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Finding oneself after critical illness: voices from the remission society

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Abstract

The number of people who survive critical illness is increasing. In parallel, a growing body of literature reveals a broad range of side-effects following intensive care treatment. Today, more attention is needed to improve the quality of survival. Based on nine individual stories of illness experiences given by participants in two focus groups and one individual interview,

this paper elaborates how former critically ill patients craft and recraft their personal stories throughout their illness trajectory. The analysis was conducted from a phenomenological perspective and led to the meaning structure; a quest to find oneself after critical illness. In this structure, illness represented a breakdown of the participants' lives, forcing them to develop a new understanding of themselves. Despite acute illness, they felt safe in hospital. Coming home, however, meant a constant balancing between health and illness, and being either in or out of control. To gain a deeper understanding of the participants' narratives of survival, the meaning structure was developed from a phenomenological life world perspective, Heidegger's concept of homelikeness and Arthur Frank's typologies of illness narratives. In conclusion listening to and acknowledging the patients' lived experiences of critical illness may support the patient efforts to establish the newly defined self and hence be vital for recovery. Phenomenology is one approach facilitating care tailored to the patients' lived experience of critical illness and its aftermaths.

Finding oneself after critical illness: voices from the remission society

“The physical existence of the remission society is modern; the technical achievement of modernist medicine makes these lives possible. But people's self-consciousness of what it means to live in the wake of illness is postmodern” (Frank, 2013, p. 18).

The term remission society refers to people who have survived life-threatening illnesses that were once fatal (Frank, 1991, p. 138). Within the current era of life-saving medicine, the number of people in remission is increasing.

For more than six decades, hospitals have offered Intensive Care Unit (ICU) treatment to critically ill patients experiencing vital organ failure (Kelly, Fong, Hirsch, & Nolan, 2014). Since then, the mortality has decreased and a growing number of patients treated in ICUs

have a better chance of survival (Kaukonen, Bailey, Suzuki, Pilcher, & Bellomo, 2014; Zambon & Vincent, 2008).

In parallel, with the successes of modern medicine the physical, cognitive and mental side effects of intensive care treatment, known as Post Intensive Care Syndrome (PICS), are increasing (Inoue et al., 2019; Needham et al., 2012). Patients may survive intensive care treatment, but increasing mortality rates, a lack of independence and an impaired quality of life have been documented post-ICU (Yende et al., 2016). Moreover, a scoping review recently summarised the complex social support needs of former ICU patients (King et al., 2019).

The chronology of patients' critical illness stories has been described as being at death's door, to being on a road to recovery where life has become less predictable (Jensen, Overgaard, Bestle, Christensen, & Egerod, 2017). Moreover, a recent review of 22 qualitative studies revealed that despite ICU survivors' experience of positive emotions and life satisfaction, they may also experience a wide range of mental, physical, social, and functional impairments after hospital discharge (Hashem et al., 2016). Thus, it seems that critical care research and practice can be improved, focusing more on outcomes that are meaningful to patients and their families (Gajic, Ahmad, Wilson, & Kaufman, 2018).

Although researchers already in the early 2000s argued that long term outcomes should be included in intensive care (Angus & Carlet, 2003), recent research shows that ICU patients still do not have access to well defined, evidence-based rehabilitation pathway (Karnatovskaia et al., 2015, Jonasdottir et al., 2016, Mehlhorn et al., 2014). Hence, a more systematic, personalised needs assessment is lacking throughout a patient's illness trajectory, and currently serves as a bottleneck when it comes to health care supply. This calls for changes, through illness trajectory and long-term follow-up, asking for a more tailored,

individualized care (Laerkner, Egerod, & Hansen, 2015; Laerkner, Egerod, Olesen, & Hansen, 2017; Laerkner, Egerod, Olesen, Toft, & Hansen, 2019).

Patient-centred care has become a well-known term, defined as care provision that is “consistent with the values, needs, and desires of patients and is achieved when clinicians involve patients in healthcare discussions and decisions” (Constand, MacDermid, Dal Bello-Haas, & Law, 2014, p.1). From a patient perspective, core elements of patient centeredness have been defined as effective communication, partnership and health promotion (Little et al., 2001). Effective communication occurs when a patient’s own perspectives on illness are explored and acknowledged, when healthcare plans are developed in close collaboration with the patient, and when care is based on the patient’s past illness history and health context (Constand et al., 2014). Despite this holistic aim, research on patient-centeredness has relied extensively on quantification and measurements (Constand et al., 2014; Mead & Bower, 2000; Ree, Wiig, Manser, & Storm, 2019). This perspective of research may fall short when it comes to promoting care, which is tailored to each person. Aiming for objectivity in studies of human behaviour, using the same ontology as in physics, was one of the main critiques raised by phenomenologists (Merleau-Ponty, 1968, p. 20).

Patients’ personal stories may facilitate an increased sensitivity toward their preferences for healthcare through the different stages of critical illness and follow up /rehabilitation (Kelleher, 2006). Former patients have to some extent written about their experiences in pathographies, which may “challenge our knowledge and attitudes about quality of life and dignity in serious illness and shed light on experiences that are to a small extent reflected in medical professional literature” (Holmoy & Frich, 2006, p. 3299, our translation). Narratives have a long tradition in literature, and illness narratives are increasingly used in health research (Herrington & Parker, 2019; Joyce, 2015; Kalitzkus & Matthiessen, 2009).

The aim of this study was to provide a deeper understanding of how former critically ill patients narrate their own experiences of the illness trajectory from the acute stage throughout rehabilitation and long term follow up.

The first-person perspective on illness

This study is grounded in phenomenological philosophy in order to describe the lived experiences of the patients in question. According to Toombs (2001, p.1) the philosophical perspective of phenomenology has been largely ignored although this perspective can provide extraordinary insight into many different areas of medicine. Among others, the meaning of health, illness and disease, and the relationship between the sick person and the one who professes to help can this approach give new and valuable insight. She highlights that the “reality” of illness-as-lived” may include certain unvarying eidetic characteristics such as loss of wholeness and bodily integrity, loss of certainty and concurrent apprehension or fear, loss of control, loss of freedom to act in a variety of ways, and loss of the hitherto familiar world (Toombs, 1987, p.234).

Taking such a philosophical perspective can help to illuminate fields that lie in darkness, and problematize what is taken for granted, so that one can get closer to the overlooked and most significant, but also painful, aspect of understanding human existence (Martinsen & Kjær, 2012, p. 19, our translation). In a phenomenological view, humans are always in the world, or beings-in-the-world, as Heidegger puts it (1962, p. 78). According to Merleau-Ponty (2012) our lived body is intentional, habitual and purposeful, always directed towards the world. In action, the body expresses “I can” and thus represents opportunities. He further described how these embodied intentional habits can be changed by illness: “I am conscious of the world by means of my body. At the same moment that my usual world gives rise to habitual intentions in me, I can no longer actually unite with it if I have lost a limb.

Manipulable objects, precisely insofar as they appear as manipulable, appeal to a hand that I no longer have (Merleau-Ponty, 2012, p. 84). As Toombs (1988, p.204) outlines with reference to Merleau-Ponty: embodied consciousness is, in the first place not a matter of “I think” but of “I can”. Bodily changes, such as those caused by critical illness, change the being in the world along with the ability of what one can do. Heidegger described the tension between the experience of being-at-home and not-being-quite at home as an inescapable part of human existence. The world is mine and not mine, as it is uncanny, uncontrollable and unknown (Heidegger, 1962, p. 233-4). Svenaeus (2000a, 2001, 2011) draws it further and shows how (bodily) illness can be understood as an un-homelike being-in-the-body and being -in-the-world. «The self must, however, always be understood as acquiring its meaning and identity by way of its being-in-the-world (Svenaeus, 2001, p.99). Thus, after illness, patients may lose the feeling of homelikeness in the body as well as in the familiar world (Svenaeus, 2011). Illness breaks with the familiarity of living (Toombs,1987). The body becomes alien and opportunities to act are suddenly changed. Moreover, new medical technologies are increasingly transforming earlier patterns of meaning (Svenaeus, 2009). When critical illness occurs, patients may therefore have a need to retell the past and to re-envision the future, to address this alienation.

Sociologist Arthur Frank has devoted attention to illness narratives, which may provide an insight that not only embraces the narrator’s story, but also in relation to the social context of the person. “This voice is embodied in a specific person, but it is equally social taking its speech in postmodern times we live in” (Frank, 2013, p. 18). Frank wrote about his own experiences of having cancer and becoming a member of the remission society and claims that there is a need for people within this society to tell their stories (Frank, 1991, p. 138) as illness narratives “give voice to experiences that medicine cannot describe” (Frank, 2013, p. 18). Although ill people still surrender their bodies to medicine, they also

increasingly share their own stories. Frank (2001, p.233) calls this need to tell one's own illness story *`a narrative imperative.`* "Consciousness must tell its experience, both to itself as means of re-establishing coherence in a milieu where routine expectations no longer hold, and to others as a means of seeking new terms of intersubjectivity" (Frank 2001, p. 233). He has outlined three different types of narrative.

The first and most common being the *restitution narrative* (Frank, 2013, p. 75-96), representing a wish from an ill person that other people want to hear. This narrative takes a typical course. First, a person becomes sick, and then undergoes a treatment phase as a remedy for the disease. During this period, the patient is exempt from their usual responsibilities and is under the control and authority of recognised professionals who fix the body. Metaphors like "as good as new" are at the core of the restitution narrative, but they also provide a model for how stories are told. A neglected limitation of a restitution story is when the impairment is chronic, where one does not become as "good as new," but changed.

The second type of narrative is the *chaos narrative* (Frank, 2013, p. 97-114), which is the opposite of a restitution story. A chaos story is more of an anti-narrative, lacking both order or narrative sequences and a happy ending. These stories are unpleasant and challenging to listen to, because the storyteller truly is wounded and has lost control. Although the story is chaotic, it is important that these stories are told as the chaos can be identified and reconstructed. What the narrator needs, is first and foremost a listener.

The last type of narrative is the *quest narrative* (Frank, 2013, p. 115-136). "The story is one medium through which the communicative body recollects itself as having become what it is" (Frank, 2013, p. 127). In the quest narrative, the person's experiences alter their perspective on life, such as the ability to prioritise issues, putting health first and recognising limitations. The quest is about finding new ways to work with illness, which **gives** the storyteller courage to continue to live a meaningful life despite the changes.

Although one should be careful to place informants into typologies, as Frank also warns against, typologies provide an opportunity to reinforce some qualities and characteristics across the individual's story. Further, narratives may help the listeners "to hear different threads in the fabric of the ill person's story" (Frank, 2010, p. 119), and by that, increase their understanding of how illness may affect life.

Methods and ethical considerations

Based on a life-world perspective, this study is grounded in phenomenology to illuminate the experiences of those who have been critically ill from onset throughout rehabilitation and long-term follow-up. Insights into such experiences may have an impact on professionals' understanding and caring for diverse health challenges.

Management staff at two hospitals and one patient organisation were contacted, and a contact person was selected at each site, who helped to distribute information letters to persons who met the inclusion criteria.

The sample consisted of nine participants, four women and five men with an average age of about 60 years. They had all been admitted to an intensive care unit over the last five years due to various severe circulatory, respiratory or neurological diseases. All of them gave written consent to participate. They were also informed that participation was voluntary and that they could withdraw from the study at any time without a given reason.

Although individual interviews are most commonly used in phenomenological research, focus group interviews were chosen to evoke recognition and stimulate dialogue and an exchange of stories among the participants, which in turn could contribute to varied descriptions of the studied phenomena (Krueger, 2014). We sought to explore the informants' experiences in breadth, variety and shades (Dahlberg, Dahlberg, & Nyström, 2008). Before opening for dialogue, each participant told his or her unique illness story. Then the group

context stimulated discussions where lived experiences were expressed, compared, and new nuances and perspectives emerged, and thus providing increased understanding of participants' life situation. The interview guide contained broad topics, e.g. the experiences of critical illness, and what it was like to be cared for in the illness trajectory. The moderators encouraged the participants to talk as freely as possible and asked them to elaborate on topics when necessary.

The research team included five nurses and three physiotherapists, seven of whom were senior researchers, along with one PhD-candidate. Two nurses served as moderator and co-moderator of the focus group interviews, respectively. The group discussions were led by the moderator while the co-moderator supported, observed, took notes and facilitated the active participation of all group members during the interviews. Two focus group interviews were conducted and lasted for approximately two hours. In addition, one individual interview was conducted with a participant who was not able to attend the group discussion. The interviews were audio-recorded and transcribed verbatim. In the interview situation, the moderator emphasized being sensitive to the participants' personal boundaries. However, they were surprisingly open about their experiences and showed a clear need to tell a coherent story.

The present study is part of a larger project where the aim was to explore the research topics that two different patient groups (critically and chronically ill) considered to be important, based on their illness experiences (authors blinded, 2019). Working with the analysis of this first article (authors blinded, 2019), made us realize that each participant had a need to tell their unique story throughout critical illness, rehabilitation and long-term follow-up. We became aware of the patients' experiences of the transitions in the health care system, such as the transition from being in the acute phase to going to a regular ward, being sent home from the hospital. We therefore re-read the transcripts from the interviews with the participants who had been critically ill, searching for descriptions of how they lived through

the whole process of acute illness, follow-up and rehabilitation. We asked for what it was like to be cared for in the illness trajectory. Reading the transcriptions anew with this focus, allowed us to cultivate certain qualities, characteristics and properties of the phenomenon. Delving into each and every individual story, looking for some characteristics of the process, brought different voices together, enabled each voice to be heard alongside other voices, thus giving shape to the narrative /typology (Frank, 2012).

The goal of a phenomenological analysis is to arrive at a meaning structure that describes the phenomenon based on the entire data material. In description of his method, Giorgi (1985, p. 20) claimed that individual experiences could be subsumed into one typology. In a later publication, the term ‘typology’ seems to be replaced by “intrastructural variability”, which means that each variant belongs to the same structure. Even if “every single description is going to be different from every other”, the meaning can be identical (Giorgi, 2009, p. 132). “A phenomenological description is to be able to follow the words into their many terms, into different contexts of meaning to get the patient’s impression. It is to discover the unexpected in the known, and to unfold the meanings of the words” (Martinsen, 2003, p. 11 our translation).

Through an open and reflective approach, a meaning structure based on the experience from all participants, was synthesized and will be presented as one typology. This does not mean, however, that the experiences appear identical in all the participants, but there are some similarities across the variations.

Audio files and transcripts of the focus group interviews were stored at the research server at the University. The study was reported to the Data Protection Officer for Research, Norwegian Centre for Research Data AS (NSD no 52287).

Typology: A quest to find oneself after critical illness

Anne has been close to death due to a severe illness. She had been suffering from headaches and went to the doctor several times but did not feel that she was taken seriously. One morning she noticed that something was completely wrong. Her face felt crooked and she could not speak clearly. Yet, she managed to call the emergency services and was admitted to hospital where she was diagnosed with cerebral haemorrhage, which caused a long stay at an ICU. Health professionals saved her life and she is very grateful, but she does not try to hide the fact that the road back to life has been long and difficult. She and her family have felt alone and abandoned, and things could have been different with more support from the healthcare system.

The story is typical for the participants in the current study. Some of them described about various symptoms some time before they became acutely ill and admitted to an ICU due to various severe circulatory, respiratory or neurological diseases. Nevertheless, several also felt that the disease came like a bolt from the blue.

Although most of the participants did not register details on the journey to the hospital, they remembered the relief they felt when they arrived. Then, they felt safe and could put their destiny in the hands of others. A man, who had had multiple heart attacks, greatly appreciated that the ambulance worker followed him all the way to the emergency room. Reflecting on his experience, he said “The ambulance worker who picked me up at home and was sitting next to me in the ambulance remained in the emergency room until they followed me into the operating room. He was there all the time. He was the only one who had been with me from the start and he was somehow a lifeline. It was amazing.” The ambulance worker represented continuity in a chaotic situation.

All the participants expressed that they experienced the treatment as effective and life-saving, for which they were very grateful. Being monitored in the ICU gave them a sense of security, although several also could tell about strange and unreal experiences. A woman said for example: “You get morphine and the whole world is turned around - I had so many hallucinations, such as coming to a new hospital every day. It was absolutely crazy.” Several of the participants, regardless of the diagnosis, remembered similar experiences. In retrospect, some said that they had wanted health professionals to sit down with them and inform them

about what they were experiencing. One of the women said: “I missed that health care professionals focused on what had happened to me, especially why I experienced all the weird things... because this could probably have helped me out of it ... for me it was like everyone around me - also my family - was weird ... I didn't understand that it was I who had lost the grip on reality. ... So they could have communicated to me in a better way, even though I had no language, I understood something.” In this situation, most of the participants felt it as important that close family members stayed with them all the time. Another female with a severe stroke, emphasized how important it had been for her that her husband had been nearby throughout her ICU stay. Most of the participants, however, realised that it had been a tough time for their relatives too.

Even though some of the participants sometimes missed the presence of health professionals, they felt all very safe in the ICU. When they were moved to an ordinary ward, however, several experienced fragmented communications with health personnel, and they longed for a closer follow up related to their feelings of uncertainty due to their specific situation and further treatment. Sleep difficulties were also common. A man who had undergone heart surgery, said that it was impossible to sleep because of noise from fellow patients and nurses who went in and out. Still, the informants had many positive experiences during their hospital stay, and they felt safe and cared for and remarked that the healthcare professionals were highly competent, efficient and caring. One of the women was in particular impressed by a young doctor who visited her in his spare time during a phase when she was critically ill, which made her feel grateful. Most said they were told that their condition was critical and even life threatening, so they understood that they might not survive. Although this was dramatic, they appreciated honesty. And they survived.

After returning home there were new major challenges. One of the men who was operated for lung cancer, reflected on comments made by the health professionals when

leaving the hospital: ““Now you're healthy," the doctors at the hospital said. And that was of course very reassuring, although it will take five years before I finally am declared healthy.”

A woman also questioned that health personnel considered her healthy at discharge, which she did not feel at all. She, like several others, felt that being discharged was like being left in the open, without knowing what to expect. One of the men said, “I felt completely forgotten and left to myself.” He believed that there should have been an interdisciplinary follow-up consultation where a patient’s needs could be considered and addressed before leaving the hospital.

Several of the participants had to learn very basic things all over again. Their body didn't respond as it used to, and they didn't understand why. Previous activities and habits suddenly became unfamiliar.

Both the participants and their relatives were, for example, unsure of which limits should be set for the patient in the beginning. What could and should they do, and what should they avoid? Many wondered who had the responsibility to make such decisions. A woman wanted a rehabilitation stay, where she could receive continued supervision and information, guidance and training. However, her application for such a stay was rejected because she was too ill, which amazed her greatly. Eventually she managed to join a training group under the auspices of the hospital, which gave her a new impetus to continue training. She looked at rehabilitation as a vital help toward continuing her life. At the same time, she had a feeling that the health services looked differently on this and questioned whether rehabilitation is taken seriously or “just a side activity for enthusiasts?” Several also asked for an opportunity to share experiences with others that had been through acute illness. One of them asked, “What about being in a group of peers (of survivors) who for example could gather once a month for sharing and processing the experiences?” Processing his experiences

together with peers could have mitigated his wife and children from the strain of being his only support.

The participants were not prepared for the many losses they would experience, nor that they could experience depression. They were all grateful for surviving a very critical illness, and therefore could not understand why they were depressed. This was a challenge because they felt that they could not talk about it. They had survived, been given their life as a gift, but still felt no joy. They wished that they had been prepared for this, and that there had been an offer of psychological follow-up during the rehabilitation phase. There was a lot to struggle with alone. Although the participants gradually returned to life, not least because of their own efforts, there were always challenges. There were many losses that they had to deal with, which led to feelings of grief. This loss encompassed many things besides the loss of ordinary activities of daily life. The loss of job, colleagues and a large part of their social network, were huge difficulties. One of the women said, “Losing a meaningful job I was enjoying – a great sorrow to me ... My job as well as my colleagues, it was like losing some of my identity”. In social contexts, she found it difficult no longer being able to present herself as an active person. She felt empty and had a difficult time adapting to life in new ways.

Neither were their relatives prepared for the many challenges in everyday life. A woman, who needed a lot of help after a stroke, thought that there should have been a follow up for close relatives. Her husband had to arrange all practical tasks alone besides his full-time job. No relatives were offered a sick leave. One spouse even quit her job to take care of her husband. Also one of the men was concerned about the situation of the relatives; “They are somehow completely left to themselves and may have been suffering all along”. Since there was no training or education program for caregivers, the participants had to inform and educate their family members to the best of their ability, which was challenging.

Gradually, the participants managed to find meaning in many other aspects of life, although the sadness that accompanied their losses did not disappear. Several mentioned their grandchildren as inspiration to live a meaningful life despite their illness.

The participants concluded by saying that they have a good life after all. Many can still do important things, but it has been – and still is – a long and heavy road to find oneself after critical illness. They believe that a rehabilitation program or a better follow-up had made it easier for them to get back to life, but they had a feeling that health professionals looked differently at this.

The need for recognition and support through a critical illness trajectory

The meaning structure ‘A quest to find oneself after critical illness’ show that one’s body and life are changed drastically when critical illness strikes, and that life can no longer be taken for granted. The illness led to a breakdown of the participants’ everyday life, changing the possibilities of what they could do and changing many of the ways in which they understood themselves.

The meaning structure given in our study may be characterised in Frank’s terminology as a quest narrative. A quest narrative can be understood in terms of a travel metaphor, where patients meet adversities and experiences that enable them to overcome obstacles (Frank, 2012, 2013; Kvale & Brinkmann, 2009). However, Frank notes that “each story will draw on aspects of all the three narrative types” (Frank, 2010, p. 119). The same goes for the current typology. The chaos narrative is, for example, in the foreground for most of the participants at the beginning of their story, when illness strikes like lightning. The restitution narrative is seen when the acute crises is over, and they are relieved to have survived. However, their stories consist predominantly of the quest narrative, encompassing lessons learned. Being discharged from hospital and left to themselves without understanding the changes and

challenges to their every-day life was a difficult process to overcome. Frank (2013, p. 117) says that the quest story meets suffering head on, and that the narrative emphasises positive change via difficult and trying circumstances. Our typology has visualized how the participants conveyed the quest narrative as a lesson they had learned. They had worked through and processed the necessary changes and challenges. Other studies have also recognized patients need for establishing a new orientation in life after critical illness (Jensen et al., 2017).

Even though the experience of illness is involuntary, the meaning that one creates from the experience of illness is somewhat voluntary, which is a sentiment that is echoed in other studies (Carel, 2012; Thomas-MacLean, 2004; Wenzel et al., 2002). However, the typology indicates the need for increased awareness that being healthy or ill has different meanings in relation to the perspective on which it is based. Toombs (1987, p.223) emphasizes that professions develop `habits of mind` that give meaning to what is interpreted. If a biomedical perspective or `habits of mind` with an organ focus meets a life-world perspective, there may be a possibility of violation or epistemic injustice, because even if the organ is treated and functioning, the person holding that organ may still feel ill and not as good as new (Carel & Kidd, 2014). As Toombs outline (1987, p. 227): “In seeking explanation, the patient seeks a validation of his experience, a means to reasonable account for his feeling that something is wrong”.

According to Kottow (2017, p. 138) the empirical turn of phenomenology should help understand the meaning of disease-as-lived and contribute to bridge the gap without disturbing the essential distinction between the lived experience of illness, and the medical focus on diagnosing disease entities and securing a scientifically based therapeutic approach. As stated by Gajic et al (2018, p. 4) “The best critical care research should seek to exploit the union of biography and biology, seeking to understand how illnesses and treatments interact

to affect both the pathology and pathophysiology of disease, and also how patients and their families experience and make sense of illness and its aftermath.” Toombs (1987, p. 235-236) argues that health personnel need to take the patient’s experiences into account, the illness - as-it-is-experienced, because such experiences reveal what illness means to the patient.

The participants in this study were surprised by being told at discharge that they were healthy following life-saving treatment. They could not understand this utterance and they wondered how these words could be true, given they did not feel healthy. According to Frank (2013), although people in the remission society are effectively well, they can never return to the life they had before. Could it be that conventional medical thinking and the narratives of health personnel are locked in a restitution narrative? And is this perspective a continuation of the biomedical approach in which humans are divided into parts (organs), which are being repaired and becoming the same as before? The phrase “as good as new” is at the heart of the restitution narrative and seems to cover the way health personnel describe a patient’s course of illness. If this is the case, however, it stands in contrast to Frank’s description of the remission society whose residents feel they constantly are in remission. They apparently live a normal life, but despite doing ordinary things periodically, they also miss out on a variety of activities, as exemplified by the woman who said that before she became ill, she had a job that she loved and which she identified with. Now that she is no longer able to work due to the physical limitations of her illness, she feels that she has lost some of her identity. Although she feels happy to have survived serious illness, she also experiences periods of depression. She feels unprepared for the daily loss of her past life, and the grief that comes with this loss. The patients’ need for a new orientation after critical illness has earlier been reported, including fear for relapses, and the struggles with loss of earlier capabilities and roles (Jensen et al., 2017). More specifically, a recent review has shown how the burdens after critical illness may be related to symptoms of post-traumatic stress disorder, anxiety, depression,

irritability, boredom, loneliness, and wishing they had not lived. Physical health reductions in mobility, activities of daily living, fatigue, appetite, sensory changes, muscle weakness, and sleep disturbances were also common and represented threats to relationships and the ability to participate in social roles and activities including hobbies and work (Hashem et al., 2016). One may say that the typology described an unhomelike being in-the-body, from which it was impossible to escape. Thus, this alien or uncanny body is at the same time their own body (Toombs, 1988, p.217). Adjustment to, and reconciliation with their own body was paramount and needed. The participants' process or struggle consisted of understanding and adapting to bodily changes, including the otherness and the alien, in the hopes of regaining familiarity with their changed body. Even though they told about a new familiarity and homelikeness in some aspects of life, most of the participants still perceive their body as vulnerable and somewhat unpredictable, even years after critical illness.

Our findings revealed how the hospital staff had focused mostly on the acute pathophysiological aspects of the participants' disease, but not on all the practical and existential changes that the disease caused, which the participants first came truly aware of after returning home. Thus, according to Frank, medicine becomes guilty of reducing the patient's suffering to a general view, and the remission society "question their place in the medical narrative" (Frank, 2013, p. 11). The participants in this study called for a broader understanding of their situation. They particularly called for a rehabilitation stay and a follow-up program after discharge. Thus, their story reveals the limitations of the medical narrative. Toombs (1988, p. 222) argues that part of the healing function is "to assist the patient in reasserting his autonomy in the face of the disintegration of lived body. This implies paying explicit attention to the various disturbances in the patient's world and in the perceived change in the relation between self and body".

However, the participants' stories also contained a lot of strengths that constitute aspects of the remission process. Knowing the danger of romanticising illness, Frank (1991, p. 136) argues that illness can be a source of self-reflection. By this he means to say that although we may be victims of a disease (except in situations where it can be prevented), we are not only victims of our illness, "Because we can choose how we experience illness, we can be more than victims." According to Frank, this presents an opportunity for the remission society. "Half victims making half-choices are my fellow citizen in the remission society" (Frank, 2013, p. 138).

Rehabilitation and regaining homelikeness was a long and hard process for the participants. It was first and foremost an active adjustment to a new way of being-in-the-world and they called for help and assistance from health personnel during this process (Svenaesus, 2000a). Svenaesus writes that health personnel should not only cure disease but should also provide possible paths back to homelikeness (Svenaesus, 2000b). To do this, health personnel must listen to and recognise the patient's experience of how the disease has changed the everyday life, so they together can find the best possible methods of follow-up or rehabilitation. Being rehabilitated and regaining homelikeness means moving forward, to a new and different form of being-in-the-world, and not the one present before the onset of illness (Svenaesus, 2000a), as is described so clearly in the story. In this context, it may be pertinent to mention Ahlzen's comment on Svenaesus' expression of unhomelike being-in-the-world (Ahlzén, 2011). He questions whether Svenaesus by this "makes it reasonably possible for us to rightly delimit the tasks of medicine" (Ahlzén, 2011, p. 329). We can agree that it may be necessary to delimit medicine from non-medical problem and that we should not talk of unhomelikeness that cannot be linked directly to an experienced illness. In the present study, however, the participants' sufferings are a direct consequence of critical illness. Without some kind of follow-up, these patients and their families are left to themselves, when

there should be a place for them in the health care and room for their stories: “Members of the remission society, who know medicine from the inside out, question their place in the medical narrative” (Frank, 2004, p. 310).

Being-in-the-world is, in accordance with Heidegger (1962), to be in a relationship with the world and other people. We discover ourselves in relationship with others. Frank (2013, p. 14-15) is inspired by Levinas when he emphasizes that it is through self-reflection that one becomes aware of one’s responsibility for others. One does not assume this responsibility of goodness, human life requires it: “The world I reach out to, is a world in which I see myself” (Frank, 1991, p. 141). Suffering allows for self-reflection, and thus the opportunity to disregard oneself and recognise that one “is no longer the beginning and end of all things” (Frank, 2013, p. 153). Seeking a relationship with others is crucial. “The ill person is then no longer the passive patient imagined by the sick role” (Frank, 2013, p. 150). This is also true for the participants in the study, exemplified in our study by the woman who sought relationships with people in a training group who were in the same situation as herself, and when she realised that her grandchildren were an inspiration to continue living life. However, all the participants, also called for support in transitioning back to life at home while they were in the hospital, and they had wanted to understand that they could not expect to be healthy in the same way as before their illness. This means that health personnel must also become aware of their responsibilities to patients, understanding the need for critically ill patients to receive more complex and long-term follow-up. The professionals’ language may, according to Frank (2013, p. 25), be too distant from the patients’ experience, which may lead to ignoring the voice of those suffering.

There is a potential risk in categorising the informants’ stories into one typology, which is a danger that Frank is also aware of and warns against. “Typologies risk putting stories in boxes, thus allowing and even encouraging the monological stance that the boxes

are more real than the stories, and the types are all that need to be known about stories” (Frank, 2013, p. 119). On the other hand, it may be beneficial to show that the study has led to insights that extend beyond the individual participant’s experiences. Although phenomenological research is based on subjective experiences, one will always aim to understand something substantial or intersubjectively recognisable (Dahlberg & Dahlberg, 2019). However, this requires diversity and openness in the face of the varied experiences. Typologies provide an opportunity to reinforce some qualities and characteristics across the individual’s story.

An objection may be that we have used focus groups in a phenomenological study. One may think that phenomenology and focus group are not related to each other. Bradbury-Jones et al (2009) reveal through their own research as well as pointing to other studies, that focus groups can enhance rather than compromise phenomenological research. They even go further and says that phenomenology is beneficial because the perspective stimulates discussion and open new perspectives. We argue that focus group interviews do not fragment the individual story but strengthen the story by bringing different voices together, giving shape and clarity to a story across all the individual stories. Nevertheless, as Bradbury-Jones (2009) argue, the approach requires a critical awareness of the research methodologies and methods.

Listen to the patient`s story

The current study has revealed a persisting abyss between patient narratives of critical illness and recovery, and the services offered by contemporary healthcare, which seem to be mostly dominated by a bio-medical view of illness. Patient narratives should be recognised beyond their diagnostic use and valued to improve the dignity, health and quality of life of patients after critical illness. Emphasising dialogue and mutual understanding through phenomenology

has been suggested as the essence of medicine. According to Toombs (1987) what the patient needs, is support in establish the integrity of a newly defined self. She outlines a phenomenological eidetic approach as an opportunity to create understanding between physicians and patients, in that the physician temporarily puts aside the 'habits of sight' and focuses on understanding of illness-as-lived. Carel (2012, 2013; 2014) promotes a phenomenological and philosophical approach to patient's illness experiences, offering a phenomenological toolkit for patients, not intended to replace medical knowledge or treatment but to supplement it. Phenomenology is uniquely suited to explore experiences as it distances us from habitual ways of understanding. Carel (2014) highlights embodiment, meaning and being in the world as three aspect of existence that are significantly modified by illness. Through this perspective, medicine cannot be explained purely through a scientific nor a humanities approach. Rather, it should be explained as an ontological entity and a basic aspect of life (Carel, 2012; Carel & Kidd, 2014; Kottow, 2017). According to Gadamer (1996), truth is connected to being receptive of others and their world, seeking to merge horizons across a productive distance. Moreover, health is not only the absence of disease, but is a way of being in the world, in which a person who experiences wellbeing is open to new things, "ready to embark on new enterprises and forgetful of themselves" (Gadamer, 1996, p. 112), accordingly, patient illness stories are vital in assessing patients' health. Recognising health in this phenomenological rather than biological form, both in health care and research, has the potential to improve health services and patient outcomes. This seems to be especially important for people who belong to the remission society.

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