A New Normality Illuminated by Past and Present! A Qualitative Study: Experiences and Challenges of Everyday Life in Patients With Advanced Heart or Lung Failure

En ny normalitet set i lyset af fortid og nutid! Et kvalitativt studie: Oplevelser og udfordringer af hverdagslivet hos patienter med svært hjerte- eller lungesvigt

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Abstract
The aim of this study was to gain insight into the phenomena of everyday life as experienced and coped with by patients living with advanced heart or lung failure. We employed a qualitative design using a phenomenological hermeneutic approach. Data derived from 10 nursing consultations in a holistic setting. Ricoeur’s theory of interpretation inspired the text analysis. The study emphasizes time (past, present, and future) as an overall everyday life theme, playing an essential role associated with improvements or poor outcomes related to physical, mental, and intersubjective challenges. Patients accepted and lived with the challenges, experiencing changes, as transition, but also coped with their new normal, which involved improvements or poor outcomes, some invisible to the community. Assumptions about everyday life changed significantly, the changes possibly essential for intersubjective relations. A reflective approach, can help patients to evolve, using knowledge from the past and present to cope with the future.

Keywords
Qualitative study, Parse, Schutz, Ricoeur, patients’ experiences, advanced heart or lung failure, everyday life, phenomenological hermeneutical, Denmark

Abstrakt
Formålet med denne undersøgelse var at få indsigt i hverdagslivets fænomener, som de opleves og håndteres af patienter, der lever med fremskreden hjerte- eller lungesvigt. Vi anvendte et kvalitativt design med en fænomenologisk hermeneutisk tilgang. Data er indsamlet fra ti sygeplejekonsultationer afholdt i en holistisk ramme. Ricoeurs fortolkningsteori har inspireret til tekstanalysen. Undersøgelsen fremhæver tid (fortid, nutid og fremtid) som værende et overordnet hverdagsstema, der spillen en væsentlig rolle relateret til bedre eller mindre gode resultater i forbindelse med fysiske, mentale og intersubjektive udfordringer. Patienterne accepterede og levede med udfordringerne, oplevede forandringer, som en transition, men magtede også det nye normale, som indebar forbedringer eller dårlige resultater, hvoraf nogle var usynlige for andre. Antagelser om hverdagslivet ændrede sig væsentligt, heriblandt var nogle ændringer muligvis væsentlige for intersubjektive relationer. En reflekterende tilgang kan hjælpe patienter til at udvikle sig, ved at bruge viden fra fortiden og nutiden til at håndtere fremtiden.

Nøgleord
Kvalitativt studie, Parse, Schutz, Ricoeur, patient oplevelser, svært hjerte- eller lungesvigt, hverdagsliv, fænomenologisk hermeneutisk, Danmark

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**Introduction**

In recent decades, advances in medical technology have increased life expectancy and improved quality of life in patients living with chronic diseases (Pons-Fauada et al., 2019; Reynolds et al., 2018). According to the World Health Organization, living with a chronic disease can be challenging (Coggi, 2013). Approximately 50% of patients living with a chronic disease in developed countries follow their treatment as scheduled and clinically recommended, possibly adversely affecting their quality of life (Hassan et al., 2019; Megari, 2013). Living with chronic disease in general, and with advanced heart or lung failure in particular, involves experiencing challenges related to treatment and underlying diseases (van Houtum et al., 2015). The challenges include symptoms and issues that influence everyday life, combined with an overwhelming sense of feeling confined (Chang et al., 2016; Hutchinson et al., 2018). Patients must handle physical, mental, and social challenges while adhering to their medical treatment (Mangolian Shahrbabaki et al., 2017). Declining physical function and social participation leading to social isolation can cause concerns about health impairments in the future (Castelino et al., 2018). Previous studies indicate that fatigue is one of the most common symptoms and negatively affects activities of daily living, mainly due to physical rather than psychological issues (Alpert et al., 2017; Norberg et al., 2010). A high level of general fatigue is associated with reduced physical activity, which means participating in rehabilitation can be a challenge (Van Cutsem et al., 2017). People who are chronically ill are largely willing to cope with what is happening to them (Chang et al., 2016) but require the necessary self-management knowledge and skills to organize their everyday life, supplemented by know-how related to participating in society (Dawson-Rose et al., 2016; Health Quality Ontario, 2013).

Since everyday life is challenging for patients living with advanced heart or lung failure (Graarup et al., 2016), the aim of this study is to gain insight into the nature of these challenges and how patients cope with them in everyday life.

**Background**

Patients with advanced heart or lung failure face a demanding everyday life since their physical, mental, and social conditions change as the disease progresses. These changes can be interpreted as transitions from one state of health to another (Chick & Meleis, 1986). From a nursing perspective, transitions occur when fairly stable states change, which means they are seen as both a result of and resulting in change, just as they comprise critical time points or events (Chick & Meleis, 1986). Patients can experience transitions as challenging but, if they are prepared and know what to expect, transitions can be healthy. Since a feeling of connectedness and continuity with nurses is essential to facilitating healthy transitions (Meleis et al., 2000), in this study we chose to do nursing consultations to provide a forum for reflection on and the facilitation of these transitions. By providing a framework for delivering individual care, the nursing consultations served as a vehicle for enabling the partnership between the nurse and the patient (Brown, 2005). Communication skills are a critical aspect of creating an open and inviting atmosphere with time for reflection. Barratt and Thomas (2019) found that nurses engaging in personable, everyday styles of communication taking into account the patient’s lifeworld enhances interactions and benefits the patient, just as making the patient feel that the nurse has sufficient time for the consultation is also essential. From the nurse’s perspective, nursing consultations can reveal significant, valuable knowledge in terms of acknowledging the patient’s situation (Wilkinson et al., 2016).

Based on this background, we conducted a qualitative pilot study to explore whether nursing consultations can provide an opportunity for patients with advanced heart or lung failure being followed permanently in our ward, and being treated with medication or who underwent a transplant, to reflect on the challenges and worries they experience in their everyday lives (Graarup et al., 2016). The findings showed that attending nursing consultations was acceptable, useful, and meaningful for patients and enabled them to reflect on everyday challenges (Graarup & Højskov, 2020).

Following the pilot study, nursing consultations were implemented for patients being treated for advanced heart or lung failure. Parse’s (1998, 2014) human becoming theory served to inspire the framework for the nursing consultations, which comprised a dialog between a patient and a nurse, with the patient setting the agenda. Like other nursing theorists, Parse’s approach is based on the German philosopher Heidegger’s (1991) phenomenological and hermeneutic understanding of human beings. Ontologically, Heidegger’s philosophy focuses on being, that is, on what it means to be a human being. Applying Parse’s theory, our approach, which focuses on dealing with patients’ everyday life and management of treatment, is based on a holistic view of patients. The nursing consultations, which provide a space for dialog between patient and nurse, initially cover topics such as life before the disease, what life is currently like, and short and long-term visions about life in the future. The consultations comprise discussions, silent engagement, and shared reflections, providing patients with the time and space to explore, discover, and address their own health desires.

After conducting nursing consultations for more than 6 months, we examined the diverse variety of issues patients raised and concluded that additional research involving
further exploration of the content of the nursing consultations was required. Reflecting on these issues led us to ask the following question: What phenomena characterize the health situation of this group of patients in their everyday lives? Thus, the purpose of this study was to gain insight into the phenomena of everyday life as experienced and coped with by patients living with advanced heart or lung failure in the context of nursing consultations.

Methods

Scientific and Theoretical Framework

Because this exploratory study concerns gaining insight into the phenomena of everyday life as experienced and coped with by patients living with advanced heart or lung failure, we chose a qualitative approach. The nursing consultations described above were part of the planned patient care, making them an obvious source for collecting the empirical material. The French philosopher Paul Ricoeur’s phenomenological hermeneutical approach underpins our study, creating a useful foundation from which to explore first-person accounts of the experience of everyday life in patients with advanced heart or lung failure and that brings the process of humanbecoming into focus in our patient group (Missel & Birkelund, 2020; Ricoeur, 1976).

In keeping with our approach, we apply ideas by Austrian American philosopher and social phenomenologist Schutz (2015) and Israeli American sociologist Antonovsky (1993), which enables us to more fully elaborate upon and strengthen our interpretation, understanding, and discussion of the findings. Schutz (2015) examines the perspective of everyday life based on the belief that every human being is unique and that the world exists here and now for each individual while also simultaneously containing the past and future (Schutz, 2015). Knowledge of everyday life remains intact if certain assumptions remain unchanged, but if unfamiliar events disrupt it, for example, being diagnosed with a chronic disease, the usual model of interpretation fails, hindering understanding of concepts or relationships that form the individual’s everyday life (Schutz, 2015). Antonovsky (1993) theory of salutogenesis provides an understanding of how coping, defined as a sense of coherence (SOC), succeeds if viable, proper resources are available.

Participants and Recruitment

The setting was a nursing consultation that took place in an undisturbed room at a department of cardiology at a university hospital in Denmark as part of an annual follow-up program at the out-patient clinic. To obtain a variety of perspectives on everyday life, we identified and consecutively recruited a mixture of patients with advanced heart or lung failure being treated with medication or who had undergone a transplant and were participating in an annual follow-up visit between October 2018 and January 2019. At the visit, we invited them to participate in a one-on-one nursing consultation that would be audio-recorded. Potential participants were ≥18 years of age, spoke Danish, and were not diagnosed with dementia. Ten patients (n=7 males), ranging from 28 to 60 years of age, with a mean age of 52, were included. Eight were married and more than half of them had employment.

Data Collection

The first author, who had experience conducting nursing consultations on a daily basis for 6 months, collected the data. Nursing consultations, which lasted 12 to 46 minutes (mean 30 minutes), were audio recorded, after which the authors transcribed them verbatim. Given that consultations took place during the annual checkup, the nurse began by asking patients how they were doing and facilitated dialog by stating: “Please tell me more about . . .”, or asking questions like: “What does that mean to you?” and “What were your thoughts about . . .?”, all of which were designed to encourage patients to unfold the personal phenomena of their lived experiences.

Data Analysis

Data were examined using a phenomenological hermeneutic approach aligned with Ricoeur’s (1973) theory of interpretation, which aided our endeavor to explore and understand the perspective of patients living with advanced heart or lung failure in everyday life. Distanciation was achieved by using the verbatim transcriptions from the nursing consultations (Dreyer & Pedersen, 2009). The interpretation of the data included three levels: a naïve reading, a structural analysis, and a critical analysis and discussion (Ricoeur, 1973). Each author individually analyzed and interpreted the text before jointly discussing the findings at each of the three levels. The first level, which included reading and rereading the text to grasp its meaning, involved taking a phenomenological approach and being as open as possible to allow the text to speak in order to make initial assumptions (Missel & Birkelund, 2020). Interpreting a text requires identifying not only new perspectives in accepted understandings but also recognizing being-in-the-world, that is, following the text’s movement from what it says to what it talks about (Ricoeur, 1973). To achieve that kind of understanding, the next level of interpretation involved a structural analysis (Table 1) to validate and refine the naïve interpretation (Missel & Birkelund, 2020). This consisted of describing units of meaning (what is said about various aspects of everyday life) before identifying and defining units of significance (what is talked about. i.e., describing the essence of aspects of everyday life), which led to the emergence of key themes, sub-themes, and patterns (Missel & Birkelund, 2020).

The third and final level of interpretation comprised a critical analysis and discussion of the sub-themes identified and deliberated upon during the structural analysis (Missel & Birkelund, 2020), which had added new theoretical positions and led to a more comprehensive understanding of the
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Ethical Considerations

This study was carried out in accordance with the Declaration of Helsinki II and approved by the Regional Research Ethics Committee and the Danish Data Protection Agency (file no. VD-2018-136, RFC 6379 Suite I). Adhering to confidentiality requirements, the researchers explained the study’s purpose, that the audio recordings would be destroyed after transcription, and that the data would be anonymized. Patients independently and voluntarily participated in this study, just as they provided informed written consent. Nurses conducted consultations respectfully and with an appreciative attitude.

Findings

Overall, the phenomena patients with advanced heart or lung failure experienced in everyday life were chiefly time related, pendulating between time points and shedding light on how the past, present, and future affect everyday life.

In our patient group, the phenomena of time play an essential role and is associated with improvements and poor outcomes related to their physical, mental, and intersubjective challenges due to the prognosis of having a serious disease. Based on data from the nursing consultations, we identified four sub-themes: (1) receiving a gift with a moral obligation attached, (2) effect on various aspects of everyday life, (3) a new normal in significant social circles, and (4) disability as a constant companion. These sub-themes highlight the meaninglessness and meaning of the losses and rewards patients living with advanced heart or lung failure experience in relation to their symptoms and disease prognosis.

The following section presents the four interrelated sub-themes that emerged during the structural analysis of the text from the nursing consultations. The phenomena of time are embedded and unfolded in the sub-themes. Patient quotes illustrate our findings, revealing what was said, coupled with our analysis of what was talked about.

Sub-Theme 1: Receiving a Gift with a Moral Obligation Attached

The patients are happy to experience everyday life being a part of the family. For some it is rewarding to be a part of the group of colleges at work, for other finishing working life can be a relief. Having an active life is approached in individual ways.

| Meaning units | Condensation | Subthemes | Key Theme |
|---------------|--------------|-----------|-----------|
| “I am back in the role as a father, and that means a lot to me. I can be a part of my kids’ life, see them go to school, one of them finished college this year – all these special moments you are able to experience – it is amazing” (P7). | The patients are happy to experience everyday life being a part of the family. | Family pattern | Different aspects of everyday life |
| “Gradually I started to work again. It is simply so rewarding to get away from home and talk to some colleges” (P7). | | Working life | |
| “Sometimes I have been between sleep and awake in doubt; do I have to go to work today? It is a relief to have finished; I am fine staying at home” (P3) | | Retreat from working life | |
| “I never really got started being active. Years ago, I couldn’t exercise – it was dangerous for me. I believe there is an ingrained fear in me – telling me it is a bad thing to get my heart rate up” (P8) | | Functional level | |
| “I walk, take the stairs and bike – I almost never go by bus – and the walker is gone. Yesterday I decided to get my own internet shop” (P9). | | Different aspects of everyday life | |
| “I play a little golf. It is nice to exercise outside, and it is so funny. I like to snorkel too” (P5). | | | |

Table 1. Example of Structural Analysis.
home quarterly, allowing me to easily stay up to date.” Women in our patient group may long to have children but understood the dangers of becoming pregnant: “I will never secretly do it [get pregnant] – I don’t dare to.” Patients were aware that living with advanced heart or lung failure and receiving complex treatments, taking costly medication, or undergoing a transplantation necessitated that they skillfully observe stringent guidelines. They must take medication on time, take their blood test results into consideration, and avoid a risky lifestyle. The nursing consultations showed that they realized that structured, careful everyday living, for example, taking their medication on time, leads to substantial physical and psychological benefits. They accepted that their ability to act spontaneously was constricted. By obeying guidelines after treatment, the patients hoped to achieve the best possible quality of life. In essence, they understood that their treatment was a gift with a moral obligation attached, that their present actions could bring future benefits.

Sub-Theme 2: Effect on Various Aspects of Everyday Life

Patients reflected on their personal everyday lives. Each of them their own memories of the past, a life in the present, and dreams for the future. For some, although returning to family life after their transplant was an enormous challenge, they coped with everyday life and followed their strict medication schedule knowing that this was required to achieve a better quality of life with a chronic disease. One participant explained, for instance: “I’ve resumed my role as a father and that means a lot to me. I can be part of my kids’ lives and see them go to school. One of them finished college this year – I’m able to experience all these special moments. It’s amazing.” It is essential for people living with advanced heart or lung failure to be able to actively take part in special events, a feat most people take for granted.

Patient attitudes toward their work life vary, their illness and treatments causing them to see everyday life from a new perspective: “I gradually started to work again. Getting away from home and talking to some of my co-workers is simply so rewarding.” Others described a sheer sense of relief at not having to work anymore: “Sometimes I’ve been very unsure about what to do, what a nightmare. Should I go to work today? It’s a relief not to think about that anymore. I’m fine with staying at home.”

Physical activity is another central aspect of everyday life. Guidelines, especially for chronic diseases, recommend being physically active. Even though patients understand its importance, planning physical activity can feel overwhelming due to the logistics of how to get to the health and exercise center, how to relate to others, and what exercise to do. Some patients said finding the time or staying focused was difficult, “I never really got started with being active. Years ago, I couldn’t exercise because it was too dangerous for me. I believe there’s an ingrained fear in me telling me that getting my heart rate up is a bad thing.” Others were relatively active during the day: “I walk, take the stairs, and bike. I almost never go by bus – and my walker is gone. I play a little golf. It’s nice to exercise outside and playing is such fun. I like to snorkel, too.” Most of the patients were active in everyday life but at different levels. They were all aware of the importance of exercise, but fatigue or work could hinder plans to exercise, a lack of time or physical strength also causing them to refrain from exercising. Despite their awareness of its value, others were unable to be active for various reasons, such as disability or chronic pain. Possessing knowledge about the right path to follow and being unable to do so was a frustrating dilemma.

Sub-Theme 3: A New Normal in Significant Social Circles

A new normal arises after receiving a complex treatment since patients must follow stringent guidelines and explore how their treatment affects their new circumstances in terms of building a meaningful everyday life. Returning to normalcy, for example, having a job and co-workers to talk to, involved having dreams for the future. Some patients worked part-time or had a special agreement with their employer: “I work 10 hours a week and I have a permanent buddy. Sometimes I have to take a break to normalize my breathing. Some co-workers – they don’t understand – but my buddy does. We knew each other before I got sick.” This patient also described what he would miss if he had to stop working: “I like to be in contact with customers. We meet so many different people in our job. I would certainly miss that.”

Being together in various communities was highly appreciated. Physical activity increased physical capacity but also positively influenced mental health. Patients who used to do sports related it to a better quality of life: “It annoys me that I can’t do sports anymore. After practice, you relax and talk to your teammates. I really like to feel that I’ve exerted myself physically.” Another patient described the new normal as follows: “In the summer, we meet and go for a ride on our motorbikes, and in the winter, we meet in the clubhouse once a week to eat together. There are 20 of us. We don’t spend time drinking or smoking; we sit together, have a coffee, and talk about how our families are doing.”

Taking part in various social circles offered positive stimulation and let patients experience a sense of freedom from their underlying disease. Being part of various communities, having co-workers, and having people to spend time with helped them to be a human being and not just a patient.

Generally, patients did not want to spend a great deal of time being a patient. Instead, they wanted to focus on what they saw as the important aspects of their personal, everyday life. Traveling for hours to get to a brief appointment at the outpatient clinic was seen as an unwanted disturbance that interfered with everyday life: “Doctors are interested in continuity; I don’t need to frequently hear that I’m stable.” An important motivating factor for establishing a new normal was to take active part in the communities they were already
familiar with and had appreciated being part of previously. Having co-workers or being on a soccer team created sense of joyfulness and provided giving relationships since patients again had the opportunity to be part of the everyday life of others. The desire to incorporate highly familiar and benefi-
cial communities in their new normal can also be interpreted as the patients’ desire and need to keep some of the vestiges of their lives prior to any wreckage caused by their diagnosis. Patients prioritized a new normal that involved not wasting precious time on activities they deemed less valuable, for example, apparently unnecessary medical appointments reminding them of their disease. They preferred to spend time on everyday life with others in their social circle to prior-
itize life’s beauty.

**Sub-Theme 4: Disability as a Constant Companion**

Life is lived in a cultural context in which people evaluate and judge one another’s actions, which can make hidden symp-
toms a challenge. Sometimes chronic disease is invisible to others, but the presence of frailty, fatigue, and shortness of breath mean patients are constantly reminded of their condition. Scheduling time to recover after an activity may be a useful strategy for patients that would allow them to continue participating in what means the most to them. The patients mentioned that explaining how tired they were or that they needed help was difficult: “My kids laugh their heads off when I ask them to carry my bag. But it’s such a relief when I can walk without carrying anything. I bought a shopping cart, but my daughter tells me that only old people have those.”

Frequent daily naps and prioritizing tasks were a must. Scheduling time to meet with friends could be perceived as difficult since predicting the state of one’s health and mental state was seen as impossible. The social life of people living with a chronic disease often suffers due to frequent cancel-
ations, at times leading to isolation.

Another perpetual problem was feeling guilty about not being able to meet other people’s expectations: “It’s no fun when we’re out shopping and my wife has to carry all the heavy stuff while I do nothing.” Cultural expectations regarding tasks generally associated with a specific gender may lead to lack of self-confidence as the patient is unable to live up to them. Spousal relationships may suffer if the person with advanced heart or lung failure is viewed as lazy: “Sometimes I walk around at home unable to force myself to get started. Then my wife can’t understand why I haven’t done anything while she was at work – and I feel guilty.” High external expectations may cause physical discomfort, for example, an increased heart rate: “I could hear myself starting to snap at other people, and my wife said that if I didn’t stop it, our relationship wouldn’t last forever.” At times, patients felt that they were being pushed over the edge, in part due to the tough challenge of accepting their limitations. Patients described the challenges of everyday life living with a chronic disease, including various restraints invisible to others. Their descriptions indicate that having disability as a constant companion may prevent them from acting as an equal or responsible partner in life.

**Comprehensive Understanding and Discussion**

To our knowledge, this is one of the first studies based on empirical data derived from nursing consultations that 
explores the phenomena of everyday life in patients with advanced heart or lung failure. In this section, new theoret-
cal positions are added and comprehensive understandings are elaborated upon to create a deeper understanding of the patients’ phenomena of everyday life (Ricoeur, 1976). Due to our phenomenological hermeneutical approach to the theme and sub-themes, we shift back and forth between the reflection process and discussion. The overall theme time and the four sub-themes identified from the analysis and interpret-
tion of the text representing the patient perspective: receiving a gift with a moral obligation attached, the effect on various aspects of everyday life, a new normal in significant social circles, and disability as a constant companion.

**Time as an Overall Theme**

The overall theme time, to reflect on everyday life and the meaning of life takes place in a peaceful moments distance to concrete events (Brinkmann & Eriksen, 2003). During the nursing consultations, the patients take a moment to reflect on life and their lived life, the past and the present, making themselves open to an opportunity to decide whether their lives are being lived in a desirable way or not. The distance to concrete events allows patients to consciously try to change their lives, their future. According to Schutz (2015), there is an important distinction to be made between ended acts and ongoing actions. This is in line with Parse’s (2014) assumptions about quality of life and quality living as she presents them. To describe the concept of act, Schutz explains three dimensions of time: (i) the ongoing action as experienced later, (ii) the ended act, experienced in the present because we are reflecting upon it, and (iii) the anticipated action that can transcend the present and contain possibilities for future experiences. The word act is empty because the word alone does not exist. Every action is motivated by intentions and has a subjective purpose and content of meaning that evolves through reflective interpretations of the terminated interpretations. Our findings emphasize the ended acts experienced in the present as a patient reflects on the lived experiences. The anticipated action that can transcend the present and contain possibilities for future experiences also appears when patients expressed desires concerning their future everyday lives (Schutz, 2015).

**To Follow Guidelines in Everyday Life**

Renewed vitality can be described as the wish and ability to take responsibility for one’s own life (Liu et al., 2020).
For patients living with advanced heart or lung failure, receiving specialized, complicated treatments can be compared to being offered an overwhelming, unexpected gift. However, this gift may place enormous demands on the patient’s lifestyle since accepting the gift entails obeying follow strict guidelines for the rest of one’s life (Ivarsson et al., 2013; Mangolian Shahrbabaki et al., 2017). Studies show that self-management and educational programmers play a significant role in terms of improving quality of life in patients living with a chronic disease (Camus-Garcia et al., 2021; Jonsdottir, 2013; Sindhu & JayaKumar, 2018), which aligns with our findings, which show that patients with advanced heart or lung failure have an inherent desire to pursue a high quality of life by adhering to medical guidelines.

Previous studies have focused on compliance, adherence, concordance, and underlying reasons for not following recommendations (Fraser, 2010; Khair, 2014; Lawn, 2011). Patients living with an advanced chronic disease enter into a lifelong relationship with nurses, who inform and advise them, on one hand, to do as they are told and, on the other hand, expect self-management (Felzmann, 2012). Some patients will profit from being directed in this particular manner; however, others may find it challenging. Our study highlights the significance of the therapeutic relationship between patient and nurse. As a result, relational ethics and care ethics become relevant to the extent that they identify key characteristics of a constructive ethical approach to this relationship (Felzmann, 2012). A recent review that pointed out the differences and similarities between the terms compliance, adherence, concordance, empowerment, and self-management concluded that the concept of care for patients must be guided by the promotion of quality of life and prevention (Settineri et al., 2019). Listening to patients can bring forward useful insights and knowledge that can assist healthcare professionals in providing strong indications and advice about suitable medical treatments, as recommended and supported by a European Patients’ Forum position paper (2015). Paradoxically, the patients experience feeling squeezed between time available to live life and recommendations from guidelines, which are experienced as limiting by the patients. Therefore, the relationship between patient and nurse is important when everyday life and guidelines are to be reconciled. The aim of the relation between the patient and the nurse is to make the recommendations acceptable to each patient.

Inspired by salutogenesis, Antonovsky (2012) perspective on coping with challenges led to his decision to focus on health instead of illness, which is why he inquired about what makes people stay healthy despite facing multiple stressors (Antonovsky, 2012). According to Antonovsky, big and small crises and conflicts in life that are difficult to handle can be a challenge for everyone. They can be too much for some people, while others may learn from the same crises or conflicts and evolve, providing them with additional experience to cope the next time challenges appear (Antonovsky, 1993) and allowing them to acquire what Schutz (2015) describes as a natural approach. In other words, they gain the ability to find meaning and acquire what Antonovsky (1993) calls a sense of coherence (SOC), which involves (i) comprehensibility, (ii) manageability, and (iii) meaningfulness. Keeping SOC in mind, it can be argued that patients living with a chronic disease can more easily adhere to guidelines if they are understandable, manageable, and meaningful (Antonovsky, 1993). Findings in this study show that guidelines are followed, but that compliance and adherence might not need to be characterized as SOC. In contrast to this, concordance contains signs of communication since negotiation is needed to come to an agreement between patient and healthcare professionals, but guidelines still might not contain SOC as concordance only symbolizes an agreement between two human beings. Empowerment, shared decision making, and self-management characterize the activated patient, living with a chronic disease (Fraser, 2010). The patients might evolve competencies if the challenges they face in life are understandable, manageable, and meaningful. Communication regarding treatments ought to be grounded in complete and comprehensive information, be available, and be tailored to both the individual and specific groups, such as patients who are older and patients with low health literacy (European Patients Forum, 2015). Offering patients with advanced heart or lung failure an expensive or complicated treatment calls for tailored support from nurses to help render the gift understandable, manageable, and meaningful to the individual patient.

**Experiencing the New Normality**

Time is an essential aspect of Schutz and Parse’s theories. As human beings, we live in the present and move from present to future using common knowledge but also acquire new knowledge, which provides us with new perspectives on different items and life itself (Parse, 2014; Schutz, 2015). For patients with chronic diseases, building the future based on past and present experiences is natural. In line with Parse, that makes every human being unique. Personal experiences are unconsciously used to cope with the present and the future. According to the human becoming paradigm, we evolve continuously, which is also the case for patients living with a chronic disease. Changes in the patient’s condition, experienced as transition from one phase to another, require new knowledge and provides new perspectives in life (Meleis et al., 2000). Although the disease and subsequent complications affect patients’ development, invisible opportunities nonetheless become visible (Parse, 1998, 2014).

An essential part of recovery after hospitalization and rehabilitation is the return to everyday life. Being capable of recreating the normal of everyday life entails redefining knowledge and experiences about everyday life as learned and experienced in the past (Wiltshire et al., 2021). This knowledge is familiar and entirely undoubtedly. In Schutz’s (2015) description of the natural setting, this knowledge...
provides a commonsense setting in which the outside world seems given and natural; it exists here and now for oneself and others, just as it has a past and a future.

Everyday family life involves taking on various roles and social interaction as a spouse, parent, or child. For many patients, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible. In other cases, circumstances, returning to everyday family life is possible.

Methodological Considerations

This study provides insight into the phenomena of everyday life as experienced and coped with by patients with advanced heart or lung failure. The overall strength of this study is that the data was derived directly from clinical practice, was audio recorded, and transcribed verbatim. The text represents the topics in everyday life that the patients brought up to discuss with a nurse and reflect on during nursing consultations. This setting provided data that emerged naturally and that was not constructed.

The trustworthiness and credibility of our research rest on its dependability, confirmability, and transferability (Polit & Beck, 2014). The nursing consultations were conducted at the hospital as part of the annual follow-up, which increases our study’s credibility. The 10 participants provided insights into their experience of everyday life with advanced heart or lung failure. The consultations were audio taped and transcribed before being interpreted in accordance with the three levels in Ricoeur’s theory of interpretation. The two authors independently interpreted the text before meeting to compare their findings. If any disagreement occurred, a peer was invited to participate in the discussion. To achieve dependability, the first author collected data over a 4-month period. The first author and the patients already had a confidential relationship since nursing consultations are a part of outpatient clinic treatment. The authors were aware that patients are unique and that their everyday lives are differ, which means the consultations naturally diverse. We established a clear foundation by stringently following Ricoeur’s three levels in the analytic process to achieve confirmability and to acquire useful information, for example, disease-related characteristics of the patients and the inclusion criteria, which were examined to support assessment of transferability. Suitable patient quotes from the consultations shed light on how the findings can be transferred to other groups of patients with chronic diseases. The purpose of this study was to highlight our patient group’s experience of everyday life to contribute to the further exploration, mapping, and development of the continuity of nursing care in the future for the benefit of patients being treated for advanced heart or lung failure.

Conclusions

This study explored the phenomena of everyday life in patients with advanced heart or lung failure that are invisible to nurses. Our patient group was greatly affected physically, mentally, and socially. The challenges they faced were more difficult to cope with if not reflected upon. Using a reflective approach supported by nurses aided patients in making healthy transitions and in understanding the phenomena, helping turn them into comprehensible, manageable, and meaningful opportunities for coping with everyday life. In clinical practice, this process is relevant because it can help patients evolve and use their past and present knowledge in the future, which facilitates the humanbecoming process and thus their quality of life. Nursing consultations represent a haven for promoting this process.

From a nursing perspective, this study shows patients experience treatment for advanced heart or lung failure as complex and strenuous, both in terms of visible and invisible challenges in everyday life. Living with advanced heart or lung failure and receiving specialized treatment involves various everyday life phenomena related to the disease and treatment. These phenomena encompass the complexity of everyday life with its physical, mental, and intersubjective
challenges while patients fight to return to a new normal in their family lives and social circles. Their disease progression leads them to reflect on life, their thoughts often focusing on time and the possible improvements and poor outcomes affecting their new normal.

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Data Availability
Both authors have full control of all primary raw data (in Danish) and can grant the journal access to the data upon request.

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