



## ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

### Caregiving for existential wellbeing: existential literacy. A clinical study in an anthroposophic healthcare context

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#### Abstract

*Background and context:* The occurrence of existential caregiving as a natural element of healthcare is the focus of this research. According to the literature, there is a lack of understanding of this issue, from a theoretical as well as a clinical point of view. In this design 'existential' and 'spiritual' are seen as synonymous and without religious association. Existential questions are regarded as questions about life, death, meaning, love, vulnerability, responsibility and dependence. The context for the project is an integrated anthroposophic hospital that offers rehabilitation for patients with cancer.

*Aims and objectives:* With the support of an anthroposophic and caring scientific view of human beings, and by using concrete examples, the aim is to develop and deepen an understanding of existential care for patients in life-decisive phases in the care and rehabilitation of cancer. Clinical application research was used in cooperation with academic researchers and clinically active colleagues. Eleven clinicians from varying professions and two researchers collaborated over the course of two years. The data used came from 65 case reports of significant care situations experienced by the team members. A joint interpretive qualitative analysis led to the formulation of the findings.

*Conclusions:* Existential caregiving in practice requires an 'existential literacy', using the metaphor of human life as a text or a book whose contents are legible only for the one versed in the language. In order to gain a complete understanding of caregiving, an ability to read a suffering human's language and decipher its meaning is essential. The patient's narrative might open up a caregiver's awareness in a single illuminating moment. An authentic and listening attitude together with an active restriction of one's own suppositions increase the possibility of providing existential care. Compassion and professional judgement function as the caregiving compass and 'lexica' for existential care.

*Implications for practice:*

- An understanding of existential caregiving moments implies a developed insight into and sensitivity for the patient's signs and needs
- Existential caring moments have countless variations, while bodily and intimate situations are sometimes found to be an opening to spontaneous, trustful interactions. Such moments could be learning moments if reflected and shared
- For training in the ability to 'read the patient', clinical reflections in groups where existential literacy is collectively sought are an option
- Clinical application research can allow caring scientific theory and healthcare research to be implemented in practice immediately, which may enhance quality of care and ultimately benefit the patient

**Keywords:** Caring, existential caregiving, anthroposophic healthcare, hermeneutics, clinical application research

### **Background**

This research examines what modern, secular society can do to encourage existential and spiritual caregiving when faced with patients' potential and actual weakness, vulnerability, dependence and death. The situation, vulnerability, dignity and development of the caregivers are also in focus in this research project.

The context of the study is anthroposophic healthcare in a hospital with an integrative healthcare culture, in which the perception of a human being as a unified body, soul and spirit is the key to the understanding of health, illness and healthcare. Previous studies on anthroposophic healthcare from a patient's perspective have repeatedly revealed patients' appreciation of the 'holistic view' and how it has contributed to an overall greater wellbeing and improvement in health (Carlsson et al., 2006; Arman, Hammarqvist and Kullberg, 2011; Arman, Hammarqvist, and Rehnsfeldt, 2011). The results from encounters that are interpreted as nurturing and existential have been presented in various studies as a valuable aspect of healthcare. Patients give evidence in support of the care they have received, of how they have been able to rest, re-evaluate their lives and begin their own journeys to recovery and healing despite their illnesses. The aim here is to develop the findings on caring encounters in greater depth and discover more about existential aspects of care in practice.

### **Existential care: current research**

Existential care has been described in the literature and previous research as care and treatment encounters in which the person/patient's world, in other words accessing their experiences and desires, is the focus and even the goal of the care (Leung and Esplen, 2010). In this project, we view 'existential' and 'spiritual' as synonymous terms with no specific religious associations. Religion, as a part of existential and spiritual life, is a personal aspect of cultural practice and is the choice of the individual patient, whereas the caregiver should be able to maintain an open, neutral attitude to religion. The subject of human existence is often mirrored in questions about life and death, meaning, vulnerability, responsibility, guilt and freedom. Questions about dependency, love, suffering, compassion and community are also of an existential nature (Yalom, 1980; Jacobsen, 2000; Ågren Bolmsjö, 2002; Strang et al., 2002).

According to a study by Browall et al. (2010, p 67), existential care covers the ability to 'seize the moment' when the patient is in need and willing to express or share their existential thoughts. The study showed that the existential issues that are important to patients with cancer concern meaning and direction. Van Leeuwen et al. (2006) report a profound lack of understanding among nurses of their professional role in taking care of their patients' existential and spiritual needs; the caregivers' own spiritual values appeared to be of greater importance. Dahlberg et al. (2009) state that the patient can understand their own health better than anyone else so, in that sense, the patient is also an expert in existential issues. Udo (2012) concludes that existential issues are part of nurses' natural care in the surgical context; however nurses found this difficult to acknowledge owing to their own insecurity. Koslander et al. (2009) claim that to address patients' existential needs in healthcare, a holistic view of the human being is required, and argue that such a view has to combine indispensable aspects of biomedicine with humanistic existential philosophy. Lindholm et al. (2006) maintain that the acquisition of knowledge in the nursing and caring sciences always takes place contextually in some respect. The dialectic between the clinical context and the meaningful ontology is decisive in terms of whether the knowledge reaches and is appropriated by the patient. A review of the existential aspects of palliative cancer care in Canada (Leung and Esplen, 2010) concluded that clinicians, educators, administrators and community advocates had to reach a consensus on existential distress in terms of their own attitudes, beliefs and moral commitments.

Existential distress has been found among many patients seeking a deeper meaning of life. To enhance existential caregiving, clinicians need to develop their moral or clinical sensitivity and make a commitment to engage in this concern (Leung and Esplen, 2010). Being a patient and living with a chronic illness such as cancer, involves an existential struggle and vulnerability that should be understood and assessed on an individual level (Sigurgeirsdottir and Halldorsdottir, 2008). An illness like cancer constitutes a serious disruption in a person's life and challenges earlier ideas about existence and meaning (Arman and Rehnsfeldt, 2007). At the same time, these situations generally have a universal character with which most people can identify and empathise. Through existential caring encounters, the situation can gradually shift into a new biographical whole (Leveälähti et al., 2007). In their review of the existential needs of cancer patients, Heno and Danielsson (2009) establish that there is still much research left to do; clinically acceptable terms must be established and a need exists to study the effects of existential interventions on physical symptoms.

### **Anthroposophic healthcare**

Anthroposophic medicine and care is offered to patients in many countries. It is a complementary initiative, integrating a holistic anthroposophic healthcare convention to an integrative synthesis. The majority of healthcare personnel working in the field have specialised in the area of anthroposophic medicine in addition to a conventional medical education (Arman, Hammarqvist and Kullberg, 2011). Today there are at least 25 hospitals in Europe that specialise in this form of medicine and care; sixteen in Germany; five in Switzerland; two in the Netherlands; one in Sweden and one in the United Kingdom (Arman, Hammarqvist and Kullberg, 2011). Anthroposophic care is based on a holistic perspective of the person as a body, soul and spirit in balance. Anthroposophic medicine rests on three pillars: nursing care, therapeutic treatment and medical treatment (Therkleson, 2005; Arman et al., 2008). In 2009, a patient satisfaction evaluation revealed significantly better results at the clinic in question than those in conventional healthcare, despite the fact that the majority of patients in the anthroposophic clinic were women, who generally tend to rate satisfaction lower (Arman, Hammarqvist and Kullberg, 2011). A qualitative study of patients' experiences of anthroposophic care (Arman et al., 2008) revealed that the patients appreciated both the internal and external caring environments – that is, the interpersonal aspects and the physical setting. It was evident that the patients felt the improvements and satisfaction they perceived stemmed from the way they were invited and met by caregivers, the staff's attitude and the environment at the clinic. Randomised studies have not been applicable in making valid comparisons between conventional and anthroposophic care. Another limit often mentioned is that as patients freely choose this kind of complementary care, their perceptions of it are likely to be more positive. However, in a matched study of 60 patients with breast cancer, anthroposophic care contributed to positive results in patient satisfaction in addition to increased quality of life for up to one year after their stay (Carlsson et al., 2006). As with other integrative forms of healthcare, the majority of patients in the anthroposophic clinic were women with a higher level of education and social status than the average in conventional healthcare (Arman, Hammarqvist and Kullberg, 2011).

In order to study this from a holistic, and more specifically existential, viewpoint, caring science ontology has been used to shed light on the phenomena related to patients' needs for existential care. The focus of caring science ontology is on human beings as entities, naturally free, vulnerable and interdependent. Phenomena related to compassionate caring, and taking care of others as fellow human beings and to ease their suffering from contextual, ethical and existential viewpoints, are theoretical references for the research (Arman and Rehnsfeldt, 2006; Martinsen, 2006).

### **Aim of the study**

With the support of an anthroposophic and caring scientific view of human beings, and by using concrete examples, the aim was to develop and deepen an understanding of existential care for patients in life-decisive phases in the care and rehabilitation of cancer.

### **Methodological approach: clinical application research**

This study was based on clinical application research (Lindholm et al., 2006). Epistemologically, the approach of the research has its foundations in hermeneutic philosophy, as can be found in Gadamer (1989). Problematising what is taken for granted is fundamental to hermeneutical research – it is about being attentive and reflective to the processes of consciousness, especially one's prejudices and presuppositions. The hermeneutic approach can be called, according to Gadamer, an eternal movement of the human mind and represents an intertwining of what is known, the pre-understanding and what is still unknown. Gadamer makes explicit the importance of the unknown and the challenge of revealing the unknown by questioning presuppositions. This can be recognised in the hermeneutic approach in the analysis in this study.

In accordance with clinical application research, a team of researchers with scientific expertise in close co-operation with colleagues with clinical expertise was formed. The goal was to reinforce and develop the co-operation between clinical care and healthcare research. The team maintained dialogue on the questions, method, analysis, interpretations and the applicability of the findings. The concrete and detailed plan for data collection and analysis was made by all team members during the first stage of the project. Project meetings were held at the ward every three weeks in the two years between 2010 and 2012. Individual data collection and reflection was carried out in the meantime.

The actual team consisted of two researchers and ten clinically active caregivers on a cancer rehabilitation ward at an anthroposophic clinic. The caregivers consisted of two therapists, one doctor and seven nurses. The therapists were anthroposophic art therapists providing the patients with paint, modelling and movement therapies (health eurhythmmy). The ward had 13 fully occupied beds and the length of patients' stay varied from two to four weeks.

According to Lindholm et al. (2006), the ontology of caring science – the innermost spirit of caring – is the guiding principle in the search for knowledge. This includes, for example, the view that the human being is an entity comprising body, soul and spirit, and that concepts such as human dignity, alleviation of suffering and mercy are cornerstones. This principle shapes the epistemological criteria as well as the methodology used. In contrast to action research and other participatory research methods that derive from critical theory, basic theoretical assumptions are brought into clinical application research. These basic assumptions are formulated around the conceptions of the researcher; for instance, conceptions of health, wellbeing and suffering. A theory on 'Nursing care that alleviates suffering' (Arman and Rehnsfeldt, 2006) was used as the basis for the dialogues in the research team. Clinical application research involves the opportunity to reveal and show clinical evidence of caring science theory in praxis.

### **Research questions**

The research questions were formulated in the dialogue that took place in the research team during the first six months of the study. The starting point for researchers was the idea that the team study existential healthcare in some way. Selected theories and literature were introduced into the discussion, but the primary content of the formulation was actual clinical experiences from the ward. The final formulation of the research questions was as follows:

- What is the role of existential care in the everyday life of those caring for patients with cancer?
- What can be done so that caregivers feel more secure in practicing existential care?
- What knowledge facilitates and promotes existential care?
- What opportunities, challenges and obstacles does existential care face in everyday clinical life?
- What does existential care mean to the caregiver?

### **Data collection**

During the first stage of the research, as the team became better acquainted with the questions regarding existence and healthcare, different patient cases proved an important part of the dialogue.

These cases were often vivid and illustrative, and inspired broad reflections. As these somewhat short, incident-like cases seemed to deepen dialogues, it was decided to document systematically 'cases' as data for the research. Over the course of the following months, all members of the clinical research team were urged to describe any of these so-called 'meaningful caregiving situations' in a set format. First, the narrative of the case was presented, then the clinical researchers could write down their personal reflections on the case. Over a period of approximately five months, 65 cases were submitted. All members of the clinical research team contributed cases, although for the purpose of confidentiality, no names were recorded.

### **Data analysis**

Data analysis was conducted in four stages. First, once printed, the 65 cases were entered into a table with space for individual notations. The texts were then processed in project meetings by open discussion of one case at a time. We opened the analysis discussions with questions such as: What do you see in this case? What is it about? What is happening here? Simultaneously, a reflective discussion on the details, significance, understanding and possible insights occurred. The naïve and spontaneous elements that arose in the first analysis were rich and inspiring for the group dynamic. The group consisted of eight to 11 people from varying professions, which allowed for many different points of view. The researchers took written notes during the meetings. This stage of analysis took about six months of regular meetings.

In the second stage, guided by the first spontaneous analyses, the two researchers (MA and AR) formulated 25 tentative themes, more or less related to the aim and the research questions and constituting the basis of the continued joint analysis. The entire working group then discussed the theses in order to verify, understand, develop or reject them.

The third stage involved the two scientific researchers in the team building a structured thematic analysis in relation to all of the 65 cases.

1. The preliminary theses and all notes/accounts from the discussions and analyses in project meetings were read through and discussed in relation to the assumptions and the purpose of the project.
2. Thereafter, preliminary synthesising themes were formulated on how existential care can be defined. An alphabet of existential literacy was adopted as a general premise in the work.
3. In the third stage, all 65 cases were reviewed with the purpose of finding out *how*, *where* and indeed *if* they could be sorted into our themes. We also wanted to see if there was anything that we had failed to notice or identify up to this point. During the reviews, a worksheet was created with case figures. New themes were added and some were reformulated as a result of cases that did not fit under the preliminary themes.
4. In the fourth and final stage, the preliminary results were presented to the entire project group, including the clinical research team, for the purposes of dialogue and continued development prior to publication. The findings presented here are from this stage.

### **Research ethics**

All health and medical care is subject to the legal obligation of patient confidentiality. In this project ethical rules and principles for research were communicated to all clinical researchers. The research ethics were discussed by the entire group and everyone participated in the application for ethical approval. The application was approved by the regional ethics committee (2011/444-31/4). The patients were informed about the project via the ward's notice board. The personnel who wrote about their cases took care to describe situations in a dignified manner and to provide no personal data, hospital names or other details that could constitute a breach of patient confidentiality. None of the accounts included the name of the patient or staff member.

## Findings

### *The alphabet of existential literacy*

To provide care in a manner that encompasses the existence and existential needs of humans/patients in practice requires an 'existential literacy'. Human beings are complex and concrete while at the same time transient, and patients' existential needs in life-decisive periods are challenging to grasp. The philosopher Piltz inspires with a metaphor in which he wrote that human life, history and apparent reality is like a text or a book whose contents are open only for the one able to read (Piltz, 2002, p 89). Caring science theorist Eriksson developed the idea from Piltz, and believes that in order to gain a complete understanding of caregiving one must learn to read the suffering human's language and decipher its meaning and deeper motives (Eriksson, 2003, p 25).

An important part of the metaphorical existential literacy is to gain understanding of the letters of this alphabet. One main letter constitutes the perception that the value of a person is absolute and never relative; that the human being as a whole involves a constant intertwining of body, soul and spiritual/existential dimensions. Human beings are thus always in movement, always developing and have unfathomable potential (Arman and Rehnsfeldt, 2006).

### *Thematic and clinical alphabet for existential caring*

The different themes or 'letters' in the alphabet are not separated but integrated in the intertwining of clinical caring. Sensibility and open awareness for personal wellbeing and the wellbeing of others is important for the 'reading', while the use of the senses of perception is of great importance. An existential literacy is constituted for existential caring using the letters of the alphabet, which cannot be categorised, fragmented or even methodised.

### *Narration as health in a caring synthesis*

Caregiving is permeated with the insight that the patients' narratives and the caregivers' understanding of it hold the potential for alleviation of the patient's suffering and increased health. It is the acquired knowledge and practice of the caregiver that creates openness towards the patient's story. In the example below, the caregiver anticipates the patient's needs and waits to see whether or not the patient wishes to speak. The caregiver opens a room for the patient, where she can air her mood, and gives brief verbal confirmation, as well as administering treatment in order to increase the patient's wellbeing.

*'20.00, patient's room. Today, the patient has been to see her oncologist and has found out that the cancer has spread to one of her lungs. She is calm at first, when arriving in the afternoon at around 16.00. At 20.00 the anxiety begins. She asks questions like: "Why me?" "Is there a God?" "How can I go through another course of cytostatic treatment?" I try to listen, first and foremost, to let the patient express her thoughts. It feels as though she is not expecting an answer. I tell her not to give up hope, then give her a "heart compress" and a wheat pillow for her neck (tension).'*

If suffering and wellbeing are opposites but in interaction, the treatments offered after the patient has expressed her anxiety – namely, a "heart compress" (a herbal oil compress applied the heart area) and a heated pillow – are part of existential care. By expressing herself verbally the patient has shared her suffering with the caregiver. The caregiver receives and responds to her suffering and gives something to increase the patient's wellbeing in that particular moment. The care that takes place in a given moment confirms the patient in the present and thus potentially alleviates her fear about the future.

In anthroposophic care, there are a number of treatments and tools that integrate close caring actions to promote wellbeing and alleviate suffering. Other than the "heart compress" and heated wheat pillow mentioned above, the patient can be given essential oils in a soft rhythmical massage of the body. In several of the cases where the patient opened up and talked to the caregiver, one of these elements of care was used. In one case, a night nurse sat and held a compress with ointment where the patient had pain and the patient then revealed how the family had never talked about her terminal

illness and its consequences for the family as a whole. The pain then eased, and the patient fell asleep. The ointment, the physical contact and the revelation formed a caregiving synthesis in this case.

Using the metaphor of the patient as a text or a narrative, all manifestations are interwoven, that is, all that the caregiver can read from the patient, far beyond the linguistic aspects. In existential caregiving, the patient starts as an unknown text and caregivers use their knowledge and alphabet as tools to become literate.

The caregiving and health-creating aspects of expressing mean that patients can consider themselves and their lives by means of the narrative. Seeing themselves within a story of their suffering can be helpful for patients, and for suffering people, to integrate – that is, to work towards acceptance and reconciliation of the realities of life.

#### *Being authentic and compassionate is professional*

Within existential care, the personality and authenticity of the caregiver as a professional becomes an important factor. Authenticity is, thereby, a sign of professionalism. The authenticity of the caregiver often allows caring attempts to reach the patient. Reciprocity is created in the meeting between the openness of the patient and the intentions of the caregiver to provide health-oriented care and ease the patient's suffering in the present, rather than care oriented towards illness or disease. Authenticity, compassion and presence are related as letters in the alphabet of existential literacy. When the caregivers can 'completely be themselves', they can also be 'completely professional', meaning that they are not dependent on any role or method. In many cases, caregivers can allow themselves to be open, but the role can also be used as a shield. In the case of authenticity in relation to professionalism, we intend to illustrate the (natural) approach of listening, then acknowledging and acting upon what has been understood.

*'Several conversations with the son, whose mother is dying on the ward. On my way home, I meet him in the hallway. He still has that look of shock on his face and he stares at me, which stirs a feeling of compassion in me and a will to help him. At the same time, I don't have that much time; I want to go home and can't talk to him right then and there. I tell him I'll give him a hug (I mean virtually) and he actually gives me a hug.'*

This case illustrates that compassion – the sharing of suffering - is an important component of literacy. Compassion as a part of the profession and a compass in the care can be a challenge at first, but this challenge imbues the caregiver with knowledge that can later be transformed into caregiving actions.

#### *Dignifying caregiving through intimacy*

There is an innate intimacy and exposure of existential nature that can feature in the relationship between the patient and caregiver. It may be necessary both to control and support natural and spontaneous feelings of concern. In one case, the caregiver describes how she helped a severely ill patient who was vomiting and how she sat with the patient on the edge of the bed, with her arm around the patient's shoulders. The patient leant her head against the caregiver's shoulder and they sat in silence for a while. Then the patient lifted her head and said thank you, and the caregiver helped her to return to a resting position on the bed.

The vulnerability but also the dignity of a human being is, in this case, as in most bedside caregiving, related in particular to the physical weakness of the body, an aspect to which we must pay continuous attention. Here it is understood that the body is an expression of the being and also the dignity of a person, as it holds that person's entire world and reality.

#### *An activity of holding back preconceptions and presuppositions*

Existential care can entail the caregivers striving to 'tune in' to the patient and to let a feeling of

closeness emerge in the relationship. Closeness then becomes a conscious and active caregiving action. Furthermore, it means that a caregiver may not be dominated by her own will, but rather activate a will to restrain herself. By practising restraint, the caregiver can create a space for the patient, allow the patient the room for their existence, and acknowledge that the patient is allowed to have that space. The patient is thus encouraged to be as she/he is. In our cases, we have seen that it is often challenging to practice this restraint, which becomes visible primarily when it has not worked from the start, as in the following case:

*'The patient is in bed in their room, the doctor and I are doing the rounds. We did not have a clear idea of the patient's view/awareness of her condition and we wanted to discuss the possibility that the body could do no more, meaning that death was drawing near. The patient was noticeably annoyed and felt that we should not talk about this. She was expecting to talk to the doctor about lab results and treatments. She would take everything else up with her priest (I made the objection: that's not how we do things here, at this clinic we take a holistic approach to the situation). But the patient apparently had no interest in this and so we gave up our intention to use the conversation as preparation for her imminent death. The patient passed away four days later and was visited by her priest on the last day.'*

This situation is the ultimate test of the caregiver's willingness to restrain herself. A reoccurring discussion in our clinical dialogue was the issue of patients understanding the prospect of their own imminent death. An existential approach to care also entails caregivers holding back their efforts to 'inform the patient'. Literacy requires the dialogue to be initiated by a 'questioning of the situation'. This applies even when the patient is dying. Giving the patient a chance to 'prepare' is based on a notion from the sphere of the caregiver and could constitute a violation in the patient's eyes. We have seen several examples of this problem. In existential caregiving, the question of openness and respect for the patient's ability to control their own life is the number one priority. Our examples illustrate how easy it is to let the notions, culture and norms of the caregiver influence the care, and to create unintentional barriers in the process.

Each encounter has the following two aspects: first, to see and to accompany the other person in a spirit of openness; and second, to consider and reflect on yourself and the other person. In a true meeting, you leave part of your everyday individuality behind for a while. Opening up as a caregiver means being silent, listening, observing and allowing the other person the space to just exist, get their message across and to perhaps find their own answers. The person listening should commit without their own agenda and keep an open, inquisitive mind. At the same time, a part of the person/caregiver must remain attentive and alert, especially when providing care.

#### *Being open in the moment*

How do we find the 'creative openness' that we strive for? Through a synthesis of imagination, inspiration and reflection, one narrative describes how a patient tells a caregiver that he feels sad because 'everyone is in a hurry and I have no one to talk to'. The caregiver listens and registers the patient's needs, and she promises that she will return later that night. She comes back to the patient and they sit together and 'talk about this and that', as the patient expresses it.

To anticipate and to stay on the topic in question creates better conditions for observation. In a series of motion therapy sessions, the therapist notices that the patient is feeling sad and is immobile. The patient carries out the exercises with her eyes closed. The therapist reflects on this 'wall' against the world that the patient has put up, but leaves it be and only after some time does the patient open her eyes. The most remarkable thing in the therapeutic process then becomes the fact that the patient opened her eyes during therapy, which on reflection can be seen as significant progress for this patient.



Inspiration and the in-between moments often open the door to the giving of care. This is a form of aesthetic creativity in the moment. Many times, inspiration arises spontaneously from the alertness and openness of the caregiver.

*'The patient finds it difficult to ask for help and therefore avoids doing so, which makes the situation worse. I tell the patient that I understand how it must feel strange when you are used to getting by on your own, but does he understand that he is helping me do my job by telling me what assistance he needs? The patient was surprised by this and re-evaluated the situation, he possibly saw how he could contribute, and said that he now felt more comfortable trying to overcome his resistance to asking for help.'*

In this highly productive case of inspiration, the caregiver is preserving the existential vulnerability of the patient. Needing help with the most basic and intimate elements of life means exposing a person's vulnerability, which is an existential issue that the caregiver must take into account. A person's dignity is closely connected to her body; this is an intuitive knowledge in caregiving and a natural part of evident good care.

The caregiver is also vulnerable and in need of support, courage and professional development. In many encounters with patients, preconceptions and cultural norms will constitute obstacles for the caregiver. The challenge for the caregiver is to take the care beyond personal feelings and notions.

*'A patient had pushed the alarm button in her room. When I arrived she was sitting in her chair, crying heavily. She asked me to make the bed. Since she was so upset, I tried to sit down next to her to find out what was wrong and to comfort her. But she immediately dismissed me and asked me to leave as soon as I was done making the bed.'*

This narrative illustrates how complex a caring encounter can be. The patient asks to have her bed made, but is not given what she is asking for. The notion of what crying means and what is comforting makes it difficult for the caregiver, in this case, to find out what care the patient requires in that specific moment. An open and inquisitive attitude towards the patient facilitates existential literacy. While being inquisitive, the caregiver can pause, remain silent and allow the questions to arise and provide guidance. What is going on? What does the patient want? What if I was in the same situation? How can I understand?

## **Discussion**

The discussion starts with thoughts on the significance of people's, and particularly caregivers', use of their senses and the ensuing reflections. Perceptions through senses precede reflection; an impression from the senses arrives before thoughts and considerations and can subsequently be a source of reflection. This first perceptive impression that a caregiver encounters may imply a caring dimension that initiates an existential caregiving. As seen in our findings, the existential moments of caregiving arise spontaneously in patient/caregiver encounters.

Being in a state of open awareness during caregiving requires, as Martinsen (2006) describes, a sense-aesthetic presence and may open up the ability to develop literacy in existential caregiving. When this happens no dictionary is needed. Open awareness is a natural human capability that may be cultivated and developed; conversely, it may close down and disappear from the caregiver. The open senses we advocate as the prerequisite for existential caregiving comprise an essential knowledge base for reflection. Caregiving encounters are, as Martinsen expresses it, 'pregnant with impressions', and it depends on whether caregivers are open to these impressions. Martinsen claims that sense impressions have a twofold function. The impressions touch the senses and lead us to work on being open to what the impressions wish to reveal to us (Martinsen, 2006, p 59 and 2012, p 34). This means a caring awareness and a sensibility that form the basis for existential caregiving acts. However, in everyday 'doing-oriented' healthcare work, the intellect often dominates the senses, and we are, usually, urged to be critical thinkers. Ranheim and Dahlberg (2012) stress that the great emphasis that is placed on intellectual knowledge in healthcare has to be complemented by knowledge relating to responsiveness and sensibility in openness. An ability to read existentially is therefore dependent on the caregiver's use of senses and integration of them. Senses are bodily capacities that give humans perceptive input. Sensitive situation-specific attention and personal presence is, according to Delmar

(2012), explicitly a prerequisite for professionalism in caring. Ranheim et al. (2012) explain the potential of sense-making embodied in caring as a detective might piece together clues, or as creating a sphere of confidence when grasping the healing force and finding a harmonious tune. Even if reflection and a knowledge base in theoretical sources enhance development and a caring awareness in the present, to catch the present moment is the first answer to the caring encounter. We have argued that existential caregiving has its sources in 'the present tense' – the small moments where caregivers find an innovative way to comfort patients' wellbeing. Existential caregiving is, by necessity, ethical, with treating the human being as whole, irreplaceable and dignified, being the priority. Caring ethics is, according to Martinsen (2012), a holding back of preconceptions and an obligation and invitation directed to the ill or person in need, as opposed to letting a patient's experience be captured or controlled. This is an additional understanding of the assumption that an ethical openness for the other is the first letter in the existential alphabet. This openness allows the patient to guide her own needs for recovery and existential health.

Openness in caregiving intrinsically implies a shared vulnerability that could produce a need for protection. Being literate in existential aspects of caregiving is accordingly connected to an ethical responsibility towards the other. There is, as Eriksson says, a secret code hidden in the unity of body, soul and spirit within the human being (Eriksson, 2003, p 25). In a narrative a patient might 'disclose' herself and, fragment by fragment, give the caregiver insights that the patient herself may not yet be aware of. Such sharing presents qualities in caregiving that have to be sheltered in an ethical manner.

Open awareness in caregiving needs to be reflected on and contextualised. From a relational ethics point of view, a distance between patient and caregiver is understood as something unnatural. We refer to and imply clinical relevance in Løgstrup's thinking on 'spontaneous life-utterances' (Løgstrup, 1997; Rehnsfeldt, 2005; Martinsen, 2012). Life-utterances are qualities that have been witnessed and documented from existential philosophical research (Løgstrup, 1997). People react, for example, with the typical spontaneous actions that result from feelings of compassion and also mercy. It is, in other words, more natural for a person to show compassion and mercy than to refrain from it. Clinically, we have evidence of how caregivers have a desire to provide good, ethical care, but experience hindrances in this natural impulse (Arman and Rehnsfeldt, 2007). The clinical norms in the environment set rules for engagement and closeness to the patients. Through dialogue with several caregivers it was confirmed that the authenticity of caregivers and the number of spontaneous caring acts they carried out increased when alone with the patient in the room. This change grew even stronger when a caregiver had sole charge of the whole ward as sometimes can happen on the evening or night shift.

The anthroposophic view of human beings is essential for all institutions built on anthroposophic philosophy. The images of human beings encompass a continuous interaction or intertwining of body, soul and spirit, which forms an essential role in anthroposophic healthcare. By way of merging caring science literature with an anthroposophic view of caregiving, and deepening this with clinical examples, the research question has been progressed. Existential care for patients in rehabilitation for cancer can be interpreted as presupposing 'existential literacy'. By providing a starting point of listening with all senses to all the ways patients have of 'speaking' or expressing themselves, the alphabet of existential caregiving might be enlightened for caregivers.

While anthroposophic care from a professional point of view can be perceived as the correct and accurate way to treat a patient, it is vital that it also leaves room for a world of abstraction through such things as questioning, wonder, secrets and mystery. It is possible that even good holistic caregivers can become stuck and subsequently prisoners in their own preconceptions. It is therefore important, in our opinion, that the caregiver's individual sensibility, reflection and situational judgment should not be blocked in favour of a clinical model. Openness has to be continuously cultivated by reflection and advancements in theory as an essence in individual, as well as institutional, development.

### **Methodological discussion**

Starting from a hermeneutical philosophical position as clarified by Gadamer (1989), it is of importance for caregivers continuously to reflect and place themselves 'in the open', regardless of ontological connection or caregiving intentions. This is where research initiatives, such as clinical application research, can be helpful for the internal efforts to work with fundamental questions of caregiving, such as intention and reflection. Within the field of anthroposophic healthcare, we have experienced great opportunities to form an open and flexible attitude.

The innovative nature of this project allowed us to create and develop our own approach. Jointly interpretive dialogues on the data, with questions back and forth from clinical cases to philosophical theories, opened creative paths for both clinicians and researchers.

Clinical application research is an ethical approach in the sense that the clinically active colleagues are never objects but are actively involved in the scientific process. This preserves the dignity of the personnel in the clinic related to the research. The participating clinicians have been involved in all steps of the research process right up to publication. Appreciation was shown for the development of knowledge and understanding, stressing the fact that the results of the research project are already in many ways applied in ongoing patient care. The working climate on the ward has improved during the two-year project, with the project thought to be a factor in this. An evaluation on the method by the research team has been a part of the project as well. The idea behind application research is that it should have a ripple effect and spread the ideas and innovation into other caregiving environments, as well as have an impact on professionals that are not primarily involved in the research project. Discussions regarding academic research work and application of theory in the clinic have been taken to a higher level and, we hope, will remain there. The intention is for the participating clinical researchers to spread a spontaneous atmosphere of scientific thinking into everyday clinical work during the project and thereafter. Colleagues who did not participate were affected by the development in climate; as were other wards and the entire hospital. We distributed short annual reports throughout the hospital at personnel conferences. The expertise of the academic researchers has also been enriched and validated by this collaboration.

### **Conclusion**

Existential caregiving is found to be rooted in caregivers' developed intuitive ability to read the situation at hand. In a first clinical attempt to cultivate this model, the patient's explicit narrative is understood as holding the potential for her existential health. Integrated, the implicit messages from the patient by way of her lived body imply a reading of the whole human being as a text. This requires an ability to read the patient as a narrative of her life with suffering and wellbeing. This understanding may, for a caregiver, take a lifetime to cultivate, but actively working on an expanded awareness can help it develop more easily. A caregiving moment might thus become easy, spontaneous and aesthetic. The existential dimension can be disclosed in a subsequent reflection in relation to concepts and theory. Responsive caregiving in a professional preserves authenticity, gives energy for both parties and makes clear the path for the patient's existential health.

Clinical existential moments are seen to take place in vulnerable, bodily care situations in which intuition, reasoning and reflection are intertwined. The ability to become literate in existential caring presupposes the effort on the part of clinicians to restrain their own presuppositions along with a will and wish for their own personal development. Compassion and professional use of the senses function as the caregiving compass and 'lexica' for existential care.

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**A commentary by Charlotte Delmar appears on the next page.**



## COMMENTARY

### **Caregiving for existential wellbeing: existential literacy. A clinical study in an anthroposophic healthcare context**

**Charlotte Delmar**

The paper contributes knowledge within the field of caring science and addresses existential aspects of care in practice, related to the rehabilitation of patients with cancer. The underlying values are an anthroposophic framework with its understanding of the human being as a unified body, soul and spirit, and a caring science ontology with a focus on human beings as entities that are naturally free, vulnerable and interdependent.

It is interesting and essential for good nursing that the aim of the paper is to deepen our understanding of existential care in relation to patients' existential needs. Throughout the paper, the concept of existential needs is used. It can safely be said that needs are part and parcel of people's participation in life and their endeavours to give it content and form. But to gain a deeper understanding of existential care the healthcare provider has to be aware of the concept of life phenomena. Because there are distinct differences – differences that are significant in terms of whether a healthcare provider sees and hears what kind of help the sick and vulnerable person is appealing for in a situation.

There are, for example, distinctions in gratification, consciousness and rationalisation. Needs will seek gratification whether they are bodily, physiological or cultural. Their fluctuation creates inner tension that strives for release. Needs will rise and their expression is rhythmical, intensifying until satisfaction is achieved, and a new cycle begins. Life phenomena do not exhibit such rhythms. They do not have phases, but rather fluctuate between opposite poles, such as the existential phenomena hope and doubt.

The longer gratification is deferred, the stronger becomes the experience of need. The more vital a need is – for example thirst or hunger – the stronger will be our awareness of it and we will direct our attention to fulfilling the need through goal-directed activity. But an active and receptive directedness is not always structured by needs, such as compassion. The person who has true compassion is not aware he/she is compassionate.

Concerning rationalisation, technology makes a business of gratifying human needs. Needs can be refined and thus diversified. Life phenomena do not concern a question of the inexhaustible satisfaction of growing individual needs in a constant process of refinement. Life phenomena have their origin outside the realm of technological solutions. They are not about solving problems but about embracing the existential. Helping the patient in such matters means helping him to understand the various expressions of life phenomena in order to make space for those that are ethical and existential life conducive, rather than existential life constraining. The authors relate to Løgstrup's thinking on life-utterances. They are important relational ethical life phenomena, but Løgstrup is first and foremost preoccupied with determining the ethical basis for a good life. Identifying the individual existential life conducive or constraining phenomena is about what makes life meaningful or meaningless (Delmar, 2013).

An important finding is the theme 'being open in the moment' and the discussion in the paper also starts with thoughts on the significance of caregivers' use of their senses. The authors refer to Martinsen's philosophy and theory concerning caregivers being open to impressions. And they state that open awareness, sensibility and the use of the senses of perception form the basis for existential caregiving. Sensitive, situation-specific attention and personal presence are more vital than ever in a healthcare system characterised by accelerated patient pathways, early discharge and short encounters. But in order to 'read' the patient and the situation in such a sensitive way, the questions are: How does the care provider register the patient's appeal for help? What are the significant expressions?

In the paper different examples are mentioned. In the background section, referring to current research, a significant expression is when the patient is willing to express or share their existential thoughts. In the findings 'Narration as health in a caring synthesis' and 'Being authentic and compassionate is professional' the significant expressions focus on the verbal expressions from patient and family and the openness of the patient.

The dilemma here is thus that research has shown that a patient's fear of being a burden is part of a basic view of humanity. It can be difficult to express verbally the existential meaning and existential life constraining life phenomena such as despair, anxiety, shame or guilt. (Delmar et al., 2011; Delmar, 2012). Verbal expressions are only a minor part of caregiving as existential wellbeing. An interesting issue is then to identify various significant expressions and components, such as bodily expressions. That's why the use of the senses of perception is fruitful. It is the carer's active use of eyes, ears, smell and sense of feeling. Seeing is, for example, about how the body is positioned, reading the patient's facial expressions concerning pain, fear or doubt, or observing skin colour and elasticity. The care provider needs a skilled sense of smell (you can smell when a person is dying), hearing and feeling (for example the use of physical touch).

The paper addresses existential aspects of care in practice rooted in caregivers' developed ability to use the senses and to read the situation at hand. The key concepts and the findings have been developed over many years, with particular reference to the Norwegian nurse and philosopher Kari Martinsen and the American nurse and researcher Patricia Benner. Their approach and key concepts are within the framework of a care philosophy and care ethics. Why do the authors have to bring in a new concept and theory of existential caregiving when it is in line with well-known care philosophy and theory?

Furthermore I would encourage the authors to reflect on life phenomena as a supplement to human needs within the contexts of nursing theory and of concrete and specific challenges in rehabilitation of cancer compared to other suffering groups and patients.

Clinical application research was used in cooperation with academic researchers and clinicians. It means that the knowledge can be implemented as you go along. In these knowledge-sharing settings it is important to discuss whether theory is for practice or practice is for theory.

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