

ORIGINAL ARTICLE

'I want to get back!' A qualitative study of long-term critically ill patients' inner strength and willpower: Back home after long-term intensive care

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Abstract

Aims and objectives: To provide insights into what promotes and challenges inner strength and willpower in formerly critically ill patients back home after a long-term ICU stay.

Background: Critically ill patients demand great resources during an ICU stay, some experience great challenges after discharge from hospital. Knowledge about how health professionals can promote former long-term critically ill patients' inner strength and willpower after discharge is essential, but still missing.

Design: A qualitative, hermeneutic-phenomenological approach using in-depth interviews with former long-term ICU patients.

Methods: Seventeen long-term ICU patients were interviewed 6–20 months after ICU discharge. The consolidated criteria for reporting qualitative research was used (COREQ,2007).

Results: Back home after hospital discharge, some former patients coped well while others suffered heavy burdens mentally and physically, along with economic problems. They handled their challenges differently: some found comfort and insight by reading their diary written by their ICU nurses, while several were struggling alone experiencing a lonesome silent suffering; these called for a follow-up support by the healthcare system.

Conclusion: Long-term ICU patients' inner strength and willpower are vital salutogenic resources supporting the fight back to one's former independent life. However, physical, mental and economic challenges drain their inner strength to go on and succeed. Several long-term ICU patients need health-promoting follow-up support after hospital discharge.

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Relevance to clinical practice: This study disclosed a lonely and silent suffering indicating a need for development of systematical health-promoting follow-up programmes including salutogenic components such as health-promoting conversations, diaries and web-based recovery programme along with a cell phone app.

KEYWORDS

challenges back home, critical care nursing, follow-up conversations, health promotion, intensive care nursing, long-term ICU patients

1 | INTRODUCTION

Advanced intensive care medicine and nursing have led to an increasing number of survivors among the critically ill. In 2018, there were about 15,000 cases in Norwegian intensive care units (ICU), with a patient survival rate of 90% (Eirik Alnes Buanes, 2019). Increased survival following long-term ICU treatment frequently results in long-lasting complications and, subsequently, major challenges in patients' daily lives. A literature review of post-intensive care syndrome (PICS) found that formerly critically ill patients, as well as their families, show reduced cognitive, psychic and physical functioning (Mikkelsen et al., 2018). New evidence-based guidelines for ICU treatment, termed the ABCDEF bundle (A: assess, prevent and manage pain; B: both spontaneous waking and spontaneous breathing trials; C: choice of analgesic and sedation; D: delirium—assess, prevent and manage; E: early mobility and exercise; and F: family engagement and empowerment), involves vital aspects of improving critically ill patients' outcomes (Ely, 2017; Pun et al., 2019). The field of intensive care has directed the negative effects that ICU stays can have (Riley, 2018). The focus largely preventing mortality is over the last decade widened to also include the prevention of secondary harm due to intensive care (Riley 2018). Correspondingly, the ABCDEF bundle is well accepted internationally. In a health-promotion perspective, ICU nursing is not only focussed on survival from serious illness, but involves also to support the patients' existential will to keep on living (Haugdahl et al., 2018), as well as health promotion aiming at well-being and quality of life (QoL) back home. As early as in 1986, the Ottawa Charter of health promotion suggested a reorienting from the predominance of a biomedical perspective within hospitals to increasingly move in a health promotion direction (Iriarte-Roteta, 2020). Nevertheless, the health promotive perspective in ICU care (Riley, 2018) and nursing practice is still sparse (Iriarte-Roteta, 2020). Therefore, Haugdahl et al. (2021) call for the ABCDEF bundle's missing 'G', entailing the identification and utilisation of salutogenic resources in long-term ICU care.

2 | BACKGROUND

In a health-promotion perspective based on the salutogenic health theory, this study highlights the situation of long-term critically ill patients after hospital discharge. The salutogenic health model

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

- Long-term ICU patients have lived through serious illness, receiving advanced medical treatment involving several ailments.
- Back home, these individuals experience several challenges resulting from the illness and its medical treatment. To cope well at home, inner strength and willpower seem essential.
- Inner strength and willpower represent health-promoting resources, which can be facilitated and used to promote coping and quality of life among long-term ICU patients back home after hospital discharge.
- Inner strength and willpower should be considered as patient-important outcomes to help guide future clinical research at improving ICU survivors' recovery.

developed by Antonovsky explains why some people maintain their health even under extraordinary stress (Antonovsky, 1996; Haugan & Eriksson, 2021), such as a long-term ICU stay. Antonovsky understood health as a continuum between ease (perfect health) and dis-ease (no health), indicating that individuals move along this continuum always having some health resources which should be supported. Antonovsky's health theory is based on two central concepts: (1) sense of coherence (SOC), which is a salutogenic resource moving the individual towards the positive side of the ease–dis-ease continuum, and (2) general Resistance Resources (GRR) representing personal and environmental salutogenic resources supporting a person's processes towards good health. SOC involves three components: comprehensibility, manageability and meaningfulness, which are inextricably linked and considered resources to achieve coping, QoL and mental health (Antonovsky, 1996; Haugan & Eriksson, 2021). Based on the SOC literature, Idan et al. (2017) have questioned the flexibility versus stability of SOC across the lifespan. Antonovsky (1987) hypothesised that SOC develops during childhood and stabilises during the early adulthood stage. In contrast, other research proposed SOC changes over an entire lifetime (e.g. Nilsson et al., 2003, 2010). Hence, the longitudinal fluctuations as well as stability versus flexibility in individual SOC across the different life phases as well as during various life experiences are unclear.

Possibly, long-term ICU patients with a strong SOC may possess a stronger inner strength while facing serious illness, symptom severity, loss of functionality and consequently cope better.

Antonovsky (1979, 1987) coined the term GRR encompassing the characteristics of a person, a group or a community that facilitate the individual's abilities to cope effectively with stressors and contribute to the development of the individual's level of SOC. In general, the initial GRRs are perceived by four types of life experiences (Antonovsky, 1991), all of which contribute to the SOC developmental process: (1) consistency, (2) load balance, (3) participation in shaping outcomes and (4) emotional closeness (Idan et al., 2017). Accordingly, close family representing emotional closeness may be a vital salutogenic resource (GRR) to critically ill ICU patients. According to Antonovsky (1979, 1987), the GRRs may include (1) material resources (e.g. money), (2) knowledge and intelligence (e.g. knowing the real world and acquiring skills), (3) ego identity (e.g. integrated but flexible self), (4) coping strategies, (5) social support, (6) commitment and cohesion with one's cultural roots, (7) cultural stability, (8) ritualistic activities, (9) religion and philosophy (e.g. stable set of answers to life's perplexities), (10) preventive health orientation, (11) genetic and constitutional GRRs, and (12) individuals' state of mind (Horsburgh & Ferguson, 2012; Idan et al., 2017).

The literature supposes inner strength to represent an inherent life force in every human being, whereas willpower is the force that brings one's inner strength into action (Assagioli, 1974; Haugan & Eriksson, 2021). The concept of willpower is central in psychology and has been found strongly related to inner strength (Henden, 2008; Holton, 2003; Karp et al., 2014), involving an independent source of motivation for self-control (Henden, 2008). The term 'willpower' implies 'the ability to make a mental effort to maintain one's prior resolutions by blocking reconsiderations' (Henden, 2008, p. 83), especially when encountering insistence from one's own inclinations to reconsider prior resolutions. An individual's willpower can be drained and thus collapse (Henden, 2008). The burdensome experiences during a long-term ICU stay might tire and exhaust patients' willpower (Kean et al., 2017; Lykkegaard & Delmar, 2013), especially when their health problems continue back home after leaving the hospital. Concurrently, the phenomenon of willpower acts like a

muscle that can be overburdened and thus depleted. Figure 1 portrays the theoretical relationships between these concepts (Figure 1).

Long-term ICU patients are severe and critically ill; saving the patient's life is imperative. Consequently, ICU care mainly focuses on treatment supporting the bodily functions. The long-term ICU patient's pathway is extremely hard, involving several traumatic experiences and a heavy symptom burden (Alexandersen et al., 2019, 2020). In this context, long-term ICU patients' existential will is a salutogenic resource (Alexandersen et al., 2019; Haugdahl et al., 2018). As previously stated, based on the evidence showing negative effects caused by ICU treatment, ICU nursing is widening its scope to also promote peoples' health aiming at well-being and QoL in hospital and back home. However, to do so, the ICU field needs knowledge about salutogenic resources which are significant to health promotion in the ICU context. Inner strength and existential willpower represent such salutogenic resources, both of which are crucial during the ICU stay as well as back home. However, knowledge about these health resources is still scarce, in particular back home after discharge from hospital.

3 | THE STUDY

3.1 | Objectives

The objective of this study is to provide knowledge about what promotes and challenges the salutogenic resources of inner strength and willpower in long-term ICU patients back home after hospital discharge.

3.2 | Design

A qualitative hermeneutic-phenomenological approach was applied, aiming at illuminating the meaning embraced in people's experiences and their expressions (Dahlberg et al., 2008). Data were collected through in-depth interviews. Once the empirical analysis was completed, the salutogenic theory of health (Antonovsky, 1996) and the concept of willpower (Henden, 2008; Holton, 2003) were used to further illuminate the present data, providing valuable perspectives on the interpretation and understanding of the informants' experiences (Dahlberg et al., 2008).

This study is part of a large qualitative study among long-term critically ill patients, family members and nurses exploring patients' inner strength and survival (Alexandersen et al., 2019, 2020; Haugdahl et al., 2018).

3.3 | Participants

The participants were included from the database of a major hospital in Norway: an ICU nurse collected contact information for the first 30 former ICU patients who fulfilled the inclusion criteria. The first author sent a written invitation along with an information sheet including a page for informed consent. Out of these 30 former ICU

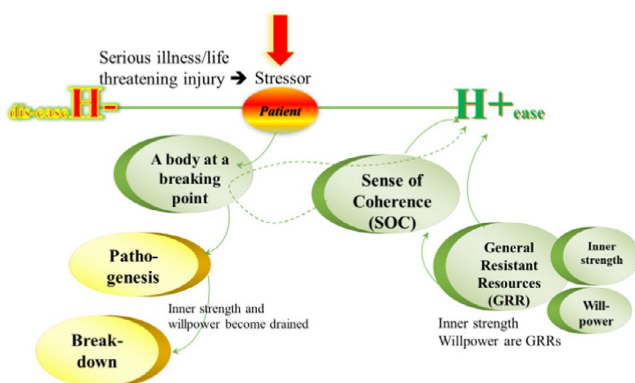


FIGURE 1 Theoretical relationships between the concepts [Colour figure can be viewed at wileyonlinelibrary.com]

patients, 17 volunteered to participate in this study; four women and 13 men aged 27–76 (median age 55).

The inclusion criteria were (a) former critically ill patients who had undergone respiratory ICU treatment ≥ 7 days, (b) were able to express themselves orally, (c) discharged from an ICU < 2 years ago, (d) ≥ 18 years old and (e) both genders represented. The length of the 17 participants' ICU stays ranged from 7–75 days, while their diagnoses included serious disease, severe trauma and complications.

3.4 | Data collection

The interviews were carried out in the informants' private home or in a university office during the autumn of 2016, 6–20 months following discharge from hospital. The interviews lasted 45–60 min were recorded and transcribed verbatim immediately after by the authors. A semi-structured interview guide was applied, focussing on the patients' inner strength and willpower for survival. The informants talked freely about their experiences; the interviewer cautiously encouraged the informants to give brief accounts of why they were admitted to the ICU and to describe which aspects promoted or diminished their willpower to fight for survival. During the interviews, the informants tended to stress life after discharge from hospital, highlighting their ability to cope with the situation at home as well as their perspectives on the future. Hence, based on the flexibility of the qualitative approach, these themes were included in the interview guide.

3.5 | Data analysis

The analysis was based on systematic text condensation consisting of four steps (Malterud, 2012, 2017). The first analytical step took place in the interview situation and during transcription. To obtain an overall impression of the content and to identify preliminary themes, the authors read the transcripts thoroughly several times, one by one. At this stage, the researchers maintained phenomenological openness while examining the data. Secondly, we identified and coded the meaning units representing different aspects of patients' challenges. In the third step, the content of each of the coded groups was condensed. Finally, we experienced data saturation was achieved and the content of each code group was summarised into generalised descriptions and concepts concerning these critically ill patients' challenges and what gave them meaning in their new life situations (Malterud, 2012).

3.6 | Rigour

Rigour was assured through the following elements: (a) the authors developed a common understanding of the research questions and conducted some of the 17 one-to-one interviews each followed by transcriptions; (b) all authors reviewed all interviews; (c) the first

and second authors developed a thematic structure; (d) all authors discussed the thematic structure and (e) all researchers discussed and verified that the analysis was a representation of the empirical data. All the present researchers are female nurses (RN), and all except one (GH) are university graduates and experienced ICU nurses. One author was employed at a University hospital' ICU, while the others were employed at the university during the time of this study. The consolidated criteria for reporting qualitative research (COREQ) were used (Tong, Sainsbury, & Craig, 2007).

3.7 | Ethical considerations

All informants received written and oral information about the study, their right to withdraw and assurance of confidentiality and anonymity. All participants gave voluntarily written informed consent to participate.

The Regional Committees for Medical and Health Research Ethics (REK-2015/2311) approved the study. In case traumatic memories were to produce negative reactions, psychological support was readily available. None of the informants made use of this assistance. On the contrary, numerous informants expressed that revisiting these events had a therapeutic effect.

4 | RESULTS

4.1 | Participant characteristics

See Table 1.

4.2 | Overview of the essentials constituting the phenomenon

The phenomena of inner strength and willpower back home after a long-term ICU stay were represented by two main categories and six sub-categories, as shown in Table 2.

4.2.1 | Meaningfulness promotes inner strength and willpower

Looking ahead: 'I want to get back!'

Getting back home proved to be a strong health-promoting experience for these formerly critically ill patients. Returning to one's work, being responsible for other people and still having interests in life were sources of motivation that inspired their struggle and fighting spirit to achieve the functioning that they had before the illness. The present informants described this in several ways:

My target number one is getting back to work!

(Id 17).

TABLE 1 Sociodemographics and clinical characteristics of the informants

Informant no.	Gender	Age in years	Diagnosis	Length of stay in days	Time since discharge from the ICU in months
1	Male	57	Sepsis	10	17
2	Male	67	Brain abscess	9	15
3	Male	62	Pancreatitis	13	15
4	Male	45	Pancreatitis	9	18
5	Male	28	Sports accident—multi-trauma	14	19
6	Male	49	Intracerebellar bleeding	28	21
7	Male	76	Pancreatitis	75	4
8	Male	57	Respiration failure	47	22
9	Male	59	Influenza	8	21
10	Female	55	Car accident—multi-trauma	41	6
11	Male	62	Amputation of leg	10	6
12	Female	59	Climbing accident—multi-trauma	15	–
13	Female	72	Circulation failure, leg	15	7
14	Female	65	Cardiac arrest	13	10
15	Male	57	Sepsis	8	11
16	Male	27	Car accident—multi-trauma	19	9
17	Male	41	Accident at work—multi-trauma	13	18

TABLE 2 Main categories and sub-categories

Categories	Sub-categories
Meaningfulness promotes inner strength and willpower	<ol style="list-style-type: none"> 1. Looking ahead: 'I want to get back!' 2. To process the past—or not: 'It is better to talk about things than hide them!' 3. Support from family and friends: 'I think I have much to fight for!'
Burdening the family causes guilt and loneliness	<ol style="list-style-type: none"> 1. Feeling guilt towards family: 'They had an even harder time than me!' 2. Quiet suffering, loneliness and insecurity: 'We don't need to talk more about this as you are on the road to recovery now.' 3. Worries about economy: 'The expenses keep piling up!'

The most important is to be at home.

(Id 2).

The only limitations are those you put on yourself, really. When I set myself a target, I am determined to achieve it. I don't want to end up in a nursery and whittle away. I just want to get back to work and start to live again.

(Id 6)

Being in good physical shape before the ICU period was an advantage in handling the challenges brought on by illness. The data disclosed a connection between exercise and getting back to one's former life and bringing progress to present life, often in small steps:

I took the car and drove to avoid the first hills uphill. The first trip. Then I said: "If I manage to cycle to

the store, then I will be happy." But we cycled even longer!

(Id 17)

My balance was destroyed; I lost the ability to walk. I did not see much; my sight returned later; I was 100% in need of care. However, my head was as good as it could be, so I wanted to be independent. I keep on doing things all the time. To do some exercising—then you get things done, not just sit down and think.

(Id 6)

In addition to focussing on physical health, several informants demonstrated personal qualities and positive thinking that showed extraordinary inner strength and willpower in bringing their desires into action:

I keep my spirits high. My ambition is to walk normally. When you are used to do everything yourself,

you really want to get back. I need to be patient. What I don't manage today, I will be able to accomplish tomorrow.

(Id 16)

I say to my wife: I am "manic" positive!

(Id 8)

And I'm very fond of my personal freedom; I'm an individualist, with the "guts" to cope on my own. I have always felt this way, no matter what happens I will manage. However, I feel that this will work—no matter what. I need to get out every day, and I often go to work to see my colleagues.

(Id 12)

Having been close to death, some patients experienced new will-power. Having been 'on the other side' positively affected health despite pain and suffering:

If I really was there, I managed to find my way back. In this light one needs to look after one's health in order to stay here a bit longer.

(Id 2)

This informant had not yet been able to read his diary but pointed out how lucky he was to survive. To recover and to be able to provide for his family was meaningful to him.

To process the past—or not? 'It is better to talk about things than hiding them!'

It was not quite clear whether the diaries written by the ICU nurses during the stays constituted a health-promoting asset. Several informants found the diaries valuable for getting a proper understanding of what they had been through during the period of illness, but some did not want to read them. For most informants, the diaries helped them understand blurry memories and process feelings linked to the experience and, probably, to put it behind them:

I was touched; I started to cry when I read that book.

(Id 3)

The diary—I have read it several times. It is very OK.

(Id 10)

It was funny, but also hard to read [the diary].

(Id 16)

If the diary did not exist, I would have wondered what really happened. I think it was a fantastic programme!

(Id 15)

Some needed to be further away in time from their ICU stay before they could read the diary:

I think it is very hard to finish it [the experience]. They wrote a diary at the ICU, but I have not read it yet. Nevertheless, now I feel that I want to read it. They took photos before the grandchildren should come, to prepare them [for how he looked]; I had so much fluid in my body. Now I feel like I can read it.

(Id 14)

It took time to process the entire ICU experience along with a serious illness as well as a changed body documented by photographs displaying a strange and frightening image. Obviously, there was a need to process the traumatic experiences; long after the ICU stay, informants expressed strong memories, and several emphasised the need for follow-up after leaving the hospital:

A reflection on what you have been through, well, in fact through the entire stay. More like, what has been done, and why and how. More of a status report then ... Yeah, when you contacted me about this I was thinking: Yes! Cool! Swell!

(Id 4)

I think it is better to talk about things than hiding them. Some things are hard, though.'

(Id 16)

Several informants stated that talking about their ICU stay and the subsequent period, as was done in the present research interviews, should have been compulsory for all critically ill patients. An informant mentioned social media such as Facebook as a channel for processing the experiences by finding supporting feedback from friends and family:

So now I use Facebook to publish my small steps forward, and this has helped me making progress as I receive all these warm responses.

(Id 12)

Despite the difficult experiences expressed above, some informants would rather look ahead than back at the period in the ICU:

I feel that I have left it behind.

(Id 8).

The latter informant read the diary together with his wife because she needed to do so. This informant may represent those who do not need to process their experiences through a diary. For some informants, health promotion consisted of looking ahead and not

dwelling in the past. Nonetheless, several found the diary valuable; thus, it seems to be a strong health-promoting resource for these informants.

Support from family and friends: 'I think I have much to fight for!'

Having a large family can be a blessing; in this study, family members gave practical support, made the informants feel important, offered a feeling of belonging and were good listeners:

I think I get healthy more quickly, I think... when you have someone who listen to you.

(Id 8).

My wife is fantastic. She is taking care of me now.

(Id 9).

Support from family and friends was a vital resource promoting the patients' inner strength and willpower in getting through the period of rehabilitation, and it was probably a crucial resource for finding meaning-in-life:

Having your children at your bedside, yeah, then you have much to fight for!

(Id 14).

4.2.2 | Burdening the family causes guilt and loneliness

Feeling guilty towards family: 'They had an even harder time than me!'

Back home the patients were attentive to the severity of their situation as well as the strain placed on their families. A sense of guilt for having overburdened the family was still evident:

It's heavy to think about I have been away. The same applies to the burdens I have put on other people, that it was as bad as it was.

(Id 16)

The heaviest part was to understand what my family and friends had been through. When everything was so insecure, whether I would survive or not, I understand how they must have suffered.

(Id 1)

One informant survived a car crash in which several others were killed. The death toll was announced in the media before the family had any other information. This informant struggled with thoughts about the load of suffering placed on the family:

This was the heavy part, for me it was not a big deal physically or mentally really, but for those around me it was a different story.

(Id 16)

For some, it was bothersome to be at the centre of attention in their social environment. Over time, experiencing other people's attention and expectations towards them and their health condition was burdensome:

Everyone kept asking my partner about how I was doing. They meant it well, but it was... in the end, she was almost afraid to walk down to the shopping centre, as everyone wanted to hear... I was after all a quite famous person... The attention was positive, but it put a strain on her.

(Id 3)

The social surroundings put forth expectations of improved health, and when things did not change, questions about the condition became an additional burden.

Quiet suffering—loneliness and insecurity: 'We don't need to talk more about this; you are on the road to recovery now'

The informants struggled with several physical challenges. Despite burdens such as pain and fatigue, maintaining their daily lives was important:

I don't sleep in the night because of the pain. Yes, I have been doing exercise. I walk a good thousand meters every day. I watch nature, which helps me concentrate on other things than my pain.

(Id 3).

I felt things were moving in the right direction, but it was very tough. I have had a hard struggle with morphine lately. I try to keep smiling, but it isn't... I find it quite hard. I try to put on a brave face, even if things are not so good.

(Id 3).

Pain, struggling and sleeplessness were difficult to handle. The pain endured over time, and the informants were anxious about burdening their families; therefore, they struggled on their own, alternating between hope and despair. The experience of meaning-in-daily-life was severely reduced, and inner strength and willpower were drained. Fatigue had a greater effect on daily activities than normal tiredness:

I'm not able to do a lot of things with my grandchildren, you know, to lift them up and things like that.

(Id 9)

I suffer from bad coordination, and I am not able to concentrate for more than ten minutes at a time. For a while, this has made me feel depressed; I am thinking, Will I ever return to my former self?

(Id 10)

The more time it took to recover, the more agonising was the burden. Loss of function and tiredness resulted in difficulty participating in normal activities.

The informants were happy to survive their serious illness and return home. However, those who continued to suffer did not want to impose their suffering on their loved ones. Consequently, maintaining the facade was crucial. They perceived their lonely fight to be meaningless; nevertheless, to surrender was not an option. The informants felt lonely:

I have tried to put distance between myself and the disease. Many things, which I thought were not there, I could read about in the diary. It has been a hard time. The worst has receded from my memory now. It is painful and I try to conceal that my whole-body shakes. I don't want my family and friends to see this. It really doesn't affect them much, but rather myself when I'm on my own.

(Id 3)

I know what the statistics say about this kind of injury, and it is not pleasant reading. I prefer not to think too much about it; it's far away, it's unreal. In a way, I've already died and been given a second chance.

(Id 6)

By saying that 'the worst is receded from my memory', this informant revealed that he knew that some 'worse memories' exist, which he has chosen not to face. These statements may reveal a breach in the perception of coherence, challenging the patient's sense of comprehensibility, manageability and meaningfulness.

As time goes by, family and friends are more reluctant to discuss the disease and the ICU experiences. At the same time, memories about the injury, illness and the hospital remain vivid; the informants found it hard to confine them to the past. At this point, there was nobody to talk with:

What I just talked to you about is not something I discuss with other people. Far from it. Even my wife and I don't talk about it. My daughter says, "This is no longer a topic. You are well and on the road to recovery now." Fair enough, I will not keep bringing it up. However, I think I will never be able to put this behind me.

(Id 2)

Nightmares experienced in the ICU resulted in much reflection after leaving hospital. Some experienced nightmares so troublesome that their absence was enough to feel good about life. The same applied to dreams linked to near-death experiences involving diseased family members:

Clearly, I haven't passed over to the other side, but I could... actually, I could remember being on my way. Even today this is how I think about it, deep inside.

(Id 2)

The first time after becoming aware of the situation, my greatest fear was that the nightmares would return—that I had to go through this one more time!

(Id 5)

A too early discharge from hospital caused immediate re-admission and a new period on mechanical ventilation (MV). The arrival back home was a bad experience:

It had been snowing heavily and it was several minus degrees. To arrive here at that time was even worse; I could do nothing about it; I had no energy. I just sat here for an hour... then I told my partner. I knew that if I take a taxi down to the hospital I would have to wait for hours for a doctor. Therefore, I told her to call the emergency number... I was on a ventilator for six days [after being re-admitted to the hospital].

(Id 15)

This informant had severe respiratory problems, causing exhaustion and insecurity after returning home. He did not understand why he was discharged; the situation was chaotic and incomprehensible.

Worries about economy: 'The expenses keep piling up!'

Economic concerns started already in hospital and contributed to draining inner strength and willpower. Following a divorce, one informant talked about his debt; his fear was that after recovering from serious illness and ICU treatment, he would end up in the same economic situation again:

It took me 20 years to escape this situation—I was so happy to finally be out of it; my greatest fear in life is to run into debts again.

(Id 15)

This informant had been on sick leave before being admitted to the ICU, and this brought complications related to public support services

that caused a reduction in income. In addition to pain and sleep problems, this informant stated that he was very concerned about his economic situation. The previous debt problems, in addition to the physical challenges, created an unmanageable life situation that weakened his inner strength and willpower:

It's not safe right now; maybe I should rather have died. I am almost at a subsistence level. Moreover, I am not able to pay my debts. It is very stressful to keep thinking about it every day. I will never be able to return to work, as it involves a lot of follow-up and training and things like that... if one does not follow up it becomes difficult to... when I'm not able to lift things, too... I do not sleep at night due to the pain and keep worry about my economy. There are these two things, pain and economy.

(Id 3)

Several informants claimed to have amassed credit card debt as a result of not being able to pay bills while in hospital, and this became a problem after returning home. The family received a blow when the principal financial provider became a critically ill patient for a period of several months:

The expenses kept running for them, and as long as I didn't have...she doesn't get anything...not being able to access anything. After a stay like this, you are hit hard economically. I decided not to give up, so I started using credit cards and expensive ways to cover my expenses. I must pay for that now.

(Id 6)

For some, the hospital stays lasted several months, causing huge economic troubles to which they were not able to respond, thus creating severe anxiety.

It is obvious that physical and mental problems together with practical problems back home pull the informants in a less healthy direction, draining their inner strength and willpower, perhaps to the point of collapse.

Despite daily problems and obligations, many stressed that it is worth trying to move forward. Meaningful experiences in daily life motivate one to handle and comprehend challenges. There is an ambition to regain one's former life and rediscover old strengths, to work towards the goal of 'becoming the same person as before' and finding meaning-in-life.

5 | DISCUSSION

This study explores what promotes and challenges the salutogenic resources of inner strength and willpower in long-term ICU patients, back home, 6–20 months after hospital discharge. Knowledge on what promotes critically ill patients' willpower as well as their inner

strength is useful in supporting the extra years of life gained by the ICU treatment worth living.

5.1 | What promotes inner strength and willpower back home?

The present informants wish, not surprisingly, to return to their former lives, to live with relatives who care and enhance their physical and mental health, and to return to their jobs and hobbies. These personal goals nourish their inner strength and willpower; accordingly, supporting ICU patients' goals is health promoting. Some former patients coped quite well at home; they were thankful for being back to their previous life surrounded by family and friends, experiencing emotional closeness and social support. In addition, these informants experience meaningfulness by identifying and using available GRRs such as inherent personal resources, coping strategies and setting personal goals (Antonovsky, 1979, 1987). Some disclosed a strong 'fighting spirit' reaching even further than their prognosis predicted. Possibly, these individuals had processed their traumatic experiences independently using their personal resources, or perhaps they did not perceive their ICU stay so badly or traumatic. The literature states two opposing views: (1) grief work processing ones' traumatic experiences, memories and suffering related to loss of functions resulting from serious illness, is imperative to become healthy and well-functioning after traumatic experiences (Bonanno, 2004), and (2) not all individuals need professional support of their grief work (Bonanno & Diminich, 2013). The most common trajectory following potentially traumatic events (PTE) is associated with consistently low levels of symptoms and distress and considered a stable and healthy way of recovery among 35%–65% of these patients. Accordingly, the second view states that many ICU patients with PTE do not need to mentally process their PTE experiences. Probably, at arrival in the ICU several long-term ICU patients possess available health-promoting resources including SOC and various GRRs and thus cope well. Hence, salutogenic ICU nursing should identify, acknowledge and use ICU patients' vital health-promoting resources.

Our findings correspond with previous research on what promotes inner strength during an ICU stay showing family support and inner strength to be vital for returning to ones' ordinary life (Alexandersen et al., 2020; Alpers et al., 2012; Wählin et al.,). Dinglas et al. (2018) recommend a core-set of five outcomes for studies reporting post-discharge outcomes for critical ill survivors: survival, physical functioning, cognition, mental health, QoL and pain. Our results suggest including a sixth outcome focussing on specific personal health-promoting conditions into Dinglas core-set, to evaluate post-discharge outcomes.

Despite practical/economic problems and physical and mental burdens, the present informants approached their problems offensively. The ICU stay was a profound experience to all informants; several expressed a need for health-promoting initiatives providing a channel to process these experiences making them comprehensible;

some just wanted to look forward. Consequently, health-promoting initiatives should cover experiences both in the ICU as well as back home to nurture inner strength and willpower.

5.2 | What challenges former long-term critically ill patients' inner strength and willpower?

Some informants experienced heavy burdens both mentally, physically, existentially and economically. As time went by and huge problems persisted, the willpower was challenged. During the ICU stay and the first time back home, the present informants received support by their family. However, over time family members were not able to continue providing the support needed. In line with previous research (Mikkelsen et al., 2018), being close to a seriously ill person is tiring over time. Our informants feared bothering their family or bringing them new burdens. Therefore, the family may not have been aware that their 'patient' was still suffering, resulting in loneliness. Our informants did not break. However, some were close to breakdown. Vacillating between despair and a fighting spirit, they often felt that their life should rather have ended. Hence, salutogenic long-term ICU nursing must include both the patient and the family (Haugdahl et al., 2021). Several studies have confirmed PICS and suffering following ICU stays among both patients and their families (Mikkelsen et al., 2018; Rawal et al., 2017), despite that the new ABCDEF bundle for ICU treatment highlights a holistic approach. A stronger focus on the ABCDEF bundle including its 'missing G' coined by Haugdahl and colleagues as 'salutogenic ICU nursing' (Haugdahl et al., 2021) seems needed. Using the SOC and GRR concepts (Antonovsky 1979, 1987), ICU nurses can and should play a role in preparing and supporting patients and families beyond the ICU, including to identify personal and environmental GRRS and supporting their SOC (comprehensibility, meaningfulness and manageability) in this specific context, as well as conveying help from a social worker to handle economic problems during and after the ICU stay. In turn, health professionals need knowledge and support to fulfil this important role in enabling the process of moving patients and their families from surviving to thriving, from dis-ease to ease; that is, making the extra years of life gained by the ICU treatment worth living.

As health and recovery are complex phenomena, the recently developed RAIN instrument seems promising in evaluating patients' recovery following an ICU stay (Bergbom et al., 2018). RAIN covers not only physical symptoms and discomfort, but also elements important to meaning-in-life such as close relationships, thoughts, and beliefs; all of which essential to individuals' inner strength and willpower. Thus, RAIN provides nurses with valuable information for health-promotion initiatives back home such as looking forward, supporting relations, existential ruminations, physical and mental strength.

ICU nursing should emphasise patients' inner strength and willpower as resources during the ICU stay as well as after discharge from hospital. ICU professionals should prepare the patient and his/her family for the new situation by identifying health-promoting resources and informing them about health-promoting

initiatives in the municipality, such as support groups and other measures.

5.3 | Implications of the findings

In Norway, follow-up programmes are not included in standard clinical practice (Olsen et al., 2017); about 44% of ICUs provide patient diaries, and 26% of these offer systematic follow-up (Egerod et al., 2013). In many countries, the healthcare system provides different kinds of post-ICU follow-up. However, these tend to manifest as experimental set-ups rather than systematic interventions (Huggins et al., 2016). Furthermore, the content of follow-up programmes has not been standardised (Moi et al., 2018). The lonely and silent suffering disclosed in this study indicates that still there is a need for further development of health-promoting follow-up programmes led by ICU nurses. A follow-up programme could include several salutogenic components:

(1) *Diaries* written by ICU nurses represent a means of meeting formerly critically ill patients' needs. A recent systematic review suggests that ICU diaries decrease anxiety and depression and improve QoL, and they might also result in less PTSD among ICU family members (McIlroy et al., 2019). Reading the diary was very valuable for several informants in this study. While writing diaries, an advanced focus on ICU patients' salutogenic resources such as inner strength and willpower might be helpful for ICU patients back home.

(2) *Health-promoting conversations*: In this study, several informants expressed the need to talk to someone about their ICU experience, about nightmares they still remembered and feared, and about present burdens of practical, economic and emotional matters. However, the present informants did not receive systematic follow-up consultations: health-promoting initiatives are suggested to be systematically implemented in long-term ICU care. A Danish intervention study found, however, that a recovery programme including three post-ICU consultations was not superior to standard care during the first 12 months post-ICU (Jensen et al., 2016), indicating no effectiveness on family members' health-related QoL or sense of coherence (Bohart et al., 2019).

Ågren (2019) evaluated the effect of a nurse-led family intervention including health-promoting conversations on families with a critically ill member. Outcome measures show positive effects on family functioning, stress and mental health. Contrariwise, Wade (2019) reports that a nurse-led preventive, complex psychological intervention initiated in the ICU did not significantly reduce patient-reported PTSD symptoms 6 months later. Ågren (2019) used a health-promoting perspective collecting data 6 months past the ICU stay, while Wades (2019) initiated the implementation in the ICU for 1 week, focussing solely on illness outcomes.

There are several reasons why the preventive, complex psychological intervention may not have worked. First, although a recent systematic review suggested that addressing risk factors early and initiating them in the ICU may be beneficial, the timing

of the stress support sessions by Wades (2019) may have been too early. Perhaps patients are still too ill and fatigued to focus on (and remember) the therapeutic messages taught and/or to make best use of the relaxation and recovery programme. In addition, the sessions were based on therapeutic techniques deemed appropriate for patients in early recovery (i.e. those potentially still enduring the traumatic experience), precluding the use of more challenging techniques such as exposure to traumatic memories (one element of trauma-focussed CBT), and the latter may be required to reduce PTSD symptom severity. Secondly, three sessions were not delivered to all patients. Even though more than 80% of patients received at least two stress support sessions, approximately one-third of patients did not receive session 3. For those patients who received three sessions, a reduction in anxiety was reported. Given the main reason for not receiving session 3 was discharge from hospital, an intervention that follows patients into the community seems required.

These results highlight the need for further health-promoting intervention studies including both patients and family members based on their individual needs during ICU recovery. Some patients in our study preferred to leave the ICU memories behind them and look forward. These individuals probably represent those who continue on with low levels of symptoms and distress in spite of burdensome experiences (Bonanno & Diminich, 2013). Alternatively, the ICU memories are so heavy that they represent a burden that hinders a healthy psychological mind and thus need to be suppressed. These cases would probably benefit from health-promoting follow-up consultations.

(3) *A cell phone app or a web-based recovery programme:* Resources to create follow-up programmes or consultations that extend beyond the physical location have till now been limited, although knowledge about patients' difficulties back home are partly known. The focus on and resources devoted to intensive medicine are comprehensive; however, they are disproportional to the problems critically ill patients experience back home. One way to meet this challenge is through web-based intensive care recovery programmes (Ewens et al., 2019). A self-directed mobile mindfulness programme for survivors of critical illness was found to reduce psychological and physical symptoms similar to a telephone-based mindfulness programme and better than an educational programme (Cox et al., 2019). Another option could be a cell phone application that facilitates communication between former ICU patients, health professionals and support groups for formerly critically ill patients. Increased insight into critically ill patients' difficulties after a long-term ICU stay may inspire ICU nurses to initiate follow-up programmes that provide advantages for formerly critically ill patients, nurses and their families.

5.4 | Limitations

The present informants represented one ICU ward at one large university hospital in Norway, indicating a limitation. However, some

of the present informants were transferred to ICUs at local hospitals for further treatment. This implies that the present data cover experiences at different ICU units/hospitals, including a university hospital and local hospitals. Furthermore, the present informants represented the most critically ill; patients with shorter ICU stays may experience different challenges. Hence, the present findings may not cover short-term critically ill ICU patients' experiences, difficulties and preferences.

All authors participated in the interviews and in creating the transcripts, and all took part in the different steps of the research process, denoting a strength of this study. Attentiveness to the researchers' pre-understanding was emphasised during the interviews and data interpretation (Corbin & Strauss, 2008). The authors' awareness of their pre-understanding, aiming at phenomenological openness, strengthens the findings. The informants were encouraged to tell their stories with minimal interruptions and were sometimes gently guided into talking about the research topic.

The length of time between the ICU stay and the interview varied, and a long interval may have affected the memories of the ICU experiences. However, the narratives were rich and detailed, and seemed to be independent of the time interval, possibly because such existential experiences are bodily grounded and can therefore be aroused and narrated despite a long-time span (Storli et al., 2007). The salutogenic perspective on ICU nursing emphasising patients' salutogenic resources represents a new perspective and approach in long-term ICU nursing, which is a strength of this study. Nonetheless, other theories might provide fruitful perspectives.

The fact that all informants survived severe challenges during their ICU stay might indicate that these individuals represent the most resourceful patients. Out of the 30 invited former ICU patients, 13 did not participate. Possibly, these individuals represent a more vulnerable part of this population suffering a severe symptom burden. Moreover, individuals who because of unknown reasons did not want to talk about or share their experiences back home after the ICU stay did not participate. Possibly, those with the heaviest symptom burden, accompanied with those who did not survive, are not represented in this study. Hence, the most vulnerable segment of this population might be unnoticed, and their experiences may remain unshared.

6 | CONCLUSION

This study provides new insights into the situation back home after a long-term ICU stay. Silent suffering and the fight to maintain inner strength and willpower were demonstrated by some, while others were coping quite well. All informants experienced several burdens back home that they handled in different ways, expressing different needs for health-promoting initiatives. While some found comfort and insight through reading diaries written by ICU nurses, others missed someone to talk to about problems and questions they still had. Some experienced such severe difficulties that survival seemed undesirable, while others merely wished to go on and leave the traumatic experiences behind.

Long-term ICU patients demonstrate a comprehensive need for different kinds of health-promoting follow-up support after hospital discharge. A cell phone app providing a platform connecting formerly critically ill patients and establishing contact with ICU professionals represents a cost-effective, health-promoting strategy to accommodate individual needs, thus supporting health, well-being and coping.

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CONFLICT OF INTEREST

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

AUTHORS' CONTRIBUTIONS

Study conception and design: IA, HSH, TEP, SBL BS, RE, GH. Data analyses and interpretation: IA, HSH, BS. Manuscript revisiting: TEP, SBL, GH. Final approval of the manuscript: All authors.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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