



# Striving for a safe ground—A lifeworld approach of family members' experiences of the critical illness trajectory

Stine Irene Flinterud MSc, CCN, Assistant Professor<sup>1</sup>  | Asgjerd Litleré Moi PhD, CCN, Professor<sup>2</sup>  | Eva Gjengedal PhD, CCN, Professor Emerita<sup>3</sup> | Sidsel Ellingsen PhD, CRNA, Associate Professor<sup>1,3</sup>

<sup>1</sup>Faculty of Health Studies, VID Specialized University, Bergen, Norway

<sup>2</sup>Department of Health and Caring Sciences, Western Norway University of Applied Sciences, Bergen, Norway

<sup>3</sup>Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway

## Correspondence

Stine Irene Flinterud, Faculty of Health Studies, VID Specialized University, Ulriksdal 10, Bergen 5007, Norway.  
Email: [stine.flinterud@vid.no](mailto:stine.flinterud@vid.no)

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## Abstract

**Aims and Objectives:** To explore the experiences of family members after they have lived through a close one's illness trajectory starting with critical illness and intensive care treatment, throughout hospitalisation and after their return home, and describe what was important and challenging for them during this time.

**Background:** Being family during and after critical illness and intensive care treatment may be traumatic and challenging. An in-depth understanding of family members' lifeworld throughout a close one's illness trajectory is needed.

**Design:** A qualitative design with a phenomenological approach.

**Methods:** We held ten interviews with eleven next of kin, nine of which were individual and one with a parent couple. The interviews lasted 90 minutes, on average, and were transcribed verbatim. Giorgi's phenomenological method guided the analysis.

**Results:** The overall structure was 'striving for a safe ground for themselves and their close one', which was dependent on the three constituents of 'in need of care', 'to take on responsibility' and 'to create new understanding'. Throughout the illness trajectory, the family members required care to increase their feelings of safety in the context of their close one being unsafe. They described taking on responsibility for their close one—a responsibility that increased after hospital discharge—as demanding new knowledge which they were often unable to obtain.

**Conclusions:** Families of critically ill patients need to be seen on their own behalf. Moreover, when taking on responsibility for their close one, they regularly need more knowledge than they get. There seems to be an absence of a support system for families with caring responsibilities after their relatives are discharged from hospitals.

**Relevance to Clinical Practice:** This study shows the importance of family carers being considered in their own right, as well as their individual needs throughout a close one's illness trajectory. There seems to be a gap in the knowledge of what family members require when their close one is discharged. Indeed, a better support system is essential for families following a hospital discharge.

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## KEYWORDS

critical care, family, family support, intensive care, next of kin, phenomenology, qualitative methods

## 1 | INTRODUCTION

Each year, thousands of people worldwide become critically ill or injured and are admitted to an intensive care unit (ICU). In 2021, close to 15,000 people were treated in Norwegian ICUs (Buanes et al., 2022) and, for each of these, numerous relatives and friends are affected. The medical condition of their close one is critical, and treatment is given in a highly technological environment, which may be stressful to the families. Hence, being a family member in an ICU may be a significant burden with the potential to affect one's health (van Beusekom et al., 2016). Family members have reported their experiences of psychological distress, such as high levels of anxiety, depression and stress (Abdul Halain et al., 2022), symptoms known as 'post intensive care syndrome-family' (PICS-F), which include depression, anxiety, post-traumatic stress disorder (PTSD) or cognitive deficits (Needham et al., 2012). The prevalence of symptoms has been reported to be highest during a family member's intensive care treatment, with depression being reported in 14%–97% of cases, anxiety in 0%–73% and PTSD in 14%–81% (Johnson et al., 2019). Further to the stress and symptoms prevalent during ICU stays, symptoms may persist after a family member returns home. Symptoms of depression, anxiety and PTSD have been reported by up to 43%—that is higher than in the general population—of family members 6 months after their relative was discharged from hospital (Johnson et al., 2019). A study investigating the prevalence of PTS symptoms in the same population in Norway found that approximately half of the participants experienced high levels of PTS symptoms when the patient was admitted to the ICU, decreasing after the first 6 months, with approximately 20% still reporting symptoms 1 year after ICU admittance (Alfheim et al., 2018).

## 2 | BACKGROUND

Being a close relative to a patient in an ICU has been described as a traumatic and chaotic experience, where hope and despair coexist (Nelderup & Samuelson, 2020). To help family members cope, Frivold et al. (2015) highlighted the importance of informational and supportive care to meet their worries and uncertainties. This included both the importance of receiving honest information regarding the patient's condition and feelings of compassion and personal interest shown by the healthcare professionals to family members to help them understand and manage the situation (Frivold et al., 2015). Moreover, support groups, targeted information (e.g. communication or educational programmes, leaflets or brochures) or measures regarding the physical environment in the ICU and flexible visiting hours have been recommended as best practices to meet family

### What does this paper contribute to the wider global clinical community?

- The intersubjective dimension is important throughout the trajectory when a close one falls critically ill.
- Families take on a huge responsibility when their close one is discharged from hospital, often lacking the knowledge they need to feel safe in their changed life situation.
- Better support systems in the community are needed for families of former patients who need help and support post-hospitalisation.

needs in this context (Kynoch et al., 2016). In 2017, Guidelines for Family-Centred Care in the Neonatal, Pediatric and Adult ICU were published (Davidson et al., 2017). These guidelines foregrounded the following five different aspects when caring for a family in an ICU: the ability to be present in the ICU; receiving support; communication measures; consultations with ICU teams that can guide families regarding their needs (e.g. psychological, spiritual or ethical); and environmental and operational aspects, such as guidelines and hospital policies concerning, among others, decision-making, noise reduction, the use of private rooms to improve family satisfaction and family sleep (Davidson et al., 2017).

Relatives experience increased responsibility and changes in their everyday life after a family member's critical illness (Frivold et al., 2016). In a grounded theory study exploring the challenges of being a spouse of an ICU survivor, Agard et al. (2015) identified the core category as how the spouses' role shifted to that of a caregiver and back. This was described as a dynamic process wherein they assumed the responsibilities of a caregiver with their main concern being to promote patient recovery, while simultaneously being their spouse in charge of their everyday practical and social life (Agard et al., 2015). The caregiver burden may well affect family members after hospitalisation. When investigating this burden, Torres et al. (2017) found that approximately half of the participants reported no overburden 3 months after the patients' discharge, while roughly 35% reported low overburden and 15% reported moderate-to-high overburden. Furthermore, caregiver burden has also been found to correlate with adverse physical or psychological outcomes, potentially leading affected family members to develop adverse physical or psychological events (Milton et al., 2022). The families of ICU patients are at risk of psychological morbidity, and the caregiver role may cause stress in which they seldom receive any formal support (Stayt & Venes, 2019).

In a recently published review on families of critical care patients support needs, Millward et al. (2021) found five key needs, namely those for security, making sense of the situation, finding a balance, holding everything together and trust. Frivold et al. (2016) found that a need to maintain control or adapt to changes was necessary in the everyday lives of relatives following a close one's critical illness. The participants in their study reported experiencing psychological factors, such as guilt, sadness, anxiety or memory loss, which they often had to cope with on their own or through their social support networks. To meet these challenges, Frivold et al. (2016) suggested a better support system for family members in this situation. As noted, Millward et al. (2021) illuminated five key family needs, as well as the different interventions which could be helpful for meeting them: Written information, care coordination and navigation, input from intensive care staff after discharge to support continuity and the provision of family support groups.

As noted above, family members report experiencing symptoms and burdens both during the hospitalisation process and following discharge. While some recent research has explored families' needs, there remains a lack of studies adopting a lifeworld perspective taking the whole illness trajectory of a family member into account. Therefore, to increase our understanding of the needs of family members throughout their close one's illness trajectory, this study aims to explore the experiences of family members after they have lived through a close one's illness trajectory starting with critical illness and intensive care treatment, throughout hospitalisation and after their return home, and describe what was important and challenging for them during this time.

### 3 | METHODOLOGY

We applied a qualitative lifeworld perspective, where the descriptive phenomenological method according to Giorgi (2009) was used to analyse the qualitative data. He emphasised that researchers must attain an attitude from their specific discipline when performing descriptive phenomenology (Giorgi, 2009). Accordingly, as per our background as anaesthesia and intensive care nurses, we conducted the study from a caring perspective. We live our everyday lives in the natural attitude where the world around us is taken for granted (Giorgi, 2009, p. 87). When taking a phenomenological approach, one seeks descriptions from the participants of their natural everyday lives. However, as researchers, we strived for an openness and to encounter the data within the phenomenological reduction in order to see beyond, and question, what would immediately appear. Hence, we sought to take an open approach and obtain the participants' experiences from the entire illness trajectory of their family member striving to avoid our pre-understanding to interfere. When performing the interviews, the interviewer encouraged detailed descriptions of the participants' experiences. When analysing the transcriptions, we sought to encounter the materials as pure experiences, without using our own interpretations, and describe the variations of the phenomena of which the participants spoke (Giorgi, 2009).

### 3.1 | Participants

This study was part of a larger piece of research, where both former patients and the primary next of kin documented in the patient record were included. The inclusion criteria pertained to the former patients, who were aged  $\geq 18$  years, having ICU length of stays  $\geq 4$  days, being mechanically ventilated  $\geq 48$  h and able to perform an interview in Norwegian (Flinterud et al., 2022). A contact person in the ICU sent invitation letters to eligible participants being both the former patients and their main next of kin (the latter of which shall hereafter be referred to as 'family member'). The family members who wanted to participate contacted the first author. A total of 11 family members participated, 6 of whom were women and 5 men. The age of the participants ranged from being in their 20s to their 60s. At the time of interview, six participants worked full time, one worked part time, three were retired and one was on sick leave. In addition, most of the participants stated to have been away from work because of their close one's critical illness for some days to a couple of months, while one was still on sick leave due to her husband's critical illness 1 year after the onset of the critical illness. The participants' relationships to the former patients were one daughter, one parent couple and the remainder were spouses. Nearly all ( $n=10$ ) of the participants had children, one of whom had children under the age of 16. All but one lived with their family member who had been critically ill, except for the parent couple, who lived in a separate house close to their son.

### 3.2 | Data collection

Individual interviews were conducted with all participants except for the parent couple, who were interviewed together. The interviews were conducted by the first author from February 2017 to April 2018 and were held between 3 and 8 months following their family members being discharged from hospital. The participants chose the interview setting. Seven interviews were performed in the participants' homes, two in their workplace and one in the hospital itself. The interviews aimed at capturing the participants' lifeworld during their close one's illness trajectory. The interviews were not uniform, rather following each individual participant's story. However, we had an interview guide so as to ensure that the interviews covered such areas as physical, mental and social aspects, as well as spiritual and activities/work dimensions from the entire illness trajectory of their close one. Additionally, the participants were encouraged to talk about their experiences with user involvement and the follow-up services they had experienced in order to guarantee broader descriptions. The interviews began with an open approach where the participants were encouraged to talk about the onset of the event that caused the intensive care treatment of their close one, continue with their experiences of being a family member in the ICU and further on throughout hospitalisation and finally after the patient's return to home. Questions regarding what they had experienced as important, helpful, challenging and difficult during the trajectory

from the ICU, general ward, rehabilitation and post-discharge were asked. The interview guide was used to ensure that all desirable areas were captured. The interviews lasted between 1 and 2 h, with an average duration of 90 min. They were digitally recorded and transcribed verbatim.

### 3.3 | Data analysis

Giorgi's phenomenological method guided the analysis (Giorgi, 2009). We read the transcriptions multiple times while simultaneously listening to the recordings, after which we transferred them into NVivo version 12, where the analysis continued. After gaining an overall sense of the entire material, each interview was analysed. The analysis began with reading the interview and dividing the text into units of meaning. Once done, transformed meaning units sensitive to the caring perspective were written, and transformed meaning units concerning similar themes were gathered. This was done with each interview, before gathering transformed meaning units concerning similar themes from all of the interviews. We then wrote second-order descriptions from all interviews. The analysis process involved alternating between using different invariant meanings until an overall structure depending on three constituents was found in the material (see Table 1 for an example of the analysis).

### 3.4 | Ethical considerations

Both the former patients and their family members had to consent to participation before they could be included in the study. At the start of each interview, the issue of consent was reiterated and the participants were made fully aware that they could withdraw at any time before the article's publication. As the family members had been through challenging experiences during the illness trajectory, we showed special consideration towards this. In agreement with the ICU contact, the participants could reach out to them if they had questions or needed someone to talk to regarding their experiences during their close ones' ICU stays. The participants were encouraged to talk about their own situation and not that of the patient. The study was recommended by the Norwegian Centre of Research data (Ref. No. 397448) and by the Data Protection Officers at each hospital.

## 4 | FINDINGS

When the participants' close one suddenly became critically ill, their normal everyday lives were disrupted and shaken, and new experiences and perspective became apparent. Throughout the process of intensive care treatment and subsequent recovery of their close one, a general structure of 'striving for a safe ground for themselves and their close one' was found among the participants. The structure was dependent on the three constituents, namely 'in

need of care', 'to take on responsibility' and 'to create new understanding'. At the onset of their close one's critical illness, the need for care lay as a foundation. Receiving care from the healthcare professionals was essential for the effective management of the situation. Simultaneously, the participants assumed responsibility for their close ones, having their best interests at heart and doing their utmost to improve or ameliorate their situation. During the illness trajectory, they found themselves in unknown situations, and needed to create new understanding to regain a safe ground. The constituents cover both aspects which were given to them and which they gave their close one. They were described in a multitude of variations, both when the participants experienced them and when they were notably absent. In the following, these are presented separately. However, in the participants' experiences, they were in an interplay, meticulously intertwined, by both being present and interacting throughout their close one's illness trajectory.

### 4.1 | In need of care

At the onset of the critical illness, the participants lives were fundamentally shaken. They often described chaotic situations, such as when one participant spoke of her father's collapse in her car: 'Well, it was complete chaos. I became hysterical. But, at the same time, I acted on instinct; the things I had learned suddenly just came to me: I must do this (start CPR)'. (E) After the emergency services arrived, she described how her feelings of hysteria continued in that she kept crying uncontrollably and was not able to calm down. When experiencing a chaotic situation, some healthcare professionals connected with the participants and helped them regain their composure: 'He (the paramedic) came into the car, shook my hand, and then I took a deep breath. He really helped me calm down. But then when he got out of the car, I started to cry again'. (E)

Being cared for during the first, and most critical, period of their loved one's admission to the ICU was described as important. Feelings of insecurity and vulnerability were reported, as well as how vital was the care provided by professionals for their own feelings of safety. The participants described feeling care through non-verbal communication, such as gestures and looks:

Well, I especially remember this one nurse, she was there the day she [the wife] was admitted. She impressed me so much! The way she spoke to her daughter [his wife's daughter], and how she explained things to my mother-in-law, who does not speak a word of Norwegian or English. My mother-in-law was so upset, but this nurse talked directly to her, doing her best to explain although she knew that my mother-in-law did not understand the language. And my mother-in-law told us how she understood and calmed down, despite not understanding the words she said.

(B)

TABLE 1 Giorgi's method of analysis from meaning unit to structure.

Structure	Striving for a safe ground for themselves and their close one		To create new understanding
Constituent	In need of care	To take on responsibility	
Second order description	There were variations in the way the healthcare professionals met and supported the participants. They needed the healthcare professionals to be interested in them and their situation. The participants needed to feel prioritised and seen in their own right, not only as side tasks during their critically ill family member's treatment.	The family members described taking on a changing responsibility throughout the illness trajectory. Being the patients' protector, lawyer and source of support were described. They assumed responsibility for supporting their close one practically, physically and mentally.	It was important to understand how the health system worked, and getting to know the hospital's context and culture. Gaining information about the condition of their close one was important, both throughout the hospitalisation and after discharge.
Transformed meaning unit	He felt that he and his family were well taken care of by the healthcare professionals. The intensive care nurses in the ICU were described as especially important.	The family experienced being responsible for the treatment of their close one. They thought that, if they had not spoken on her behalf, the healthcare professionals might have ended the treatment and let her die.	She would have wanted to know about her close one's condition at an earlier stage when his condition began to deteriorate.
Meaning unit	'I, I'm very impressed with the ICU. I'm positively surprised and, as a family, I felt we were informed at all times. I'm especially impressed by the nurses in the ICU. I experienced very positive treatment.' (B)	'The most traumatic thing was that we, her family, could decide if she should live or not. Because the doctor said that they would normally end treatment in such a case due to her severity and not being able to breathe on her own. And then we, as her family, were part of the decision to continue the treatment and put her on mechanical ventilation (...) and then I think about those who do not have their family around, or if we had not been able to be there as much due to work or other obligations, what then?' (G)	'And then, I would have wanted some information about the practical issues and how to behave in relation to dad. Should I help him with everything, like make dinner or help him get dressed? Or should I let him do it himself? What was best for him? And I also wondered if I should talk to him about what he had gone through, or should we just sweep it under the carpet and try to forget? Of course, this is an individual case, but I would have wanted to know more about this before he came home.' (E)
	'Well, they asked me how I was when I came, like questions that you just answer with "I'm okay" (...) It might have been useful to talk to someone outside of his room. To talk to someone who knows what's going on but doesn't have to watch the machines and take care of him. Because I didn't get to talk about how I felt, it was just his condition, how his blood pressure was and so on.' (F)	'We were there all the time, at the most three or four of us inside his room. There was little space with all the machines, but we talked to him, held him all the time, and sang to him'. (C)	'I got good information, except for when he underwent an emergency operation. Because, when they first called me, I just perceived that he was going to a CT, so I could wait a bit before coming. But then I realised that he was critically ill that morning. And I was at home, washing my car, being in a completely different mental place. I would have wanted to know the severity earlier on that day.' (J)

In the ICU, intensive care nurses can create a safe caring space simply by letting the participants be present at the bedside. The ability to be present and experience flexibility regarding visiting hours was described as helpful in these uncertain and distressing situations. However, the participants also described how they occasionally had to shield themselves from the situation, and highly appreciated their presence during visiting hours being voluntary and according to their own needs. The need to talk about what had happened, and how they were feeling, was highlighted. However, individual needs regarding conversations with healthcare professionals were conveyed. For some, small talk with nurses during hospital visits were appreciated:

They just talked to me while I was sitting there, and I talked to them without having to ask someone to talk to me. So, they engaged with me without my having to ask for it, which I think helped me a lot.

(E)

However, others conveyed how the small talk with nurses was not always sufficient and occasionally superficial. Indeed, some felt pressured to communicate that they were feeling well, whereas, in retrospect, they would have rather had a conversation with healthcare professionals outside of the patient room:

Well, they asked me how I was when I came, like questions that you just answer with 'I'm okay' (...). It might have been useful to talk to someone outside of his room. To talk to someone who knows what's going on but doesn't have to watch the machines and take care of him. Because I didn't get to talk about how I felt, it was just his condition, how his blood pressure was and so on.

(F)

The participants described feeling vulnerable when faced with these new and uncertain situations, as well as how they strived to figure out how to act within the hospital context. For some, a safe caring environment helped them enact their habits and values, such as praying and singing around the bedside of the patient, while others faced more of a struggle. One participant reflected upon the vulnerability she felt when trying to determine how she should behave in the hospital; feeling totally dependent on how she was met by the healthcare professionals:

On one occasion, the nurse in the ward said that I should go with my husband and get dinner in the buffet. Then, when I did, the kitchen assistant told me that the food was not for me. I cried then. Because he was right, but the nurse had told me to do so. It was these little things that made me break down.

(J)

Throughout the hospitalisation period, the participants balanced caring for themselves and the patient. While being present and available for their close one was important, they described how they had to portion their time and personal resources so as to be able to also take care of themselves. The need to shield themselves and focus on something else was described as one way of handling the situation, such as being able to have flexible work hours, or simply try to relax through music or television. Moreover, support from their family, friends or religious communities were highlighted as crucial throughout their close one's illness trajectory. This support could be from having faith communities pray for them or being visited by close friends and family: 'A lot of my mates came over, which was nice. I think that was important, to talk to someone, not just about what had happened, but about other things as well.' (D).

## 4.2 | To take on responsibility

Throughout the illness trajectory, the participants described taking responsibility for creating a safe ground for their close one. During hospitalisation, some described feeling secure in the patient's condition, while others reported that their close one did not receive the highest level of treatment. Moreover, some experienced challenges related to communication or relational factors, making the participants feel that they had to be present in the hospital so as to protect or speak on behalf of their critically ill close one:

The most traumatic thing was that we, her family, could decide if she should live or not. Because the doctor said that normally they would end treatment in such a case due to her severity and not being able to breathe on her own. And then we, as her family, were part of the decision to continue the treatment and put her on mechanical ventilation (...) and then I think about those who do not have their family around, or if we had not been able to be there as much due to work or other obligations, what then?

(G)

The patient referred to above had been intubated and survived the medical treatment, but the participant conveyed how they, as a family, had experienced making the decision about whether she should live or not. In addition to feeling that their close one's treatment was dependent on their presence, several also talked about the importance of them being there when they experienced suboptimal care from the health professionals. Indeed, one participant recounted how the intensive care nurses did not seem to know how to communicate with her husband while a mask covered his entire face. They asked him several questions simultaneously, giving him no possibility of answering while breathing into the mask, so she had to take over the communication to enable him to answer:

Like, are you thirsty, do you have to spit? They asked him two questions at once. And he was incapable of answering. So, I had to hold his hand, and repeat the questions one by one, saying to him: 'pinch me once if you are thirsty, pinch me twice if you must spit'. That situation made me doubt their competence.

(F)

Furthermore, several conveyed how their close one communicated that they wanted the participants present in the hospital as much as possible, and they described how they felt responsible to do so in order to create a safe and caring environment for their close one:

Then they [the nurses] asked if maybe we could go home and relax for a bit. We tried to switch with someone else in the family, but it was very hard. For a long period, we [the parents] were his safety. There was no way we could leave. Although he's a big lad, he started to cry when we talked about going home when he was still in the ICU. There was no way we could leave him there.

(C)

As the patient's condition improved, the participants described how their role within the hospital changed, and their feeling of responsibility for creating a sense of safety within the hospital decreased. When their close ones were to communicate and talk on their own behalf, the participants expressed feeling safer for the patient's condition, which helped:

Well, you are kind of more relaxed [after transfer to a general ward]. You know there is no immediate danger and that this will likely end well. Her bones [which had been broken] will grow, and she has no brain damage or paralysis.

(B)

When their close ones were discharged, the participants reported feeling a duty of care for them. However, becoming an informal caregiver seemed to challenge the participants' feelings of safety, who described feeling somewhat nervous and alert in the initial phases of the return to home:

Well, some nights I woke up and checked if she was breathing. It was not a big issue, but I woke up sometimes, looking over at her, touching her to feel if she was warm. She has been through a lot.

(D)

Feeling responsible for their close one's situation affected the participants' everyday lives; forcing them to make numerous adjustments, such as having to take sick or care leave, or even relocating to the patient's home for several weeks in order to tend to them. Their close

ones had experienced life-threatening situations in the hospital, and the participants described how their close one could need help both physically (e.g. in terms of walking) and mentally when coping with their recent experiences:

Well, he needed me there after (coming home), like all the time. And it was okay for me to talk about it (what had happened to him), but I felt the need for some air as well. As much as he wanted me to, I could not stay with him and talk all the time.

(F)

The participants spoke of a wide range of responsibilities covering the many different aspects of everyday life, from checking on the patient at night, handling the medication, providing support, motivating their close ones to exercise and eat a healthy diet, managing medical equipment at home and driving to different outpatient clinics.

### 4.3 | To create new understanding

From the onset of their close one's critical illness and ICU admission, the participants described how they needed to create new understanding to help them effectively handle the situation. Indeed, in the initial phases, characterised by high levels of insecurity, gaining knowledge about the patient's condition was highlighted as helpful. Open and honest information was appreciated, and the participants expressed how they wanted to be informed about the condition, regardless of whether it was deteriorating.

I got good information, except for when he underwent an emergency operation. Because, when they first called me, I just perceived that he was going to a CT, so I could wait a bit before coming. But then I realised that he was critically ill that morning. And I was at home, washing my car, being in a completely different mental place. I would have wanted to know the severity earlier on that day.

(J)

Moreover, the participants needed to gain knowledge about various practicalities, such as parking arrangements, visiting hours and the hospital's normal routines. Understanding more of how the hospital setting worked could help them manage the uncertainty they felt during the most crucial time.

Nevertheless, despite improved conditions and hospital discharges, the participants reported an increasing need for knowledge to be able to foster a safe environment. Their close ones still needed help and support, which demanded that the participants had developed a new understanding about the situation to be able to support both themselves and their close one in regaining a safe ground.

And then, I would have wanted some information about the practical issues and how to behave in relation to dad. Should I help him with everything, like make dinner or help him get dressed? Or should I let him do it himself? What was best for him? And I also wondered if I should talk to him about what he had gone through, or should we just sweep it under the carpet and try to forget? Of course, this is an individual case, but I would have wanted to know more about this before he came home.

(E)

They needed information about everyday life aspects, such as medication, training and nutrition. However, receiving information through, for example information leaflet was not always enough as one participant highlighted when talking about the information leaflets her husband had received. She conveyed how she thought the information would have helped them in their situation at home; however, the leaflet had disappeared. She thought it was left among his discharge papers, but even though highlighting that they needed the information to handle their everyday life, they had not tried to find it. However, there were other means of information which were described as helpful, like one participant who spoke of how lucky she felt in having been able to participate in her husband's rehabilitation course, which had helped and given her a strengthened feeling of safety in everyday life:

I feel that I benefited a lot. Because you are reassured and you can ask any questions that are worrying you. And you get information, not only through your loved one, but directly from the healthcare professionals. Like that he could actually do the things he said he could. Physical activity is recommended; not just allowed but recommended!

(I)

Acquiring knowledge to create a new understanding about what to do and how to act was important when taking on the responsibility for creating a safe home space. However, the participants often mentioned that they had to deal with everything themselves, lacking information as to who to call or where to look for help if needed. They often strove for a new understanding and had to count on their own resources in the process.

After following their close one through the illness trajectory from the ICU, to the general ward, rehabilitation and eventually back home, some described the impacts to their own health. Indeed, while these situations could affect both their physical and mental health, information on these impacts was reported as notably absent. One participant recounted how, after weeks of staying at a nearby hotel so as to be able to visit the hospital daily, her body felt alien and extremely tired upon her return home. She also reported feeling both chest pain and nausea when completing everyday chores. Not knowing that these were likely symptoms of the stress she had been

through, she kept pushing herself while wondering if she was witnessing the return of her pre-existing heart disease. None of the healthcare professionals told her about the possible symptoms she herself could suffer afterwards. Eventually, one of her family members (who had a background in healthcare) told her to rest and relax, explaining that she was likely feeling the effects of the strain of having been in such a traumatic situation for so long. Taking this advice, she eventually returned to her normal state without having to see her general practitioner.

## 5 | DISCUSSION

This study shows that when a family member is affected by the critical illness of a close one, their life is disrupted. In this situation, family members try to find a safe ground for themselves and their close one, taking on much responsibility, and simultaneously needing care and new understanding themselves. This makes them vulnerable and their relationship with healthcare professionals becomes crucial.

Critical illness threatens the family as a whole, and disruption to the family system is one of the antecedents of vulnerability in families of critically ill patients (Baumhover & May, 2013). Tembo (2017) described critical illness as a biographical disruption that causes a breach in a person's expected life-biography. Such a biographical disruption concerns both the patient and the family, as the critical illness obstructs or unsettles the expected future of both parties (Tembo, 2017).

We argue that the disruption to the family system the participants experienced may be seen as a biographical disruption. When seeing critical illness as a biographical disruption, the temporal dimension of the lifeworld comes to the fore. Temporality contains the 'storied' nature of our lives, the humanly experienced continuities and discontinuities of time (Galvin & Todres, 2013, p. 27). We live our lives temporally, in the present moment, based on our past experiences as we look towards a future filled with possibilities. The onset of a critical illness affects both patients and their families, thus increasing insecurity by disrupting an entire family's expected future.

However, Tembo (2017) argued that the family burden might vary according to which member falls critically ill. This is important to consider when caring for families dealing with an illness. The family's strain may vary by their life situation, for example if one has small children at home, or if one's child is critically ill. In our findings, the participants experienced a disruption to their family's expected future and strove for a safe ground for the whole family. Striving for a safe ground may be seen as a way of holding everything together, which is one of the five key family needs during the recovery continuum after critical illness, according to Millward et al. (2021). While striving for a safe ground, the participants experienced their close one's dependency, acting as an advocate and supportive voice when the patients were unable to speak their minds or take care of themselves. The participants reported being concerned about the whole family's situation, and they implemented measures, such as assuming responsibility, to lessen their family's biographical disruption and



make their future more coherent. When striving for a safe ground, we argue that they worked towards mending the biographical disruption, thus building a new, more understandable biography to help ameliorate the whole family's situations.

When facing a new and challenging situation threatening their everyday lives, our participants conveyed vulnerability. This finding is supported by Wong et al. (2017), who found that the families of ICU patients live with a great deal of uncertainty and experience heightened emotional vulnerability. However, the participants reported their methods for improving the situation—which often depended on encountering caring healthcare professionals. This could give them a feeling of security to help determine their role within the ICU, such as praying around the bedside, or being present to protect and speak on behalf of their critically ill family member. Little things, however, could push them over their limits, such as the participant who began to cry when denied food at the buffet. Helping and supporting families in finding their role in the ICU has been described in a middle-range theory called Facilitated Sensemaking (Davidson, 2010). The theory describes both nursing actions to help families make sense of their new situation and the process the families go through. In our findings, it seems that small acts or gestures from healthcare professional could contribute to feelings of safety and belonging or conversely, insecurity, causing the participants to struggle to find their place. This is in line with Facilitated Sensemaking, which contain concrete interventions the families can perform in order to decrease feelings of insecurity or helplessness, to help them make sense of the situation (Davidson, 2010).

Benner and Wrubel (1989, p. 1) highlighted that care is related to attached importance; we care about those who matter to us. Based on our findings, we argue that healthcare professionals must provide more than just information and support; they must also show that each family member matters and give them the care they deserve. Healthcare professionals must be aware of the importance of being genuinely present for the families of intensive care patients. This could help foster feelings of safety in uncertain situations and further reduce the chance of what Baumhover and May (2013) highlighted as negative consequences of vulnerability: Symptoms of PICS-F such as uncertainty, loss of appetite and energy, altered sleep, interruptions of routines, roles, and responsibilities and delayed family plans.

Throughout the illness trajectory, the participants were by their close one's side, striving for a safe ground for themselves and their close ones, simultaneously dependent on being cared for and caring for those who had fallen ill. A duality of dependency was described by the family members, being dependent on the healthcare professionals they encountered while their close ones were dependent on them. The participants took on the responsibility of caring for their loved ones in various ways during the illness trajectory, enhancing their loved ones' experience of safety. Additionally, living in uncertainty and fear for their close one's life, they were utterly dependent on being cared for by the healthcare professionals.

The intersubjective dimension becomes highly important, as it relates to being in the world with others. We are relational beings,

and our findings point to how family members' worlds are influenced by their relationships with their close ones and the healthcare professionals caring for them. Galvin and Todres (2013, p. 28) highlighted how intersubjectivity can both humanise and dehumanise us, depending on the relationship. In our findings, this is illuminated by the stories of participants being seen by healthcare professionals, such as the participant who was only able to be calm in the presence of the ambulance worker. However, the opposite was also conveyed, such as the participant needing a conversation on her behalf to talk about her situation. Still, she was only offered everyday conversations around the bed of her critically ill husband. In an uncertain situation where a loved one's life is threatened by critical illness, the relational presence of healthcare professionals can be significant. This is supported by Frivold et al. (2015), who also found that family members valued when the healthcare professionals showed a personal interest in them and they experienced supportive care. Meeting healthcare professionals who communicated care verbally and through body language were highly appreciated. Hence, being met in a humanising manner and feeling cared for during traumatic and uncertain circumstances helped the participants handle the situation.

The duality of receiving and giving care is important to consider, as it may illuminate an extra dimension to the burden the families of critically ill patients may experience through an extended illness. Our findings found a variety and individuality regarding the need to talk about their own situation and needs. Nevertheless, regarding the duality family members may experience with receiving and giving care, we argue that healthcare professionals need to open up and discuss this duality with family members, giving them a chance to communicate their individual experiences of the strain to support them in handling the situation.

Vester et al. (2022) found that when their close ones recover, relatives often shield them from their problems and thoughts, leading to misunderstandings and challenges in their everyday life. If family members avoid discussing their situation with loved ones and healthcare professionals, they may feel alone, increasing their strain. In our findings, support from their friends and other family was important. Social support seems essential; however, we all have different social networks and needs regarding social activity. Hence, we argue for the importance of healthcare professionals opening up and talking to every family member on their behalf, not only about the patient's condition, to detect those needing additional help and support in their everyday life.

The participants described how they assumed responsibility for their close ones throughout the critical illness and felt dependent on knowledge and new understanding. However, the form of this responsibility tended to change during the illness trajectory. During the first period, the participants expressed the importance of being present at the hospital whenever they chose, often to safeguard and meet the needs of their close ones who wanted them there. The ability to be present has been included as a recommendation in the guidelines of family-centred ICU care (Davidson et al., 2017). In addition, in a survey investigating family involvement in Nordic ICUs,

Frivold et al. (2022) found that most ICUs allow open visiting hours. However, we found that our participants appreciated the ICU's flexibility in terms of visiting hours and the ability to be present. One participant also talked about how she appreciated that the healthcare professionals did not expect her to spend all her time at the hospital, alleviating the pressure she felt at having to be constantly present. This is an interesting finding in that it shows how structure and guidelines may be used to lessen familial burden and responsibility. Families are composed of individuals who have unique needs. Accordingly, having an open visiting policy may be an important measure for meeting family needs. However, it could also be beneficial for healthcare professionals to inform families that they are not obligated to spend all their time at the hospital, despite that being an option. This is supported in the review by Millward et al. (2021), who also highlight how families must balance being close and maintaining their own lives during the illness trajectory.

We observed the key importance of healthcare professionals being aware, open and flexible to the families' unique needs, regardless of the hospital's rules and regulations. As noted, the participants felt responsible for their close one's situation during hospitalisation and after discharge. Some even described experiencing an increased responsibility for their close ones' situation after discharged home, noting that the information they received failed to explain the responsibilities expected of them. For instance, one of the participants described not knowing how much help she should give her family member, either physically or mentally. Millward et al. (2021) highlighted how families feel unprepared, overwhelmed and insecure when taking their close ones home. They further demonstrated how families would assume bridging roles, where they would be dependent on gaining relevant information for the specific situation of their close one. In our study, the participants needed to create a new understanding of the unfamiliar situation. They described the importance of receiving information; however, receiving information exclusively was not enough. They had to incorporate the information they gained to knowledge and a new understanding, which demanded more than just receiving written or oral information. Indeed, there seems to be no system in place that provides comprehensive knowledge and guidance on post-hospital daily life.

One of our interviewees indicated that participating in her husband's rehabilitation course was hugely helpful to her and increased her feeling of safety after he came home. This might be an example of incorporating information and knowledge to form a new understanding, giving an increased feeling of safety. Nevertheless, most of our participants described being left to themselves with the responsibility of using their own resources to manage the situation. In line with our findings, Frivold et al. (2016) found that families had to use their personal resources and support from friends and family to maintain control. One of our participants spoke of experiencing symptoms after the strain of being a family caregiver within the hospital for a long time. Fortunately for her, another family member identified stress as the root cause. However, the hospital provided her with no such information. Vester et al. (2022) argued that both patients and family members must find themselves after the critical

illness. The authors identified social aspects important to post-ICU life and suggested that these should be supplemented as part of the PICS and PICS-F domains. Our study supports this, as the social domain was strongly prevalent during and after hospitalisation.

## 5.1 | Strengths and limitations

This study involved interviews with 11 family members, which were held between 3 and 8 months following the patient's hospital discharge. We wanted the participant experiences from the whole illness trajectory of their close one. However, we only interviewed them once after their close one's were discharged home, which might be a limitation as the experiences of a hospital stay may weaken over time. This may have increased the possibility that our participants had forgotten specific or relevant situations. However, we were interested in experiences from the entire illness trajectory, and we found the interviews to be insightful and containing variation of both positive and negative experiences. One of the inclusion criteria was the ability to speak Norwegian, which resulted in only ethnical Norwegians being included in our sample. Hence, there may be other needs and experiences that we missed due to the homogeneous sample. However, the participants differed in their living situations and relations to the patient, which may have contributed to variations in experiences. For the larger study, both patients and next of kin were interviewed. While each participant was encouraged to speak on their own behalf, the joint nature of the interviews may have influenced what they spoke about. Nevertheless, we found that the participants willingly spoke about the different phases of their close ones' illness trajectories. To increase rapport, the participants themselves chose the locations of the interview. This may have increased their feelings of safety and comfort during the interviews.

## 6 | CONCLUSION

Families of patients experiencing a critical illness and further recovery stage find themselves in a challenging, insecure and vulnerable situation. Being seen as individuals with personal needs promoted a feeling of safety. Our main finding was how the participants strove for a safe ground for themselves and the patient, and throughout the illness trajectory of their close one they exerted efforts to improve the situation as much as possible. The responsibility they assumed changed during the trajectory. Initially, they would act as advocates or supportive voices for the patient. Upon discharge, their roles would become more practical in nature, transforming them into caregivers in charge of every aspect of their close one's life, helping and supporting with the various needs of the former patient. Within this situation, we found a lack of knowledge given from the healthcare professionals to the families. They needed new understanding but were often left on their own to determine how best to meet the needs of their close ones. The intersubjective dimension is vital in

every encounter during a critical care trajectory, and the importance of experiencing relations that attend to each person's individuality was clear within our findings.

## 7 | RELEVANCE TO CLINICAL PRACTICE

The family members reported needing more information and support during the patient's transition from hospital to home. Accordingly, we argue that current practices should be further developed, and a system which can give the families more information both before and after the patient returns home is urgently needed. Additionally, more research should be conducted into the transition from hospital to home, including the families' specific needs, and systems that may help and support families' home situations.

### AUTHOR CONTRIBUTIONS

Study design: SIF, ALM, EG and SE. Data gathering: SIF. Analysis and writing of manuscript: SIF, ALM, EG and SE.

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### CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

### DATA AVAILABILITY STATEMENT

Research data are not shared.

### ORCID

Stine Irene Flinterud  <https://orcid.org/0000-0002-3625-4091>

Asgjerd Litr  r   Moi  <https://orcid.org/0000-0002-7158-1792>

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## SUPPORTING INFORMATION

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