to whether the cancer would progress or regress.

The focus of John’s knowledge search was to monitor and follow the development of the disease and bodily changes. He tried to maintain mainly two kinds of sociality. First, in relation to the health professionals’ judgments of the chemotherapy regimen, John strove to understand the bodily signals. Secondly, his fellow patients served as counterparts in his quest for knowledge. By talking to and observing patients who had finished their chemotherapy, John found that their future was delimited. Consequently, watchfulness in the stable “no man’s land” was developed because the stable situation could change quickly. John had enough strength, will and curiosity to seek knowledge actively and turned out to be “an experienced and knowledgeable cancer patient”.

The search for knowledge was marked periodically by the experience of temporal and spatial frames. The experience of time was connected to the periods before and after the disclosure of the liver metastasis, which had been the start of a humdrum existence, scheduled according to chemotherapy. Another marked period was the quarterly computer
tomographies that monitored whether the tumour had decreased, increased or was stable. John’s quarterly consultations with the physicians were of ultimate importance for the understanding of his physical status in relation to the size of the tumour. Being in the middle of the changing world, time is not merely the past or future or even an emphasis on the present. “The now” constitutes the temporal and spatial basis for managing uncertainty. The search for knowledge took the form of different projects. The main project was trying to understand the health professionals’ words and actions, discursive activities.

... the conversations with the physicians about the future or how everything is going to be with this [the illness] aren’t very long. They don’t want to talk about it. You see...such things are a bit diffuse here (IP 2).

This discursive blurredness resulted in an increased vigilance regarding the professionals’ intonation and choice of words. The way such communication patterns could occur was mirrored by John’s primary nurse describing the complexity in the conversations she had with patients at the unit:

N: Sometimes there are hidden questions ... but I think
I: Hidden questions ...how do you mean?
N: How the future will be...they come...if there is a physician consultation every time for chemotherapy...in that case I think...then one does not go into that discussion because the physician has the main responsibility
I: And then...they [the patients] ask hidden questions...
N: ...and it can be a bit difficult to answer such questions
I: What do you usually do ...?
N: I think I try to answer in a neutral way (IN 1).

John learned to employ the terms and discourse used by the professionals in order to participate and make his voice heard in the discursive space. He

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Table II. The Stable Path, The Turning Point and The Waiting in relation to existential meaning, knowledge-seeking foci, personal significance of own knowledge-seeking and significant learning.

| Existential meaning       | The Stable Path | The Turning Point | The Waiting           |
|---------------------------|-----------------|-------------------|-----------------------|
| Managing existential uncertainty | Confronting existential uncertainty | Living existential certainty |
| Monitoring and following the development of the disease and bodily changes | Exploring situations went through | Monitoring and interpreting signs indicating the impending death |
| Dialoguing and observing fellow-patients and their illness trajectory | A closer examination of the health professionals words and actions to find out consequences of the brain metastasis for future life | Trying to understand the health professionals avoidance of talking about the impending death |
| Observing the health professionals words and actions | Searching for a unifying picture of different reports from different health professionals |

| Knowledge-seeking foci | Personal significance of own knowledge-seeking | Significant learning |
|------------------------|-----------------------------------------------|---------------------|
| Mainly confident with the knowledge-seeking patterns, although restricted by the professionals’ discursive practices | Frustrated with the experienced difficulties in comprehending differences inherent in implicit and explicit meanings of the health professionals’ actions | To employ terms and discourse used by the health professionals |
| To employ terms and discourse used by the health professionals | To use neutral terms (those used by professionals and own) for delicate issues | To be knowledgeable about medical facts and handling of side effects of the chemotherapy in the shadow of the uncertain future being |
| To be knowledgeable about medical facts and handling of side effects of the chemotherapy in the shadow of the uncertain future being | To face the uncertain territory of life-death is inescapable | |

...
learned to avoid questions that probably should be reinterpreted by the professionals. “The future” was a term avoided by the physicians and John noticed that the term “tumour” was used in favour for the term “cancer”. “Cancer” was related to the whole life situation and the term “tumour” concerned the place and cause of cancer, and he learned the professionals’ preference for the latter. He learned to use the terms “stable”, “increased” or “decreased” for the size of the tumour. These terms signalled or revealed something about the situation as a whole.

On the one hand, John had factual medical knowledge about his treatment and about how to handle side effects; on the other hand, he was uncertain of the future. There was a duality in seriously doubting that there was hope for survival while at the same time hoping for a few more years of life. He was both knowledgeable and unknowledgeable at the same time.

The Turning Point

The turning point was characterised by confronting existential uncertainty. The changed life situation due to the diagnosis of the brain metastasis forced an awareness that life was seriously threatened at this point on his illness trajectory. Bodily signs such as dizziness and fatigue, together with what was perceived as vague, contradictory information about the disease from the health professionals, lead to an overwhelming existential uncertainty.

Owing to increasing weakness, John’s knowledge seeking patterns changed. He was unable to seek knowledge actively by himself as he once did. The importance of having or acquiring factual medical knowledge seemed to fade into the background. It was not regarded as unimportant, but his uncertain future was brought to the fore of his attention. His sociality shifted from being extrovert with a focus on sharing interests with dear friends to introvert, and a closer examination of physicians’ and nurses’ actions and reasoning in order to understand his changing life situation. John’s sociality slowly changed concurrently with the change for the worse, and became more explorative.

After the radiation therapy everything turned out to be very hard. And I understood that this is not to be trifled with because their [the physicians and nurses] attitude to me before and after the radiation was completely different (IP 3).

The search for knowledge involved strong interpretative features where the health professionals’ actions and terms had to be interpreted in order to be understandable. Their reluctance to talk about consequences for John’s life situation was not experienced as palliative and protecting, but confusing and contradictory in nature. John also pondered over the fact that he was affected bodily in two regards; the metastasis in the liver and the metastasis in the brain. Different physicians were responsible for monitoring the different cancer sites; as if there were two sides of him. One important project became the search for a unifying picture, and John reflectively explored the situations he went through and turned to literature in order to get an answer. When his situation deteriorated, he realized that only cancer patients could understand him and his changing body. At the same time as he was surrounded by dear friends, he slowly retired into himself. In an overall sense, all projects were aimed at maintaining hope in a slowly shrinking world (time and space) and sociality. There was a turning point in two senses; the diagnosis of the brain metastasis and the health professionals turning away from the patient due to the fact that there was no more curative treatment to offer, and that the bad news was difficult to communicate.

John learned to use neutral terms, i.e. not talk explicitly about the “brain metastasis” and to avoid using the term “cancer” because he found that significant others were afraid of this term and could not accept that he was seriously ill.

J: It’s not called a clot in the brain… it is called a tumour
I: It’s not called …
J: I don’t like to talk about a tumour
I: You say… you say clot in the brain instead of tumour….
J: Yes
I: Because you don’t like to talk about a tumour
J: My friends call and ask how I feel… then I say “I’ve got a clot in the brain. … They think it sound like… tumour is delicate and cancer is delicate (IP 4).

In this way, he linguistically repressed the fact that he had a brain tumour. In a way, John adopted the physicians’ discursive way of acting when they shifted terms to more neutral terms. The confronted existential uncertainty lead to a “bodily and existential conviction” that dying was inescapable. It was a knowledge that entailed a changed view of self as being in the nearness of death.

The turning point was a turn away from a life with a possible prolongation towards a life close to death and dying. That was a path towards an uncertain territory in which John sought to understand the consequences of his conditions for his future life; to
know where to be during the dying process and how long it would take to die.

The Waiting

During the waiting, existential uncertainty was changed to an existential certainty about impending death. John turned his attention towards self and interpreted the bodily signs. The increasingly dizziness, declining physical strength, the fact that he slept for longer and longer periods revealed something about his deteriorating body. He physically experienced that the substance of his brain decreased. Thus, in a way John conceptualized the changes occurring in his body. His lack of physical strength, as in not being able to get up from bed and the experience of mental impairment was something new and different from other experiences, which made him realize that he was dying. He began to live in an existential certainty. Several aspects pointed in the same direction.

The search for knowledge was mainly restricted to the spatial frames of the hospice. The spatial journey (the home; oncology unit; cancer clinic; the hospital ward; the hospice; the bed) disclosed something about the seriousness of the situation. In a metaphorical sense, the search for knowledge was more difficult to attain because the people he had learned most from were absent; his fellow patients. However, using his cell phone extended the spatial frames and connectedness with contexts and people he used to visit, as it was his “life thread” (I 5). The move from home to the hospice was a clear sign that dying was near and announced that there was no further medical treatment to offer. John summarized the experiences to understand the whole situation. He was in an institutional setting organized for the care of people with impending death. His friends treated him differently; they cried openly. Even time clearly indicated that the end was near and the room in the hospice became significant, and particular.

A large wall clock with a big pointer was placed on the wall just in front of John’s bed. The wall clock was the first thing John saw when he turned his gaze towards the wall. There was nothing else to look at except for a very small painting with a neutral motive. I noticed that John looked at the clock now and then. He said ‘Now it is twelve o’clock’ or ‘Soon my son will come’ (FN 3).

The placement of the wall clock made him control time both metaphorically and literally and as such, it contributed to the knowledge process in a symbolic and existential sense.

One important project was to get significant others to understand that he was dying. John did not any longer protect them by avoiding telling the truth or using a discourse with neutral terms. They had to face reality and re-evaluate their conceptions that he was going to die. He could not even act to preserve his own dignity. He needed help with personal care, which increased his feelings of being physically and mentally reduced. His sociality turned towards focusing on help with daily care. Even in the shadow of imminent death, he strove to be encountered as an autonomous person with retained self-value. John experienced that the nurses were waiting for his coming death. In a sense, the waiting was twofold; the health professionals waited and he himself waited. They all waited in silence. One important project was trying to understand why the nurses and physicians acted as they did and why everybody avoided talking about the impending death. It was confusing that the nurses at the hospice helped him with practical things such as personal care but did not talk about his coming death. He wanted the nurses to read the newspaper:

... but there is no time for it...they are occupied with the bathing and making the bed...and then they disappear (IP 6)

He experienced the reluctance of the hospice staff to talk openly to him about existential issues.

They’re singing the last verse... I feel it...but I want to do so much...but the nurses and doctors don’t say anything (IP 6).

Hence, not only in solitude, but also in loneliness—in protecting significant others and in the shadow of healthcare professionals—he lived in his existential knowledge of certainty that his life was nearing its end. While living in the existential certainty of his future, he sought knowledge in order to practice authenticity and face reality in new ways compared to in earlier phases of his illness. He found this restricted by professionals’ avoidance tactics and the inability of significant others to talk to him about his impending death. From this point of view, he sought knowledge to guide significant others towards insight on his impending death, and to get professionals, to open up with him about his impending death. Contrary to the stable path of his illness, he had now learned to avoid not telling the truth and not to use neutralizing terms.

Reflections

In this case study, changing knowledge-seeking foci and related learning outcomes was interpreted as related to a retired man’s story of illness going through
paths of stability where existential uncertainty could be handled, experiencing a turning point where the person was confronted with existential uncertainty, and a waiting path where an existential certainty of impending death could be handled and lived. The knowledge seeking was grounded in a succession of experiences and as such is *experiential* in nature (Dewey, 1966) and the fact that life is threatened and near the end indicates that the *existential* dimension of the quest for knowledge and understanding is fundamental and extensive in nature. The experiences were to a high degree bodily related, (e.g. having diarrhoea, nausea, dizziness, fatigue) but also social, (e.g. encounters with fellow patients, physicians, nurses, friends, relatives). Following Dewey (1966), some of the experiences “stand up” more clearly and distinctly than others, which calls for reflection. It enables the learning person to discern differences towards some kind of comprehensiveness. The data involve activities such as asking questions, listening, reading literature, guessing, doubting and examining. A changed view of that which is lived through is shaped. This knowing entails certain consequences for the rest of the trajectory.

Ashworth’s (2003, 2006) lifeworld fractions highlight a multidimensionality of aspects of significance for comprehending palliative cancer patients’ desire for knowledge and understanding. During the illness trajectory there were changes related to all fractions of the lifeworld. There was a change in the view of self from being independent and knowledgeable to feelings of being objectified but certain that death was near. Concurrent with the bodily deterioration, there was a change in sociality from being extrovert to lonely. The spatial and temporal frames shrank and projects changed towards trying to understand the restricted life-situation. The life and world as experienced had changed totally.

One striking and important finding was the patient’s need to talk about the uncertain future combined with the health professionals’ vague or sometimes contradictory communication about the same. We interpreted this as a need for existential knowing. In the analysis, the significance of professionals’ discourse was disclosed, particularly the use of neutralized terms. While the participant experienced stability and ability to handle existential uncertainty, he learned to practice the discourse tools used by professionals, particularly neutralizing terms. Later on during his illness trajectory, he abandoned this behaviour and learned not to avoid the truth or to resist from using neutralizing terms. The following example from the case study illustrates what existential and experiential knowing involves. John wondered why the nurses at the hospice were occupied with practical tasks instead of dialoguing. They seemed to be reluctant to “say something” as John expressed it. Even if he was weak and dizzy, John still, in space and time in his bed at the hospice, wanted the nurses to read newspapers and wanted to be taken to the balcony to see the beautiful surroundings. However, the nurses left the room to perform other duties. The projects (reading newspapers, moving to the balcony) could have prolonged his spatial frames and connectedness to some kind of commonplaceness. It can also be interpreted as an attempt to take control over the situation (Carter et al., 2004) or a will to participate in the care (Clover et al., 2004). McNamara (2004), p. 933) states that care in the imminence of death must be “as close to the circumstances the person would have chosen”. However, control and decision-making is always related to something and dependent on life as a whole; in Ashworth’s (2003) terms: the self, embodiedness, sociality, projects, time, space and discourse. According to the results, John experienced that the health professionals “turned away” when brain metastasis were diagnosed. However, the field notes indicate that the healthcare team confronted him with compassion. These facts point to the complexity of being involved in information provision and making sense of the illness in the end-of-life and even more to the vulnerability related to suffering of individuals who are ill with fatal cancer (see, for example, Rasmussen, Jansson & Norberg, 2000; Öhlen, 2004).

We argue that this is an example of learning at the end-of-life. It is not learning of factual knowledge such as medical facts. It is not learning of how to die, an *ars moriendi*. Instead, the learning concerns an *ars vivendi* at the end-of-life pertaining situated experiential and existential aspects related to living with the suffering and vulnerability of a person with progressive metastasised cancer (see Table II). In the example above, the lived experience was reflected and conceptualized as “not being worth certain nursing actions”. According to the newly introduced variation theory of learning (Bowden & Marton, 1998; Marton & Booth, 1997; Marton, Runesson & Tsui, 2004) we become aware of our own approach to understanding the situation in contrast with how, for instance, others understand it. In our study, the nurses seemed to interpret the situation in one way and the patient in another. It is plausible that John recalled memories of the excellent information provided by other nurses about, for instance, the side effects of the chemotherapy at the oncology unit. It is also plausible that he recalled memories of the nurses’ hesitation to talk about how life had turned out during the turning point. Such experiences served as points of contrast with the new experience of the nurses leaving the room for other duties,
practical nursing duties being interpreted as more important than reading John the newspaper or taking him on to the balcony. The example highlights that learning in the end-of-life is not only cognitive in nature but involves the entire human being, and as such is multidimensional in nature. Marton et al. (2004) state that the most important form of learning is that which makes it possible to attain a changed meaning. John learned that issues of death and dying are not addressed by health professionals. 

This case study was based on one single case. The patient’s experiences were likely to be general in some respects but idiosyncratic in others. However, the results point to aspects of significance for creating high quality palliative cancer care. Our study suggests the existential meaning and the experiential meaning of the illness together constitute a significant context for information provision in palliative cancer care. Thus, managing and confronting existential uncertainty and living existential certainty will both frame, co-create and be co-created by the knowledge seeking behaviour of patients receiving palliative care.

The event described above is presumably not seen as an example of learning by health professionals. However, all learning irrespective of agents is part of society (Dewey, 1966). Thus, the view of learning in social institutions, such as hospitals, may be formed by traditional and hierarchical ways of seeing the patient in need of care (Agar, 1985; Trostle, 1997). Perhaps a reluctance to talk about prognosis and future is related to the strict frames of the medical discourse itself (Farber, Egniew, Herman-Bertsch, Taylor & Guldin, 2003; Mishler, 1984). In order to talk about the future with palliative cancer patients, another discourse has to be adopted which involves openness towards existential dimensions. Consequently, the delimited focus on mediation of medical knowledge must be transformed towards a wider perspective. The wider perspective demands preparedness from the perspectives of the health professionals to identify “the existential”. In fact, it is a question of learning to discern the existential in the experiential. Thus, the interconnectedness between life and world must be taken into consideration and is illustrated by the fractions of the lifeworld used in the study (Ashworth, 2003). More tangibly, it involves creating opportunities at oncology units, hospital wards and hospices for patients to talk about everyday life and everyday experiences along the illness trajectory. Although the results reveal a major turning point, additional sequential turning points occur along the illness trajectory which are not directly related to the deteriorating body (see Jakobsson, Bergh, Gaston-Johansson, Stolt & Öhlen, 2006) but are existential in nature. Thus, professionals need to handle confrontations with a number of their patients’ existential uncertainties. This needs to be considered in relation to the neutralized terms used, as related by the participant in this study. “Listening” is one important strategy to enable the patient to talk. Thorne et al. (2005) use the expression “personhood” perspective to emphasise the importance of human connection in cancer care. This means openness towards patients’ stories and a willingness to discern what seems to be problematic along with that which seems to be meaningful for the patient, and implies adopting an ethical and pedagogical sensitivity. Pedagogical sensitivity means the awareness that learning is a fundamental condition in life (Dewey, 1966; Maslow, 1970; Merleau-Ponty, 1995). To understand learning in the end of life further, more research is merited. Finally, John’s poetic narrative clearly indicates the interconnectedness between life and world near death:

Death is inexorable
now
I am absolutely certain that I soon will die
From the beginning
I had plans for the future
but they disappeared
by the first snow
by the first sun in the spring
‘It is hard to die’, a song says
I could have had this summer too
‘Birds are singing in the sky’
(IP 6).

Note
1. In Ashworth (2006), an additional fraction “the mood-as-atmosphere” is introduced. However, we conducted the analysis before the article was published. We should like to point to the usefulness of that fraction when conducting lifeworld research.

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