



# Living in the Shadow: A Qualitative Exploration of the Experience of Being a Caregiver of Patients Receiving Palliative Care for a Life-Threatening, Non-Malignant, Chronic Illness

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## Abstract

**Background:** Living with a life-threatening illness is rarely an exclusively individual matter. Research about chronic illness and palliative care; however, lack the perspectives of close caregivers. The purpose of this study was therefore to gain insight into and an understanding of how it is experienced to be a caregiver of individuals living with a life-threatening, non-malignant, chronic illness and how illness interferes in the shared everyday family life.

**Material and Methods:** A qualitative research design was employed underpinned by Ricoeur's phenomenological hermeneutical philosophy as the epistemological stance. To capture the multifaceted nature of caregivers' lived experiences, narrative interviews with caregivers of individuals with kidney failure, cystic fibrosis, or intestinal failure were conducted. The family systems theory was applied as a theoretical framework.

**Results:** This research highlights the importance of broadening the focus of palliative care to include caregivers of individuals living with life-threatening, non-malignant, chronic illness, as these families also face unique challenges and require specialized care. By examining caregiver perspectives, we uncovered four themes: The ripple effect – the impact of illness on family everyday life; Make it or break it - embracing strength and role dynamics; Living fully despite chronic illness; and the Paradoxes of life. These themes can inform healthcare professionals and support services about how to develop tailored interventions and resources that address the specific needs of these caregivers, ultimately improving their well-being and quality of life.

**Conclusion:** Living, as a caregiver in the shadow of a loved one's illness is a complex and emotionally demanding experience. This study illuminated the diverse experiences of these caregivers, offering insights into their challenges, life strategies, and supportive care needs. The research extends to multiple stakeholders involved in the care and support of individuals receiving palliative care targeting the family as a unit of intervention.

**Keywords:** Caregiver; Caregiver Burden; Palliative Care; Chronic Illness; Qualitative Study; Phenomenological Hermeneutical

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## INTRODUCTION

Historically, most of the research on living with chronic, life-threatening, physical illnesses has addressed the ill persons' individual processes. However, it is increasingly recognized that illness takes place in an interpersonal context [1,2] and most likely, it is family members who are the ill persons' caregivers. This role as caregiver is defined as an unpaid non-healthcare professional who provides for the health and welfare of the ill person [3,4]. Being ill is thus rarely an exclusively individual matter for ill people or their families. According to the Calgary Family Assessment and Intervention Model [5], the family is conceived as a group of individuals who are bound by strong emotional ties with a commitment to being involved in one another's lives [6]. It is therefore unquestionable that an illness affects the family with a profound impact on how the entire family functions [1,3,7]. Family-centered approaches in healthcare have gained recognition as effective strategies for improving the quality of healthcare and enhancing the satisfaction of ill persons, their families, and healthcare professionals [8-10].



Moreover, family caregiver mastery can predict ill persons' survival [11], and the social support that caregivers receive can influence ill persons' wellbeing [12-14]. It is also reported that being a caregiver of and caring for a person with a life-threatening, non-malignant, chronic illness can be a burden and negatively influence the caregiver's own everyday life, quality of life, health, and well-being [15-17]. It is also well known from cancer research that the emotional handling of illness by the ill person and caregiver does not seem to be independent of each other [18,19] meaning that illness can also be limiting for the caregivers' life and activities [20,21]. Caregiving, although at times experienced as emotionally rewarding [3], might as such be stressful [4] and caregivers are described in the scientific literature as a "hidden patient group" [15].

Palliative care is an essential component of healthcare that aims to enhance the quality of life for individuals with life-threatening illnesses and their families. However, there has been a notable disparity in the clinical focus and research within palliative care, with a predominant emphasis on individuals with cancer [22-24]. However, there are twice as many persons with non-cancer illnesses and palliative care needs than there are with cancer [25]. Furthermore, lived experiences of caregivers in the shared everyday life with life-threatening, non-malignant, chronic illness are not fully researched and described within palliative care science research leaving gaps in knowledge and creating uncertainty regarding the potential challenges and benefits of palliative care in these families [24]. In the definition of palliative care according to the World Health Organization, an emphasis is simultaneously placed on the caregivers' health and need for support to be evaluated and treated [26].

By recognizing the valuable role of families in the care process and actively involving them as partners, healthcare organizations can create a more person-centric and supportive care environment. Within research about chronic illness and palliative care there is, however, a lack of research shedding light on how close family members or close caregivers to these ill persons are affected [7]. Applying current evidence for palliative care to caregivers of individuals with non-cancer illness may therefore restrict its applicability because another chronic illness might have a different trajectory than cancer [24,27]. Research involving such perspectives of family members or close caregivers of persons with chronic illness can improve healthcare professionals' understanding of what these caregivers go through and may enable the development of knowledge-based family-centered palliative interventions. Hence, the purpose of this study is to gain insight into and an understanding of how it is experienced to be a caregiver for individuals receiving palliative care for a life-threatening, non-malignant, chronic illness and how illness interferes in the shared everyday family life. The intention is to contribute to clinical implications so that interventions can be developed and implemented to promote a holistic and person-centered approach to palliative care that better integrates the needs of family caregivers.

## MATERIAL AND METHODS

The study was designed as an in-depth exploration of the lived experiences of close caregivers to ill persons undergoing treatment for a chronic, non-malignant illness.

### Philosophical Underpinnings

The methodology applied in this study of experiences of being a caregiver for individuals receiving palliative care for a chronic illness is inspired by phenomenological and hermeneutical aspects of the philosophy of Ricoeur [28,29]. Phenomenology is seen in this study as an epistemological stance for exploring first-person accounts of what it is like to be a caregiver for a person living with a chronic illness [28]. The starting point is about how phenomena are experienced pre-reflexively, namely experiences from the caregiver's lifeworld. In this study, we wished to look at how the caregivers experienced a life intertwined with an incurable, non-malignant disease. To gain insight into the meaning of such experiences, we combined the phenomenological descriptions

with hermeneutic interpretations as suggested by Ricoeur [30,31]. In hermeneutics, understanding and interpretation are fundamental ontological conditions for human existence. Hermeneutics are concerned with interpreting the surplus meaning contained in the human lifeworld and traces left by the caregivers through their language, attitudes, and actions. This approach provides a framework in which caregivers' lived experiences can be interpreted, and thus, a comprehensive understanding can be achieved [30].

### Theoretical Framework

As known from a scientific perspective, illness will have an impact on the family as a unit and may influence the health and well-being of all members of the family [32]. The theoretical foundation for this study was therefore an understanding of the family as a system [6]. To gain an in-depth understanding of how the lifeworlds of close caregivers were affected by life-threatening, chronic illness, and how illness interfered in the shared everyday family life, the family systems theory, as it was developed by Wright & Leahey [6], inspired the interpretations. Family systems theory offers a valuable framework for understanding the interconnectedness and interdependence of family members in the context of palliative care [33]. In palliative care, this theory helps healthcare professionals understand the complex interactions within families, including communication patterns, roles, and emotional dynamics. By recognizing the influence of family dynamics, healthcare providers can better address the unique needs of each family member and promote a holistic approach to family-centered palliative care.

### Recruitment and Participants

This study included the closest caregivers of individuals being treated for a chronic, non-malignant disease, namely persons with kidney failure treated by hemodialysis, cystic fibrosis, or intestinal failure treated by parenteral nutrition. These populations are all experiencing a life-threatening, non-malignant, chronic illness with a poor prognosis that requires time-consuming treatments, hospital check-ups, and admissions as well as high symptom burdens [1]. Participants were part of a larger cross-sectional questionnaire study [34] on quality of life, self-reported health, symptoms, and level of distress in caregivers of persons with chronic disease. The questionnaire study was carried out at the Department of Palliative Care at Rigshospitalet in Denmark where 255 persons [34] with either kidney failure, cystic fibrosis, or intestinal failure participated. These caregivers had been pointed out by the ill person to be a close person involved in the care and they were mostly family members (98%). Our experiences from the questionnaire study [34] were that a proportion of the caregivers expressed a strong desire to share more in-depth accounts of their experiences of being caregivers of a chronically ill person. On this background, we invited and purposefully [35] sampled nine of the caregivers to participate in individual qualitative interviews to allow their voices to be heard and their experiences to be acknowledged. To ensure a varied sample, we included caregivers of persons with different chronic, non-malignant illnesses, caregivers with different relationships to the ill person, at different ages and genders and from various regions in Denmark. The rationale for these differences was to obtain variation in the caregivers' experiences of living with an ill person according to the purpose of the study. The caregivers were approached by a project nurse (SL) and informed about the purpose of this qualitative interview study, and if the caregiver agreed to participate, an appointment for the interview was scheduled. The caregivers, namely seven women and two men aged 25 to 60 years of age, took part in individual face-to-face qualitative interviews, carried out by an experienced clinical psychologist (DTJ) and a senior palliative consultant (IE). During the study period, the interviewers did not meet for clinical consultations with either the ill person or the caregivers included in this study. Table 1 provides participant information.



**Table 1:** Participant information.

Participants	n = 9
Age, years (range)	25 - 60
Gender (female / male)	2 / 7
Relationship to the ill person	
Partner	7
Sibling	1
Child	1
Disease of the ill person	
Kidney failure	4
Cystic fibrosis	2
Intestinal failure	3

### Ethical Considerations

The participating caregivers were informed verbally and in writing about the study and informed that their data would be treated confidentially and that any form of data that could be linked to the caregivers or ill persons would be pseudo-anonymized. They were also told that they could withdraw from the study at any time without any implications for the ill person's further treatment. Written consent was obtained [36]. Approval was received from the authorities in the Danish Data Protection Agency under the Capital Region of Denmark (journal number: P-2020-111), and the study was undertaken in accordance with the guidelines of the Danish Ethics Research Committee.

Sensitive recruitment of caregivers living with a person receiving comprehensive treatment is important in building relationships and in establishing participation in interviews. Some ethical considerations were therefore of particular importance. Time and place for the interviews were chosen at the caregivers' convenience, interviews in the hospital setting were conducted in an undisturbed room and at the end of each interview, we provided the opportunity for the caregivers to ask questions about any ambiguities in relation to support options or other help related to their own situation. Additionally, a collaboration agreement between the research team and the healthcare team was established to consider and manage any incidents that might occur during interviews. None of the eligible caregivers declined to participate in the interviews and no adverse events occurred during or after the interviews.

### INTERVIEWS

Data was collected through in-depth interviews [28,30,37]. To gain access to the lived experience of being a caregiver of a person with a chronic illness, a narrative approach was used during the individual interviews. The caregivers were thus encouraged to talk about what they found important, and follow-up questions were asked from a dialogical position [38] by use of open-ended questions to allow the caregivers to explore and express their thoughts, see (Table 2) for interview questions that were developed for the purpose of this study. When recounting their narratives about being a caregiver of a person with a chronic illness, the participating caregivers brought about a configuration by summarizing a chain of events in their shared everyday family life with chronic illness. All ten interviews were held before the analysis and interpretation of the transcribed texts were undertaken. The interviews, lasting 50 minutes on average, were audio recorded and transcribed verbatim by a paid research assistant.

### Analysis and Interpretation

Interpretation is the central methodology in phenomenological

hermeneutical work according to Ricoeur [28,30,31]. He emphasizes that the written text, as is the case with the transcribed interviews in this study, is not simply an extension of the spoken words and argues that something happens to language when transformed into written text. When writing down the spoken word, the description of the lived experiences is liberated from the event, which means that the meaning of the text is freed from the narrators' underlying intentions. This allows the researchers to interpret and unfold the issues the text points towards. As such, language, including texts, contains connotations that can only be approached through a process of interpretation. This interpretation process is according to Ricoeur to be understood as an endless spiral, involving three levels: a naive search for the overarching meaning, which the text seeks to convey, a linguistically oriented structural analysis and an in-depth comprehensive understanding [28-30].

The first naive interpretation is superficial and involves reading and re-reading the transcriptions to capture an initial understanding. The structural analysis provided insight into the structure of the text; words and sentences were extracted that pointed towards recurring issues and themes throughout the text. The comprehensive understanding was intended for understanding the meaning and range of the issues and themes in the text and allowed us a more profound, sophisticated understanding of the lifeworld phenomena left as traces in the caregivers' descriptions. Data analysis was performed by experienced qualitative researchers (MKEL, LL, and MM) and discussed together and thereby combining perspectives from backgrounds in both social work and nursing. Data and interpretations were reflected upon and discussed at all levels in the analytical and interpretive process to finally be discussed with the rest of the research team who have educational backgrounds and clinical experiences in medicine, nursing, and psychology.

**Table 2:** Interview questions for caregivers of persons with a chronic illness.

1	Can you talk about your experiences of being a caregiver or living with a person affected by chronic illness?
2	In relation to your personal experience of illness and treatment, can you talk about how your everyday life is like?
3	What gives you/can give you a sense of meaningfulness but also challenges in the shared everyday family life with chronic illness?
4	Do you recall any situations in which you experienced something related to illness, treatment, and caregiving that interfered in your everyday family life?
5	What is/can be a threat to your sense of a meaningful everyday life with chronic illness?
6	What is important for you to maintain a meaningful everyday life?

### FINDINGS

The themes that emerged through the structural analysis of the interviews are presented in this section. The meaning of how it is experienced to be a caregiver of patients receiving treatment for a life-threatening, non-malignant, chronic illness and how illness interferes with the shared everyday family life is expressed in four themes: The ripple effect - the impact of illness on family everyday life; Make it or break it - embracing strength and role dynamics; Living fully despite chronic illness and; The paradoxes of life. This section also presents empirical data, i.e., interview quotes from the participating caregivers - not to provide proper proof or argumentation but as examples that amplify the nearness and presence of the caregivers' understanding of their experiences.



## The Ripple Effect - The Impact of Illness on Family Everyday Life

This theme delves into the experiences of caregivers as they navigate the challenges of everyday life while caring for a chronically ill family member. It highlights how illness becomes a shared issue that shapes various aspects of daily routines, relationships, and interactions within the family and with others.

The illness demands its place in everyday life, which requires the caregiver's focus, time, and resources. The illness thus changes the everyday lives of both the ill person and the caregivers regardless of the relationship between them, and everyday life is characterized by periods of ignorance and uncertainty. The illness thus becomes everyday life, but the illness also eventually becomes integrated into everyday life. In the shared everyday life, the caregiver cannot constantly think about the ill person being ill, but in periods when the ill person is unwell, it affects the caregiver and the illness and worries become more dominant and evident. In the relationships in ordinary everyday life, however, the caregiver can actively decide that illness should not dominate everything.

*Before he got new lungs, he walked around with an oxygen mask, which was a challenge because he couldn't walk or move very far. That's the time I've been with him when I've been really worried, but otherwise I don't go about my everyday life thinking about the fact that he's ill. If I have to be careful all the time, I can't live with him, because then I would be eternally anxious and worried.*

In everyday life for the caregivers living together with the person being ill, the caregiver is often the person responsible for the household chores due to limitations caused by the disease but also because the ill person must deal with the illness. Caregivers frequently find themselves shouldering a range of practical tasks, including coordinating care services and managing household tasks. These responsibilities can gradually accumulate and become a significant burden in the long run. When the caregiver thus takes care of most of the work at home, it becomes a double job to also participate in the labor market. The caregiver may therefore at times experience having to put their regular professional work on standby in order to cope with domestic and family chores, also in relation to children, while support and help must also be given to the ill person and the illness must be managed. This can have consequences for the caregiver's own career but also for the household finances.

As a caregiver, it seems natural but also necessary to understand the ill person's illness, as it is part of a shared future and relationship, regardless of the family relationship in question. It can give rise to many existential questions which can be difficult to deal with, but when you have a relationship with a person who is ill, it also involves a relationship with the illness. The fact that the illness becomes a common issue also means that much of what fills the ill person's everyday life characterizes the relationship between the caregiver and the ill person. The caregiver's mood and concerns are thus voiced and shaped by how the ill person is feeling. The common illness can even progress to become a common condition in the relationship with consequences for the caregiver's own life but also for the relationship itself. As a caregiver, you can sometimes doubt whether you can endure in the end, and the caregiver therefore makes a great effort to be with and hang in there all the way. This state of illness can have direct physical effects for caregivers living together with the ill person, which is primarily described, by the caregivers as almost chronic fatigue. For many couples, the impact of caregiving responsibilities on sleep quality was highlighted. Likewise, illness, treatments as well as trips to/from the hospital and other practical matters mean that the caregiver must be present and available far beyond what is usual, which can be debilitating and take a toll on the caregiver who will be struggling to keep up their energy.

For all the caregivers included in the study, it is also described how the illness has mental and emotional consequences for them. Caregivers

often find themselves in the position of being the primary interpreters of the chronically ill family member's symptoms. They must closely monitor changes in health, understand the significance of those changes, and react to achieve the proper support and management. However, it is also about concerns in relation to the progress of the illness, powerlessness in the face of a situation and suffering that you cannot change, bad conscience, guilt, and shame for being well yourself, sadness, despair, enormous vulnerability, and fear of death as a companion. For many, these feelings are not ones that are shared with others, as the ill person and the illness are the focal point in the family, which leaves very little room for how the caregiver actually feels. The caregivers even tell how, as healthy people, they do not deserve to be happy, so when they are with others, the vulnerability has to be packed away and then they can cry when they are alone.

*No one has ever asked me how I am doing. And as a caregiver, you do not say what it is that is affecting you; you just shut it down. It is hard all the time having to provide the good life and not having days off..., and I am hugely disappointed when I do not succeed.*

Despite the illness' impact on the caregiver's practical, physical and mental life as well as the shared everyday life, several still describe how the illness also means that the caregiver and ill person have a very close relationship. When you live with a present and life-threatening illness, it can be experienced as living more intensely together as a family and prioritizing experiences together.

In case of chronic illness, the illness moves into family life; both existentially but also practically. Treatment at home becomes part of everyday life, whether it is parenteral nutrition, dialysis, medication, etc. This means that devices and equipment become a necessary integral part of the interior of the home, but it also means that the responsibility for the correct treatment and handling of medical equipment is moved to the sphere of the home and family. The visible medical equipment also constitutes a daily confrontation with illness and suffering and a reminder of a shared life on the premises of the illness and the treatment. For the caregiver, having equipment in the home can mean that the responsibility for its proper functioning rests with the caregiver. It is often the caregiver who wakes up at night if the device beeps, the caregiver who keeps an eye on the machine, and the caregiver who is thus responsible for the home treatment, and this can be experienced as a great responsibility to bear. On the other hand, it can also be experienced as nice and comfortable when the treatment works well at home, because then together you are less dependent on others and meeting appointments for treatment at certain times. Therefore, it gives a freedom in relation to some of the other things that you also want to do together as a family or with others.

## Make It or Break It - Embracing Strength and Role Dynamics

The interruption created by the illness and thus the new framework for a common everyday life means from the caregivers' perspective that the family either makes it or breaks it. This theme is about seeing the ill person as something else than their illness and ensuring that the ill person and the caregiver thereby can become each other's source of strength and unity. The theme is also about the distribution and embracing of roles, being helper and victim and the possible inequality that this can create within the relationship.

Living in a relationship with someone who is ill is not just about suffering and worries; it is also about community and togetherness. Going through illness, suffering, and treatment together gives common strength and puts ordinary trivialities or problems into perspective - the ups and downs of everyday life become easier to handle. Illness can thus cause caregivers and the ill person to become closer to each other and the mutual relationship is strengthened by what they go through together. An inner joy and gratitude for life can arise in this type of situation. Although illness confronts the caregiver with the basic conditions of life, such as



anxiety, hope, etc., the caregiver may experience learning a lot about oneself, life choices and ways of choosing to live life through, alongside and with the ill person. Living with someone who is ill can thus make the caregiver stronger, more purposeful, and critical. The caregiver learns to prioritize and allocate resources in relation to what is the common 'good life'.

*I think it's made me much stronger, I've become more focused and critical in terms of what I want to do and what I don't want to do. I'd rather spend my resources on what I like or what I want to do. I don't want to argue about the coffee cup being on the wrong side or anything else. It has sharpened my focus on what we think is a good life together.*

Something is, however, happening with the distribution of roles between the caregiver and the ill person when an incurable illness frames and affects the relationship. The illness changes the mutual relationship and the images they have of each other, and the caregiver has to come to terms with that role and find out how and towards who one should act and react in this new role. Familiar roles become new roles, and as a caregiver you often have many roles at once – both as the ill person's lawyer and healthcare provider while at the same time also being a spouse, sibling etc. The caregiver can take on the responsibility and role as the one in control of the illness and treatment, while the ill person takes on the role of the one who needs help. This changes the relationship between the caregiver and the ill person in a way that can lead to an unequal relationship; one between a helper and a victim. Most often, the new roles are not explicitly agreed upon – it just happens that way. Especially in situations where the caregiver is an adult child of an ill parent, the roles and relationship between them seem to have been completely turned upside down. In precisely these circumstances, it can suddenly become the adult child's responsibility to manage practical matters regarding illness and treatment as well as bearing any concerns, anxiety, and frustration on his or her parent's behalf.

*Our mother-daughter roles are very much reversed. I text her to see if she's eaten, if she's remembered to do what she's told, and we talk every day. My mum and I only have each other, so I'm the main caregiver and that's just the way it is.*

As a caregiver, you may experience that you have to be prepared to help with big and small things when the ill person does not have the strength or resources themselves and you must always be ready to step in with the ill person. This means that as a caregiver you may experience having to cancel all your plans and make sacrifices for the sake of the ill person. The caregiver is as such the helpful and solid rock that the ill person can lean on. The relationship between the caregiver and the ill person is thus often dominated by the ill person's needs. This is made even more difficult for families with children. In this way, the focus is on the child's needs and the ill person's needs and dreams, so there is no room for the caregiver to focus on their own dreams, wishes, etc. The caregiver becomes a functional protector and helper who may experience losing themselves and becoming emotionally empty. But as the caregivers explain, they also may need to be seen and heard and receive care, hugs, and love because the caregivers also carry the illness with them.

*I sometimes need to be the victim too, but she's the victim, she has to have everything, she's the one with the illness. But I also have the illness, and I also need a hug. I'm the one who has to run for it and compromise, but that doesn't mean that I don't need the care and love – and my dreams should also be realized.*

If one is to avoid ending up or continuing in a relationship where the disease and the ill person are always the focal point of all activities, and if one is to avoid unequal roles, then a special awareness and reflection is needed; most often initiated by the caregivers, who experience unspoken expectations that they in particular take responsibility for cohabitation with or the relationship with the illness and the ill person. This involves empowering the ill person to assert their needs, participate in decision-

making, and engaging in activities that promote their autonomy and self-expression. Several caregivers emphasize that if the relationship between the relative and the ill person is to survive, then the caregiver cannot exclusively be an active helper for the ill person, and the ill person cannot just be a passive victim. Instead, both parties must, with joint help, focus on a sustainable and equal relationship where the needs of both are met. When this succeeds through dialogue with each other and with the help of networks and professionals, they can work together to get illness and suffering turned into something that generates strengths in the relationship and in life as a whole – so that the caregiver is not simply left with powerlessness. The caregivers emphasize, however, that it is something they must work on together within the family and that it takes time.

*It's pretty crazy to think that for the first 13 years of our relationship, it's all been about Y, and I think it's make it or break it, because if it had stayed that way, you as a caregiver would eventually become saturated and break your neck. Now it's more about the fact that both Y and I have dreams and that there has to be room for both of us.*

### Living Fully Despite Chronic Illness

How to relate to the present and a shared future, the good life, social life, and networks are all areas that fill the caregivers' consciousness. Life must be lived together, while thoughts of death, a shortened perspective of time, fear of losing shared dreams, enjoyment and the ill person appear like an underlying shadow in the caregivers' mind. There is an expiry date for all human life, a day when life ends, but this end is more present in a life together with an ill person. The awareness of losing the ill person and the shared life weighs heavily on the minds of caregivers. A common everyday life with illness is therefore not a stable life, and the unknown factor that the illness and the accompanying unknown changes it brings with it is a fact. Dealing with that fact is deemed necessary for the caregivers to be able to handle everyday life with illness and the ill person. As caregivers, it is about helping to find solutions and measures that ensure that the illness does not restrict things more than necessary; neither in the relationship between the caregiver and the ill person, in family life and other social life and in relation to activities that are part of and characterize a "normal" life. There is, however, also a special insecurity associated with life as a caregiver of an incurably ill person, namely the thought of the caregiver, as the responsible and important caring person, also falling ill. Such thoughts circle and gnaw in the caregivers' minds, and the thought of not being able to be there for the other, the thought of one's children having to live with two ill parents, etc. appear at regular intervals and are difficult for the caregivers to share with others. As caregivers of chronically ill individuals, it is common to question the validity of one's own thoughts and concerns, fearing that others may perceive them as irrational.

Despite the possibility of a shortened life together hovering as an underlying shadow in the common everyday life, the caregivers tell how they have learned a lot from the ill person over time. The learning is about how the ill person, through his or her own handling of a life with illness, shows the caregiver a special strength and active choices. In this way, the caregiver sees and learns that it is possible to be ill and at the same time have a good life. Caregivers understand the significance of seizing the opportunities that present themselves in the present. They recognize that life is fleeting and unpredictable, urging them to make the most of every moment. Over time, the caregiver learns together with the ill person that decisions should not be delayed, whether it is about buying a new armchair or going on holiday.

*I've really learnt a lot from X; that you have a say in how your life should be. Even when it's difficult. I have become stronger. We can see all the dark and negative things and let them fill our lives, but we can also actively choose not to let them fill our lives. I've learnt that you can be ill and have a good life, and you can be seriously ill and deal with these palliative things, but we're still alive; he's doing well.*



For the caregivers, everyday life will also be about how to enjoy life together with the ill person. It requires a focus on ensuring that everything does not end in logistics and practicalities. Between illness, treatment, ordering home treatment equipment, hospital visits, work, family, and other social activities, it is necessary to stop and enjoy life and each other; to be present in the moment with each other both physically and mentally while there is still time. However, it is not easy and requires special effort, attention, and reflection, which in the caregiver's experience can be more difficult for them than for the ill person. As a caregiver, one may feel a greater obligation to bring forward a life-must-be-lived focus, as the expectation for yourself is that you as a healthy caregiver and must be the one with the most surplus energy and the most resources. This sense of obligation can risk eating up the caregiver's strength so much that a feeling of powerlessness and burnout arises.

*The difference between being the patient and being a caregiver is that as a caregiver, you have a greater obligation to carry it forward. After all, I'm the one who has the energy to do it. But sometimes, when you want everything to work, because we also have to remember to enjoy it while we're here together, you can burn out. It can be difficult sometimes when you have that "remember to enjoy it" thing hanging over your head when there are all sorts of things that need to work.*

When the caregiver thus tries to keep the focus on quality in the shared everyday life here and now with death as a fellow traveler, the caregiver can therefore be subjected to pressure and stress. Several caregivers talk about how the notion of having to achieve all these wonderful and exciting experiences together, while there is still time, turns into a nightmare. The experience of being constantly behind, of not being able to reach it, is thereby the outlook for the caregiver. The caregiver's spatiality is thus shaped by a burning platform, from which decisions about everyday dilemmas and challenges but also the joys and life-must-be-lived focus must be made and lived out. Priorities, decisions, and the outlook on life in everyday life together are thus a constant balancing act and an exercise for the caregivers, which they work to handle as they go along. As a strategy and support for this, they highlight dialogue with the ill person and mutual respect for each other as important, as well as help from family and social networks. In order to keep the focus on the fact that life must be lived, the caregivers also tell how time alone with their own priorities and without a guilty conscience is absolutely central and necessary.

## The Paradoxes of Life

A life together with a chronically ill person is full of paradoxes, which in this context involve areas such as choice and responsibility, seriousness and fun, orderliness and their own needs and communication and consideration. In addition, the caregiver must also adapt to the ill person's needs, the changing and changeable situation, and the outside world - and the outside world must simultaneously adapt to the family.

Life as a caregiver of an incurable ill person can be a life full of paradoxes. As a caregiver, you have not necessarily made a choice to be part of a life with a chronic and incurable illness as a focal point. For many caregivers, it is an imposed living condition. Based on this condition, the caregivers try to make active choices about how this life should look like and be lived. Although life in relation to an ill person can sometimes be experienced as difficult and harsh, the caregivers tell how, despite doubts in the most challenging periods, they would not have wished for a different life in the world of the healthy. This life, which they have in a way been assigned, contains several life paths that are at the same time different and diverge from one another, but they are also complimentary, and they are paths that they follow in one way or another.

It is thus a life that simultaneously involves closeness and distance, seriousness and fun - but not in the same way as in an ordinary relationship. In the context of illness, it is the caregivers' experience that it is precisely the illness as a condition that leaves its mark on the relationship; it is

the illness that makes the relationship present and intense, while at the same time, it can increase the distance and perceptibility between the caregiver and the ill person. The illness also sets an agenda for when something is fun and when the exactly same thing is serious. The illness and its consequences are something that the caregiver and the ill person can both laugh and cry about at the same time. However, there are also relationships where the caregiver talks about how they, as a couple, have managed to shift the focus from the illness as a shared condition of life to love as the thing that holds them together after all, even if it is difficult to distinguish.

*Illness is not the glue in our relationship. The glue in our relationship is our love for each other. It's definitely the glue. I wouldn't have been there if I hadn't loved her. But of course, you cannot separate one from the other, because I also love what she is, and she also has cystic fibrosis, just as she is everything else.*

In order to make everyday tasks and practicalities work, the caregiver has a general need for orderliness. Much need to be put into systems, both so that everything related to illness and treatment can be carried out but also so that work and household chores can be achieved. At the same time as the shared everyday life is systematized, the caregiver also has his or her own needs; the need for full-time work in relation to both finances and identity, the need for his or her own social relationships without illness as a focal point, and the need for having time for his or her own interests. Orderliness is therefore required if everyday life is to function, and caregivers talk about how changing the rhythm can lead to a bad period which puts additional pressure on the caregiver. One of the great paradoxes of life as a caregiver of an incurably ill person is the aspect that you are together facing an illness that cannot be cured while at the same time it is precisely the incurable aspect, which is extremely difficult to talk about together.

*We don't talk about it. My mum occasionally mentions something like she has a piece of paper at home with her codes for everything. And we've talked a bit about money. She doesn't work anymore..., and then we're in the market for a new boiler, for example, and she says that she'll buy it, but I say that you don't have any money and are on a very low financial benefit, and she says: "yes, but it's better that you get to enjoy it now than when I'm dead". So, every once in a while, there's a casual remark like that.*

Several also talk about how the communication between the caregiver and the ill person is more fun than serious when it comes to death, and also how both parties quickly and easily change the subject to something more superficial and harmless. In the relationships where it was possible to talk about and relate to death in the best possible way, it was with the couples who actively chose to have children together. Considerations about raising children in a family where illness and the ill person necessarily take their place and focus on the shared everyday life, and where death is also a player, include dialogues and deeper conversations about the existential conditions on which the relationship rests. Conversations about death are, however, something that many avoid or only touch upon more superficially, and in this context the caregivers talk about it as more of a process of adaptation and acceptance in the relationship.

Adaptation is thus also about how the caregiver more or less consciously adapts to the ill person's needs, the changing and changeable situation, and the outside world while at the same time the outside world also must adapt to the family's situation and needs. The adaptation of everyday life can be of a practical nature, where it is the caregiver who is automatically responsible for waking up the children, making breakfast and taking them to school while the ill person can rest or sleep as needed and take things at their own pace. But the adaptation can also be of a more mental nature, where the caregiver comes to live in a mode of readiness for adjustment; adjusting to an everyday life that incorporates a preparedness for sudden changes. While this adaptation takes place gradually within the relationship and the family, the outside world must also adapt to this particular constellation where incurable illness sets



an unfamiliar and unknown agenda for things such as school or work relationships, spending time with family, friends and acquaintances - but also in connection with travel and in other contexts that involve others outside the relationship.

## DISCUSSION

This study is one of the first to investigate, from the caregivers' perspective, how a life-threatening, non-malignant, chronic illness has an impact and interferes with the shared everyday family life during treatment. In this study, we included caregivers to a diverse group of individuals with various illnesses. However, a common feature emerged: the severe impact of the condition on their relationships and the impact on their own life as a caregiver. The degenerative and life-limiting nature of the illnesses, coupled with the challenges of uncertainty and daily struggles contributed to this effect. Consequently, we were able to identify universal themes that transcended specific diseases and relational contexts.

Our findings in this study point to challenges experienced by the caregivers as a ripple effect impacting the family's everyday life. This ripple effect occurs when the initial disturbance of illness emergence or the progression propagates outward to disturb the family system. The caregivers thereby initiate a relationship with the illness itself, which places them in a double position in several contexts, both in the relationship with the ill person but also practically as a double job between their regular work and the work involved with the illness at home. This juggling act can trigger existential thoughts, evoke emotional reactions, result in financial consequences, disrupt sleep patterns, induce chronic fatigue, foster feelings of powerlessness, and increase vulnerability. Importantly, these conditions create a unique burden that caregivers often find difficult to share with others. Especially disrupted sleep and lack of energy is well-known from other research on caregiver perspectives in a life with advanced chronic illness [17,39]. Additionally, as the treatment progresses, the introduction of medical equipment into the home environment becomes inevitable, leading to confrontations with illness, suffering, and with the responsibility borne by the caregivers for practical matters both in everyday life and in the safe performance of treatment. Caregivers might suddenly find themselves in a caring role for which they are not really prepared [3,40]. Caring more for each other has been recognized in healthcare interventions grounded in the family systems theory [6]. By recognizing that individuals do not exist in isolation but are interconnected within familial and social networks, it seems obvious to implement palliative interventions grounded in family systems theory. Thereby, healthcare professionals can better support individuals and their families, fostering person-centered palliative care. Such interventions are simultaneously focusing on both the individual within the family and the family unit with particular attention to the interaction and circularity between the ill person and other family members [41].

The caregivers in our study also unequivocally point to the illness's intervention in a common everyday life and relationship as a make it or break it venture and life challenge. The caregivers live a life with the ill person among unifying opposites such as suffering and worrying but also community and togetherness in a trying to embrace strength and role dynamics. In this context, however, there is a transformation of "normal" family roles towards roles where the ill person becomes the victim and the caregiver the functional protector and helper. However, the caregivers as the ever-solid rock are at risk of losing themselves even though they also need to be seen and cared for. A sustainable and equal relationship between the caregiver and the ill person is urgently needed if the relationship is to survive. Help and support for this is requested from the caregivers in our study findings. According to the family systems theory [6], illness causes an alteration in a family's functional structure and roles and research indicates that enhanced patient and family-centered consultations might be helpful [19,42]. Propositions for how

to improve understanding, capability, and enhanced coping within the family and thereby maintain an equal and dignified relationship between the caregiver and the ill person can be found in the family system theory literature [41,43].

For relatives sharing a life with someone with a chronic life-threatening illness, death is an accompanying factor and a present fact that must be recognized. An attitude of living fully despite chronic illness in a here and now approach and not delaying or postponing dreams and needs to sometime in an uncertain future is particular necessary. This approach to life is supported by a study of people facing terminal illness in which it was illuminated how these patients continued to focus on living and remain within their biographies and the contexts of their lives, even when their functional status declined [44]. In that study, the interviews provided a kind of a legacy which is also known from Dignity Therapy [45] and which might be included in a healthcare interventional approach to families receiving palliative care for chronic illness. To stop and enjoy life and each other here and now do, however, as described in our findings, require a special effort and attention and a greater obligation to bring forward such a life-must-be-lived focus is placed on the caregivers' shoulders. Being subjected to pressure and stress by this responsibility, the foundation for the caregivers' own space for everyday decisions and dilemmas is at risk of being shaped by a burning platform. From cancer research, it is well-known how early specialized palliative care not only eases psychosocial burdens and the major stressor in ill persons and their caregivers but also enhances coping together [46]. Integrating palliative care early during cancer disease has allowed palliative care clinicians to develop longitudinal relationships with ill persons and families, expanding their role beyond symptom management to include helping the families live well through adaptation and effective coping [46-48]. The family systems theory furthermore suggests interventions that are focusing on strengths within the family and encourages curiosity and reflection through the asking of questions that are respectful of multiple realities [6]. This allows attention to be focused on the influence between illness and the family with particular emphasis on suffering experienced in the context of illness and everyday life.

Chronic life-threatening illness is an imposed living condition for caregivers. In our study, the caregivers, however, expressed how they did not wish for a different life in the world of the healthy. Our findings highlight how illness makes the relationship present and intense while at the same time the illness can increase distance. A great paradox in such a life, from the caregivers' perspective, is the aspect that you are together in dealing with an illness that cannot be cured while precisely the incurable aspect is extremely difficult to talk about together. It has been described how communicating with each other in families dealing with advanced cancer is troublesome due to the fear of causing emotional distress [19]. Furthermore, research suggests that coping strategies such as avoidance behavior or emotion-focused strategies are associated with distress and caregiver burdens [49,50]. Relief from such illness-related suffering for the caregivers should within the family systems theory [32] have roots in an approach targeting the family as a unit of intervention in a collaborative relationship between the family and healthcare professionals.

The impact of chronic, non-malignant, life-threatening illness on caregivers is, as illuminated in this study, an area of critical need in healthcare. It is reported how disparities in access to palliative care exist for ill persons and their families with and without cancer [22]. Having a cancer diagnosis thus facilitates more easy access to specialized palliative care. By providing access to specialized palliative care services, healthcare systems can offer a multidimensional and individualized approach that improves the overall well-being of ill persons and their families. To achieve this goal, it is important to raise awareness among healthcare providers, policymakers, and the public about the specific challenges faced by individuals with chronic illnesses and their families. We hereby call for promoting equal conditions and access to specialized palliative care that supports families affected by chronic illnesses, enabling them to



receive the comprehensive care and support they need to live as fully and comfortably as possible.

## Clinical Implications

This study has illuminated how chronic illness had severe effects on the family relationships due to the degenerative and life-limiting nature of the illness and through dealing with uncertainty and daily challenges. The findings of the study might assist in devising useful interventions that can be tailored to target the need for palliative support for these families. Based on existing research on the importance of early and equal conditions and access to integrated palliative care, we propose that people with life-threatening, non-malignant, chronic illnesses and their caregivers should be systematically offered referrals to specialized palliative services while developing and upgrading basic palliation in the main ward, including a special focus on caregivers. The intention of these initiative is to focus on the whole family unit for the family to enhance coping, improve emotional well-being, and to care more for each other. This will also help to focus on and ensure equal access to specialized palliative care whether you live in a family with cancer or other serious illnesses.

Approaches to family-centered consultations targeting the family as a unit of intervention is furthermore suggested to be anchored in clinical healthcare practice. Such interventions might help identify the ways a family perceives problems related to the illness so that members can discover new solutions. Additionally, interventions can be directed towards assisting family members in addressing their beliefs about the illness and becoming aware of their interactions and behaviors within the family unit. These interventions aim to foster a supportive environment where family members can effectively support and care for each other.

## Methodological Considerations

This study is one of a few qualitative studies illuminating the ways in which chronic illness had severe effects on caregivers. The qualitative interview method provided insight into caregivers' perspectives and illuminated the meaning of a shared everyday life with a chronic ill person. Thus, the qualitative design was appropriate for this research [35]. The trustworthiness of the findings and interpretations was ensured due to the in-depth data collection, prolonged engagement with the data, and theoretical interpretations. An additional strength of our study is the utilization of the caregivers' own words to illustrate the identified themes. This approach enhances the trustworthiness and credibility of our findings [51].

A particular strength of the study's design is the sample and researcher variation consisting of caregivers of persons with different chronic illnesses and researcher variation in backgrounds such as nursing, medicine, social work, and psychology which is valuable in terms of internal validity and transferability of findings to other chronic patient populations [35,52]. The starting point for our explorative investigation was a wish from the caregivers included in a cross-sectional survey study. They had a special need to express themselves and talk about their experiences as caregivers, which makes the study significant and more meaningful. It is important to acknowledge that despite our efforts to select participants with variation in gender, age, and relationship to the ill person, among other factors, there is a possibility of sample bias in our study. The inclusion of caregivers was based on their voluntary desire to participate, which may have resulted in a self-selection bias. While this limitation should be acknowledged, it is important to note that qualitative research aims to explore and understand experiences and perspectives in-depth rather than providing statistical generalization.

## CONCLUSION

This study recognizes that the mental, emotional, and existential consequences of chronic illness on caregivers should not be overlooked. Integrating a systematic focus on caregivers of persons living with

chronic, non-malignant, life-threatening illness should be a continuing effort in policy, clinical practice, and research to optimize palliative care, support, and coping. In clinical healthcare, the family context needs to be taken into consideration as a crucial aspect along the treatment trajectory in chronic life-threatening illnesses. Equal access to early integration of specialized palliative care should be ensured whether the family are dealing with cancer or other serious illnesses. There is a need for a systematic approach to identifying those patients and caregivers who have specialized palliative care needs, so that these families are referred to palliative care units, teams, support, etc. that have such expertise. This research contributes to the further development of truly family-based interventions within specialized palliative care for families living with chronic illness by pointing out how caregivers experience that the illness has a ripple effect and impact on family everyday life, how they must work alongside the ill person to make it and not break it while they embrace strength and role dynamics, how caregivers must prioritize and focus on living fully despite chronic illness, and finally, how they have to live a life full of paradoxes that cannot be dealt with in the here and now. In conclusion, chronic, non-malignant illnesses have a profound impact on family relationships, characterized by the degenerative and life-limiting nature of the illness and the continuous challenges posed by uncertainty and daily struggles.

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