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## **ORIGINAL ARTICLE**

# "Never in my mind to give up!" A qualitative study of long-term intensive care patients' inner strength and willpower—Promoting and challenging aspects

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## Abstract

**Aims and objectives:** To explore aspects that promote and challenge long-term ICU patients' inner strength and willpower.

**Background:** Considerable research has been devoted to ICU patients' experiences; however, research on long-term ICU patients is limited. Studies in a health-promoting perspective focusing on long-term ICU patients' inner strength and willpower are scarce.

**Design:** A qualitative, hermeneutic-phenomenological approach, using in-depth interviews.

**Methods:** Seventeen long-term Norwegian ICU patients were interviewed once, at 6–18 months after ICU discharge. The consolidated criteria for reporting qualitative research was used (Data S1).

**Results:** The lived experience of the phenomenon "inner strength and willpower" and what promotes and challenges this phenomenon in long-term ICU patients were represented by four main themes and nine subthemes. Promoting aspects comprised of two main themes and five subthemes: (a) "No doubt about coming back to life" with subthemes; "Strong connectedness to life; feeling alive and present," "Meaning and purpose; feeling valuable to somebody." (b) "How to ignite and maintain the spark of life," with the subthemes: "Practical solutions, coping skills from previous life experiences," "Provocative and inspiring experiences" and "Vivid dream experiences that ignite the willpower." Two main categories and four subcategories represented challenging aspects: (a) *Exhaustion, weakness and discomfort*; subthemes; "Physical challenges" and "Mental discomfort" and (b) "*Tiring delusions*," subthemes; "Living in the worst horror movie" and "Feeling trapped."

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**Conclusion:** This study expands on previous studies by providing insights about what promotes and challenges long-term ICU patients' inner strength and willpower during their recovery trajectory.

**Relevance to clinical practice:** Insights into the variety of long-term ICU patients' experiences during the recovery trajectory are important for ICU nurses to support and facilitate ICU patients' inner strength and willpower.

#### KEYWORDS

advanced nursing, critical care, health promotion, intensive care, long-term ICU patients, phenomenology, qualitative study, willpower

## 1 | INTRODUCTION

Internationally, long-term intensive care patients are defined by a stay of 7 days or more, representing about 10% of all intensive care patients (Carden, Graham, McLennan, & Celi, 2008; Moitra, Guerra, Linde-Zwirble, & Wunsch, 2016). In Norway, approximately 15,000 patients are treated annually in intensive care units (ICUs). The medical conditions of long-term ICU patients often fluctuate due to complications such as infections and re-intubation. ICU stays beyond 7 days are associated with a high mortality rate (Carden et al., 2008; Moitra et al., 2016) and elevated rates of psychopathology (Kean et al., 2017; McGiffin, Galatzer-Levy, & Bonanno, 2016). In spite of multiple challenges from long-term, life-threatening illnesses, along with medical treatment and nursing interventions, some long-term ICU patients demonstrate an exceptional inner strength (Smith, Dingley, & Roux, 2018) and will to go on living (Alpers, Helseth, & Bergbom, 2012; Engstrøm, Nystrøm, Sundelin, & Rattray, 2013). Nonetheless, many ICU patients demonstrate decreased inner strength, showing powerlessness and withdrawal, expressing a feeling of proximity to death (Cutler, Hayter, & Ryan, 2013; Lykkegaard & Delmar, 2013; Nortvedt, 2014). Inner strength and willpower to go on with one's life can be understood as health-promoting resources. Based on our experience of the exceptional inner strength of some ICU patients while other patients display hardly any inner strength, this study explores what promotes and what challenges long-term ICU patients' inner strength and willpower, in a health-promoting perspective.

# 2 | BACKGROUND

#### 2.1 | Theoretical framework and previous research

The salutogenic health theory of Antonovsky (1996) centres on health-promoting assets. Individuals who coped well in spite of critical life challenges inspired Antonovsky to develop the concepts of salutogenesis and sense of coherence (SOC). SOC involves an individual's ability to comprehend that one's life is comprehensible, manageable and meaningful (Antonovsky, 1996, 2012). We find that the SOC concept is applicable to ICU patients during their recovery journey (Drageset, Ellingsen, & Haugan, 2017).

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

- Long-term ICU patients represent one of the most demanding groups in medical hospitals; they suffer serious illnesses requiring tremendous health costs. This study provides new insights into the subjective lifeworld, experiences and needs of long-term ICU patients during their recovery trajectory.
- Knowledge about the health-promoting perspective along with inner strength and willpower may contribute to improved quality and efficiency of long-term ICU care.

The theory of human willpower has a long tradition represented by ancient philosophy, later exemplified by Nietzsche and Schopenhauer (Karp, Lægreid, & Moe, 2014) and still central in recent psychology (Henden, 2008; Holton, 2003; Karp et al., 2014). The concepts of self-control and strength of will, or willpower, seem closely related; willpower is an independent source of motivation for obtaining self-control (Henden, 2008). The term "willpower" includes "the ability to make a mental effort to maintain one's prior resolutions by blocking reconsiderations" (Henden, 2008, p.83), especially when encountering resistance from one's own inclinations to reconsider prior resolutions. An individual's willpower is a limited source, which can be drained and thus collapse (Henden, 2008). Many ICU patients wish to return to their previous life before the illness causing their ICU stay. However, their illness generates heavy physical and mental stresses, such as pain, suffering from feeling cold and thirsty, resentment of the endotracheal tube, vivid and frightening dreams, and a lack of information about their situation and future plans (Karlsson, Bergbom, & Forsberg, 2012; Meriläinen, Kyngäs, & Ala-Kokko, 2013). Such burdensome experiences might tire and wear out patients' willpower during the ICU recovery trajectory (Kean et al., 2017; Lykkegaard & Delmar, 2013). Concurrently, the phenomenon of willpower seems to act like a muscle, which can be trained in different ways, such as dealing with distressing feelings, facing and dealing with goals (Karp et al., 2014). However, this muscle can be overburdened and thus depleted.

Some concepts, relevant to long-term ICU care, seem closely related to the concept of patients' willpower, including *inner strength* (Alpers et al., 2012; Smith et al., 2018), *the will to fight* (Alpers et al., 2012; Wåhlin, Ek, & Idvall, 2006) and *resilience* (Bonanno, 2004; Bonanno & Diminich, 2013). A recent literature synthesis defined "inner strength" as an inner, relational and personal phenomenon, which supports positive movement through challenging life events (Smith et al., 2018). "Resilience" refers to the ability to maintain relatively stable, healthy levels of functioning after adverse events, including more than just an absence of psychopathology (Bonanno, 2004). Thus, resilience might act as a vital resource for long-term ICU patients' recovery, during and after the ICU stay. Further research is required to understand the relationships between these concepts of willpower, inner strength, will to fight and resilience (Smith et al., 2018).

A meta-synthesis (Egerod et al., 2015) of ICU patients' experiences, in general, portrayed their being as characterised by liminality, unboundedness and mystery, signifying a bordering state of choosing life or death. Furthermore, a systematic review of aspects promoting ICU patients' perception of being safe (Wassenaar, Schouten, & Schoonhoven, 2014) concluded that "feeling safe" supports their recovery process. Several features were found to be important for ICU patients to feel safe, such as knowing and understanding what was happening to them, regaining control, hope for the future and trust in the health professionals (Wassenaar et al., 2014.). These patients are completely dependent on doctors and nurses to stay alive (Lykkegaard & Delmar, 2013); thus, longterm ICU patients experience not being able to trust in one's bodily functions (Engstrøm et al., 2013; Karlsson et al., 2012), accompanied by uncertainty and anxiety concerning one's future and the possibility of dying (Engstrøm et al., 2013; Karlsson et al., 2012).

A long-term ICU stay most often is a traumatic event. Working through negative thoughts, memories and emotions related to losses has been seen as imperative to becoming healthy and well-functioning after a traumatic experience (Bonanno, 2004). This viewpoint is fundamental to ICU nurses, who commonly face different reactions related to their patients' traumatic incidents. Bonanno and Diminich (2013) examined acute, adverse events, identifying six prototypical outcome trajectories following "potentially traumatic events" (PTE): (a) continuous health dysfunction (5%-15% incidence); (b) chronic dysfunction (5%-30%); (c) delayed symptom elevations (0%-15%); (d) recovery characterised by a temporary period of psychopathological symptoms that after some time (months) return to pre-event levels (15%-25%); (e) improved dysfunction characterised by elevated stress prior to the PTE that decreases markedly after PTE (5%-10%); and (f) "minimal-impact resilience" (35%-65%). The latter is found to be associated with consistently low levels of symptoms and distress following PTE and considered to represent a stable and healthy way of functioning. Opposing the dominant view that focuses on the need for grief work over loss, Bonanno and Diminich (2013) assumed that the most common trajectory following PTE is the "minimal-impact resilience" trajectory.

However, evidence displays that long-term ICU patients suffer from a variety of afflictions and struggles during and past their ICU stay, including postintensive care syndrome (PICS). PICS is characterised by mental, cognitive or physical impairments and may lead to disabilities (Hodgson et al., 2017; Mehlhorn et al., 2014; Moitra et al., 2016). Former ICU patients experience different degrees of disabilities. After discharged from hospital, they report lower quality of life, a lower return to school or employment, and ongoing care requirements (Kean et al., 2017; Svenningsen, Langhorn, Ågård, & Dreyer, 2017). Long-term ICU patients undergo multiple challenges, advanced medical interventions and nursing care; as a result, these patients consume a significant proportion of healthcare resources (Moitra et al., 2016). Nonetheless, studies focusing on inner strength and willpower in long-term ICU patients along their critical recovery path are scarce. Therefore, in a health promotion perspective, the present study explores long-term ICU patients' experiences of aspects that strengthened or weakened their inner strength and willpower during their recovery journey.

## 2.2 | The study

## 2.2.1 | Aims

The aim of this study was to retrospectively explore the experiences of inner strength and willpower among long-term ICU patients throughout their illness trajectory. Moreover, this study aimed at a deeper understanding of aspects that promote or challenge longterm ICU patients' inner strength and willpower.

The research questions were as follows:

- Which aspects do long-term ICU patients experience to promote (essential to) their inner strength and willpower?
- Which aspects do long-term ICU patients experience to challenge and/or weaken their inner strength and willpower?

## 3 | DESIGN AND METHODS

To explore long-term ICU patients' experiences of inner strength and willpower, as well as to understand how to promote their inner strength and willpower during the patients' recovery process, a qualitative hermeneutic-phenomenological approach was applied. This approach aims at illuminating the meaning embraced in people's experiences and their expressions (Dahlberg, Dahlberg, & Nyström, 2008; Van Manen, 1997). Once the empirical analysis was done, the salutogenic concept of health (Antonovsky, 1996) along with the concept of willpower (Henden, 2008; Holton, 2003) was used to further illuminate the present data (Dahlberg et al., 2008), providing valuable perspectives in the interpretation and understanding of the informants' experiences.

## 3.1 | Setting/Informants

A purposeful number of informants were extracted at a university hospital treating all ICU patients in a certain region of Norway. The actual ICU had ten single rooms and a 1:1 nurse-patient ratio. Most nurses had a postgraduate specialisation in ICU nursing. Cardiac surgery and transplant patients were not treated in the actual ICU.

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The inclusion criteria were patients who: (a) had been mechanically ventilated (MV) and stayed in the actual ICU for 7 days or longer, (b) were able to express themselves orally, (c) had their ICU stay within the past 2 years, (d) were of either gender and (e) were older than 18 years. Exclusion criteria were patients still in hospital. The first 30 patients recorded in the hospital's ICU database who met the inclusion criteria, received a written postal invitation to participate. In total, 17 out of these 30 participated: four females and 13 men, aged 27-76 years (average 55.2 years) with comprehensive illnesses. Their ICU stays ranged between 8-75 days (average 20.4 days) (Table 2).

## 3.2 | Data collection

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During autumn 2016, six different interviewers conducted individual in-depth interviews (using the Norwegian language) with 17 long-term ICU patients in Norway in the participant's home or in a university office. The researcher introduced herself and gave a brief introduction about the purpose of the study. Then, informants were invited to give a short description of the reason for their ICU stay and to speak freely about their experiences of factors that promoted or inhibited their inner strength and willpower during their stay at the ICU. The interviews lasted for 45–60 min. By means of a semi-structured interview guide with open-ended questions, the researchers facilitated a deeper understanding of the informants' experiences and their subjective lifeworld (Postholm, 2010; Dahlberg et al., 2008). The interviewers recorded and transcribed the interviews verbatim.

### 3.3 | Ethical considerations

All informants received written and oral information about the study, including their right to withdraw, confidentiality and anonymity. All participants signed an informed consent form. The Regional Committee for Medical Ethics (REK-2015/2311) approved the study. In case of negative reactions during or after the interviews due to facing traumatic memories of the ICU stay, professional psychological support was at hand. None of the informants needed such help. Instead, the informants in general demonstrated a great need to talk about their ICU experiences; in some cases, the interview was perceived to be therapeutic.

# 3.4 | Data analyses

The data were analysed by a hermeneutic-phenomenological approach (Dahlberg et al., 2008; Postholm, 2010) including five analytical principles. After each interview, the interviewer wrote a field note reflecting on one's senses, intuitions and experiences during the interview. Initially, the authors read the transcripts to gain an overall impression. Then, the transcripts were read carefully, one by one, breaking the data apart, discovering meaningful units, themes and subthemes (Dahlberg et al., 2008; Postholm, 2010). Third, a reflective discussion guided the preliminary development of themes, directed by the questions: "Which aspects promote long-term ICU patients" inner strength and willpower?' "Which aspects challenge and/or weaken their inner strength and willpower?" Parallel to this discussion, reading of literature in the lifeworld research and theories of willpower (Henden, 2008; Holton, 2003) and salutogenesis (Antonovsky, 1996, 2012) inspired the further interpretation of the data. Then, the analysis continued through an iterative process of moving back and forth between the separated meaning units and their meaning structure. A thematic structure was developed, portraying the participants' descriptions as closely as possible to the native data, yet also revealing meaning beyond those descriptions. Fifth, themes of meaning were derived, representing the essence of what promotes or challenge ICU patients' inner strength and willpower (Table 1). Relevant theoretical perspectives were cautiously applied to further illuminate the present data.

## 3.5 | Rigour

The researchers are female and experienced nurses (RN), university lectures/professors and graduates in ICU nursing. One author was occupied at an ICU, while the others were occupied at the university during the time of this study. Concerning prejudgements, the authors expected that long-term ICU patients with a strong will to recover would successfully do so, while the ones lacking willpower would experience a slower and therefore prolonged ICU recovery process. Moreover, our prejudgements involved the belief that good nursing care and family presence would support and strengthen the patients' willpower and promote their recovery. To meet the informants and the transcripts openly, the researchers made effort to bridle (Dahlberg et al., 2008) one's preunderstanding. Rigour was assured by the following central elements (Dahlberg et al., 2008; Lincoln & Guba, 1985; Van Manen, 1997; Postholm, 2010):

<b>TABLE 1</b> Example of the the	matic process
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Meaningful units	Subtheme	Main theme
<ol> <li>1: I had no other thoughts than to get on my legs and be active again</li> <li>1: Never in my mind that I should not survive!</li> <li>2: I am going to walk again!</li> <li>2: I was not giving up!</li> <li>2: I had that spark of life! I never lost it at all!</li> <li>3: No, never give up!</li> <li>3: That spark of life is still there. It has to be.</li> <li>4: Never a doubt about whether I was going to survive!</li> </ol>	1.1. Connectedness to life; feeling alive and present	1. No doubt about coming back to life

### TABLE 2 Informants' characteristics

Informant no.	Gender	Age in years	Diagnosis	Length of stay in days at central ICU	Days on MV	Time in months since ICU stay when interview was taken
1	Male	57	Sepsis	10	8	15
2	Male	67	Brain abscess	9	9	13
3	Male	62	Pancreatitis	13	12	13
4	Male	45	Pancreatitis	9	-	15
5	Male	28	Sports accident—multi trauma	14	9	17
6	Male	49	Intracerebellar bleeding	28	13	19
7	Male	76	Pancreatitis	75	-	8
8	Male	57	Respiration failure	47	11	20
9	Male	59	Influenza	8	7	19
10	Female	55	Car accident – multi trauma	41	11	12
11	Male	62	Amputation of leg	10	9	6
12	Female	59	Climbing accident – multi trauma	15	9	8
13	Female	72	Circulation failure, leg	16	16	11
14	Female	65	Cardiac arrest	13	10	7
15	Male	57	Sepsis	8	7	9
16	Male	27	Car accident – multi trauma	19	14	8
17	Male	41	Accident at work – multi trauma	13	11	-

- 1. All authors developed a common understanding of the research questions and took part in the one-on-one interviews and the transcription.
- 2. All authors reviewed all interviews.
- 3. The first author developed a thematic structure.
- 4. The first, second and third authors discussed the thematic structure.
- 5. All the researchers discussed and verified that the analyses were an accurate representation of the interviews.

The consolidated criteria for reporting qualitative research (COREQ) were used (Tong, Sainsbury, & Craig, 2007) (Data S1).

## 4 | RESULTS

## 4.1 | Participant characteristics

Table 2 lists the sample characteristics.

# 4.2 | Overview of the essentials constituting the phenomenon

The lived experience of the phenomenon "inner strength and willpower" and what promotes and challenges this phenomenon in longterm ICU patients were represented by four main themes and nine subthemes, as shown in Table 3. Two main themes and five subthemes represented inner strength and the willpower needed to recover. Inner strength and willpower is characterised by a strong connectedness to life. Patients' meaning and purpose of life and being valuable to somebody were essential for the inner and silent sureness about coming back to life. Second main theme involved the ICU patients' experiences of how their willpower was ignited and maintained. The related subthemes found were practical solutions and coping skills from previous life experiences, experiences that inspired and provoked inner strength and willpower, and vivid dream experiences which ignited their drive to recover.

Challenges to the inner strength and willpower are represented by two main themes and four subthemes. Exhaustion, weakness and discomfort consisted of two subcategories: physical discomfort, exemplified by an informant's experience of having "a devil in [the] throat" (i.e. intubation), and mental discomfort. The second main category framed "tiring delusions" involved subcategories comprising experiences at the border of consciousness which was expressed as "living in the worst horror movie," as well as feeling trapped.

## 4.2.1 | No doubts about coming back to life

Surprisingly, these seriously ill long-term ICU patients expressed convincingly that they never had doubted about their survival.

## Connectedness to life; feeling alive and present

While replying to the issue of what was essential in promoting their willpower and will to recover, some informants viewed this

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#### **TABLE 3**Overview of themes

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Research question	Main themes	Subthemes
What promotes the inner strength and willpower?	No doubts about coming back to life	Connectedness to life; feeling alive and present Meaning and purpose; feeling valuable to somebody
	How to ignite and maintain the spark of life	Practical solutions; coping skills from previous life experiences Provocative and inspiring experiences Vivid dream experiences that ignite the willpower
What challenges inner strength and willpower?	Exhaustion, weakness and discomfort	Physical challenges—"a devil in [the] throat" (i.e. intubation) Mental challenges
	Tiring delusions	Living in the worst horror movie Feeling trapped

question as irrelevant. Most of the informants revealed that they had never questioned their survival during their ICU stay. Even though being in a critical medical condition and bearing a heavy symptom burden, they felt safe, having no feelings or thoughts related to not survive:

> I experienced, I just had to get on my legs again, and then it was to use the time and the road. However, I was never in doubt about surviving!

> (Id\_1)I did not have any feeling that I had been in danger for my life...That life spark... [thinking] ... I never, in any way, had any thoughts that this would not end well. That was far away from my mind! Nevertheless, I was irritated that it took such a long time. (Id\_4)

These expressions showed no doubt of surviving as well as no experienced danger for one's life, despite being in a severe medical condition. Their optimism can be understood as coming from one's inner strength and a "minimal-impact resilience" way of coping. The informants expressed impatience and wanted to contribute actively to a move more quickly towards recovery. However, their physical condition caused heavy suffering, which drained their inner strength and willpower. Even with their suffering, impatience and irritation, they continued to fight for recovery, demonstrating willpower to go on.

During the interviews, the informants shared their thoughts about death. In the face of life-threatening medical conditions, several informants did not think of death at all:

> No, not when I was in a coma. No, I never felt close to death. I felt alive and present. It is possible I understood [that I was close to death], but I have never been dramatizing things. I have always thought like that. (Id\_5)

This statement expresses a conscious sense of connectedness to life, even while in a coma. This might result from being sedated. Nonetheless, this seems to express a sense of inner strength and willpower, encouraging one's belief in recovery. Likewise, some participants highlighted a conviction to recover: When I woke up, I never thought that I would not recover. Not at all. I had no thoughts about not recovering.

(Id\_9)No, no, no. I never thought of that! I never thought of the consequences—that I should not manage to walk again. It might be me "in a nutshell"—wilful! [laughing]. (Id\_12)

These informants highlighted the importance of their own attributes of not to "dramatize" things and being "wilful"; these expressions signify an inner strength and willpower impelling them to move towards an improved functionality.

### Meaning and purpose; feeling valuable to somebody

The relationships with other people seemed to be of great importance for releasing and nurturing the long-term ICU patients' willpower. In this context, the injuries of the body were less weighty; being important to others as a person was essential and positively influenced the ICU patient's inner strength and willpower to bear the suffering and go on forward:

> Gradually, when I understood how injured my body was, I thought: I am their mother! They do love me even if I lose my sight in one eye or if I must limp the rest of my life. Therefore, my aim was to go on as a human being anyway! I never thought about giving up!

> (Id\_10)When you feel a sign of life in yourself, then you are strong inside yourself. You cling to life, and you want to come back! (Id\_11)

Despite admitting how serious her situation was, this patient found strength in recalling "I am their mother! They do love me," regardless of her injured body. She recognised her value as a person, which seemed to activate and nurture her inner strength and willpower. Moreover, the sense of "a sign of life in yourself" seemed to activate the inner strength: "then you are strong inside," which made her hope for and work on her recovery. This activated the impetus and willpower to get back to her daily life.

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During the first period in the ICU, the most seriously ill ICU patients are sedated. When waking up, some informants were astonished by their family's reactions. It seemed that these informants were not aware of or did not understand the severity of their situation:

> My wife cried, you know. I did not understand why. What is going on? In addition, when my brother came... he was crying too! ... I had no feeling of ever having been in danger for my life!

> (Id\_4)In a way, I was afraid, but not in the way that I thought it was serious, because I knew they could help me. Therefore, I had no anxiety. (Id\_7)

Although the reactions of their relatives touched them deeply, the informants had no worry stemming from that their life was critically threatened. We interpret these experiences as a sense of inner strength, a sense that made them believe in their survival.

## 4.2.2 | How to ignite and maintain the spark of life

#### Practical solutions and coping skills from previous life experiences

During the interviews, these previous long-term ICU patients reflected on how they ignited and maintained their spark of life. In doing so, one approach was to search for practical solutions, understood as a kind of problem-focused coping of the situation at the ICU:

Usually, I am used to fix things! I get irritated when things do not... flow!

(Id\_4)I am a practical person. I work as a carpenter, so I'm always looking for practical solutions. To me, it's natural to search for practical solutions, also in a life-threatening situation. I don't look for problems but solutions.

(ld\_5)I'm no theoretician... I have always been working on practical issues... To me, when life is difficult, doing practical work is important. (ld\_8)

The informants emphasised important aspects of coping in this life situation, such as focusing on small things, which they were able to manage:

As soon as possible, getting the sense of controlling a small piece in my life—that means a lot to me.

(Id\_10)You don't have to run a marathon to recover but the small things in everyday life, they are important! (Id\_8)

To experience progress towards recovery, the use of personal and thus well-known coping strategies was vital. Their individual coping strategies protected them from being overwhelmed by feelings. In line with problem-focused strategies, these ICU patients concentrated on small, practical actions.

While lying in a bed in the ICU, the sounds from the ventilators and infusion pumps are stressing and disturbing to many, making it difficult to relax or sleep. Hence, a lack of rest might tire long-term ICU patients and consequently challenge their inner strength and the personal resources needed to recover. An informant turned this tiring and boring situation into something creative, related to his professional background as a music producer:

> These pumps–I am producing music, you know– and when there were only one or two pumps left, I thought; this sound I'm going to use–so I recorded it on my iPhone! I am going to use this sound in a song! I must use this for something positive! (Id\_4)

This coping strategy of transferring the exhausting sounds from the advanced equipment at the ICU into music reflects a personal problem-focused coping strategy. Moreover, this episode emphasises the importance that ICU nurses recognise the patient as an individual person while supporting his/her coping during a long-term ICU stay.

An informant was seriously injured by a car accident, in which she lost her boyfriend. This was obviously a hard situation to cope with. Her way of thinking supported her coping, giving a direction during the painful and demanding time in the ICU:

> Painful things that I knew I should talk about were placed in a mental drawer, although I knew the importance of talking about these things. My mental drawer helped me getting through, day by day. (Id\_10)

At times, the hard reality that causes huge challenges is too hard to face. To wake up at the ICU to such a brutal life situation is demanding. By facing and handling only small pieces, one by one, this ICU patient seemed to protect herself from breakdown. By means of coping skills from previous life experiences, that is, breaking the strains down to small pieces, she conserved her inner strength and supported her willpower. Based on knowledge and good intentions, ICU nurses might support and facilitate such a patient by encouraging her to talk about the loss of her boyfriend to facilitate her grieving process. Consequently, the ICU nurses might push the patient into an "inner work" that she is not yet ready to take. This quotation shows that respect for and awareness of one's mental situation and personal coping strategies are fundamental to the patient's recovery.

Another informant demonstrated a rather pragmatic and grounded attitude towards life:

I have a strong will to live, but for many years I have thought that 'if it is my turn... then it is okay'. I have always thought like this; if it's happening, then it's happening. I have a relaxed approach to my death... now; I know I have been ill for a long time... (Id\_15) These statements demonstrate a variety of ICU patients' coping strategies. Knowing the patient as a person is important to understand and individualise the support in a way that bolsters the patient's inner strength and willpower.

#### Provocative and inspiring experiences

Some informants demonstrated an extraordinary will to direct their energy towards a goal, such as recovering to a healthier state than the doctors could predict:

> I thought and asked, 'What are my possibilities of ever walking in the mountains again?' Then a doctor answered, 'Perhaps you can start riding in the mountains?' I felt irritated by the doctor's doubt that I was going to walk again! Ha, ha [laughs]... I nearly threw her out of the room!

> (Id\_12)Even though the doctors told me that my spine was broken, and I would not be able to move my legs again, I thought, 'I have to make the best out of my situation'. I have never had dark moments in my life. The doctors were quite clear—we cannot get your legs fixed. 'Well, well, these are your words. We'll see! I am going to do whatever it takes to make them move again, so we'll see'. A message like this makes me even more motivated to disprove it! It was a tough message, but... at the same time okay. (Id\_5)

Despite severe injuries and pain, this ICU patient was not depressed, showing an extraordinary fighting spirit: 'A message like this [about his broken spine] makes me even more motivated to disprove it!' (Id\_5). This reaction shows a strong will to invest great effort to get to walk again. In the face of the medical expert's negative conclusions, this patient expressed anger and protest, refusing to accept their judgements. We could easily interpret this response as a defence mechanism. Nevertheless, while conducting the interviews, some informants proved that they had reached far beyond the medical prognosis as well as achieved recovery faster than predicted to be possible or likely.

#### Vivid dream experiences that ignited the willpower

All informants experienced their life as being in a limbo between a conscious and unconscious state. A majority of the participants shared experiences of positive, inspiring dreams or meetings with deceased relatives. In this state between life and death, such positive experiences could prove to be a turning point. During her stay at the ICU, an informant saw her [deceased] parents and thought they were coming to fetch her. She framed this experience as "a memory," which was very clear, very real and very important to her:

They were suddenly there, and I thought; 'Oh, they have come to fetch me'. Moreover, that is all right!

This felt better than when I understood it was not going to be that way. How am I going to fight back myself? Weird! The moment was very short; they were there for a very short time, so I thought I had to fight back myself. To me, this was an important moment; I will die, or I must start fighting to get back. (Id\_14)

While being in limbo, balancing between life and death, another informant experienced that she actively decided to choose her life:

Twice I had the feeling of being clinically dead... so I had to escape to survive! ... For some unknown reason, my feet felt so cold—I was so uncomfortable that I decided to get back! Therefore, I did! (Id\_12)

A third informant, injured in an accident, experienced a comforting and calming meeting with his deceased relatives, who told him to make a choice:

> In the moment when it smacked, I became unconscious. Before I woke up, three people who have been very close to me came to see me on a mountain. We were elevated together in four pillars of light into heaven—they explained to me, that this life was over, and I had to choose where to live my next life! However, suddenly I was in the ICU, looking down on myself for a moment, and suddenly I was inside myself again!—An extraordinary experience! (Id\_ 5)

This person had no beliefs about what happens after life; however, this experience made him feel safe while facing death. These experiences, during a state of sedation though, implied a conscious meeting with significant persons; a bonding that enhanced the patient's inner strength. The patients' experiences from these meetings, which directed him to make a choice about going on with his life, seemed to activate his willpower. This understanding contrasts the common pathological understanding of ICU patients' vivid dreams during sedation.

## 4.3 | Challenges to the inner strength and willpower

### 4.3.1 | Exhaustion, weakness and discomfort

#### Physical discomfort-"a devil in [the] throat"

As expected, physical discomfort represented a sapping of the informants' inner strength and willpower. The physical strains seemed to vary. Some ICU patients emphasised their experience of pain as the worst burden, even though receiving pain treatment. Their pain affected their hope for recovery negatively, causing depressive symptoms:

> I had severe pain... I did not see any future. The pain was the worst-because it was present all the time. (Id\_3)

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The experiences of struggling to breathe, dryness in one's mouth and invasive respiration equipment like masks or tubes were recalled as hard and exhausting memories from the ICU stay:

> When lying there, awake, feeling the tube in my throat: it was the worst during the whole stay. You cannot swallow, so they have to suck your mucus. Ah—it was so terrible! I did not understand why they didn't take it [the tube] away and THEN wake me up! Why did I have to be awake with this devil in my throat?!

> (ld\_4)Afterwards [when extubated], having that mask, it made me so terribly dry in my mouth, with a coating on my teeth. That mask was killing me, more a plague than a benefit! (ld\_9)

Several patients did not understand why they had to use the tube or the mask. The feeling of discomfort and not getting enough air made them fight against the mask and against the nurses as well. Because of the terrible discomfort, they tried to extubate themselves. When they finally succeeded in getting rid of the tube, it felt like a victory. Despite the efforts made by the nurses and doctors to inform the patient prior to releasing the tube, an informant did not understand the steps of the procedure: he was wondering why they had placed a garbage can by his bed.

Some experienced sleeplessness, not being able to eat and a terrible feeling of powerlessness:

I felt completely empty for energy; I was unable to move!

(Id\_1)... there were no muscles left when I woke up.

(Id\_6)... I was caught in... a strange experience... no power in my torso. I was not able to rise or anything.
I wanted a cup of coffee... I saw the cup, but I was not capable of reaching it! They had to help me...
However, drinking coffee by means of a straw was not good...
(Id\_17)

The experience of discomfort and even shame related to the fear of not controlling the bowel function resulted in distressing thoughts, especially the first time the patient tried to get out of bed:

There was much stress with all the wires... I was thinking; 'Am I going to poop on the floor, or what is happening?'

(Id\_4)The worst was not being able to go to the toilet yourself. It is tragic... being a grownup and you must lie and... poop in the bed. That is not... something that you like! (Id\_17) These informants experienced different exhausting physical strains. Correspondingly, their inner strength and their willpower were drained as well. In addition, the physical discomfort seemed associated with their mental discomfort.

#### Mental discomfort

Some informants told the interviewer that, at an early stage on their pathway towards recovery, they had no will to fight for their recovery. Their mind was roughly aware of being seriously ill. Still, they were not able to respond to this critical fact. The situation was extremely demanding, making each minute more than enough to deal with:

I had enough by just being at that time. I was not able to think any further.

(Id\_3)While sitting in my bed for two minutes, I wanted to lie down to sleep. I did not think about my future at that time. I was so worn out that I was not able to think about how this should end. (Id\_2)

During this demanding phase of the ICU stay, acceptance seemed to be crucial. Some expressed comfort in their religious faith, accepting that someone else was deciding their life and death, while others accepted that one's life was reaching the end. While lying in bed, without being able to move, not even their hands, some experienced loneliness. At the point of recognising the comprehensive injuries of their body, for a period they felt depressed and wanted to die:

> When I understood how bad my condition was, I got terribly depressed. Then I decided if it's really as bad as this, I will not go on. For a while, I had been happy to let go of my life. (Id\_6)

These quotes exemplify long-term ICU patients' experiences of bodily and mental discomfort and demonstrate the diversity and individuality of their challenges. Moreover, this shows that these patients' willpower was worn out and thus drained; the willpower might have been used too hard for too long a time.

## 4.3.2 | Tiring delusions

## Living in the worst horror movie

Nightmares involving terrifying experiences related to the present situation or to the earlier daily life of the individual afflicted 11 of the 17 participants in the study:

> Some ugly pictures passed by. I didn't dare close my eyes and sleep because the pictures were so frightening!... It was like the worst horror movie!

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(Id\_1)I believed my children were kidnapped by the director—the one that owned the house. (Id\_12)

Nightmares that deprive a sufferer of sleep and rest and cause anxiety and stress are certainly not health promoting, but they may be an expression of an inner fight—the willpower fighting against the stresses of both body and mind.

### Feeling trapped

Feelings of being trapped or pursued, as well as patterns of restlessness and sleeplessness, were typical:

I stood in front of a door and wanted to go in... but I could not open it... I felt like I was suffocating!

(Id\_ 8)I had many terrible nightmares, I felt trapped. Very trapped. This was my worst experience. (Id\_10)

Several informants experienced their nightmares as terrifying: some found these experiences to be never-ending. These patients longed strongly for an immediate alleviation of this state, indicating that the nightmares tapped and thus negatively influenced their inner strength and willpower.

## 5 | DISCUSSION

The aim of this study was to explore long-term ICU patients' lived experiences of the phenomenon of inner strength and willpower throughout their illness trajectory. In addition, this study aimed at in-depth understanding of what promoted or challenged the inner strength and willpower of the long-term ICU patients. Although these patients represent the most seriously ill ICU patient group, studies focusing on their inner strength and willpower to recover are scarce. Therefore, in a health-promoting perspective, this study expands on previous studies by providing insights about what promotes or inhibits long-term ICU patients' inner drive to recover.

## 5.1 | To mobilise the inner strength and willpower

The present results showed that long-term ICU patients, at the border of consciousness as well as a conscious state, experienced a sense of inner strength and a conviction that they would survive, despite their serious injuries. Similar findings have been reported among critically ill patients and older women (Smith et al., 2018), reporting a sense of "inner forces" and "finding strength," both of which can be interpreted as a sense of inner strength. In the present study, many seriously ill ICU patients surprisingly did not think about dying, implying a strong connection to life. Alpers et al. (2012) and Engstrøm et al. (2013) found that despite physical strains, ICU patients expressed a strong will to go on living, but also describing anxiety and fear of dying among ICU patients (Alpers, 2012; Engstrøm et al., 2013). Karlsson (et al., 2012) described ICU patients who actively avoided thoughts of death and were searching for support from their religious spirit or power. In this study, some ICU patients found comfort in their religious belief, including acceptance, comfort and inner peace drawn from their faith. Hence, religious faith might support one's willpower and inner strength.

Henden (2008) claimed that "the will" is a mediating, executive capacity needed to sustain the execution of one's intentions. In line with Henden (2008), the present participants disclosed a willpower brought into action by means of different personal coping strategies. Furthermore, the ICU patients' experience of progress and thus success by means of their coping strategies strengthened their willpower. In the present study, although at the border of unconsciousness, ICU patients experienced a sense of inner strength caused by significant meetings in their dreams or delusions. These meetings seemed to represent a turning point, at which the patients were pushed to make a choice about life and death. In line with the present findings, previous studies have shown experiences on the border of consciousness to be filled with personal meaning as well as healing potential (Storli, Lindseth, Asplund, 2008, 2009; Egerod et al., 2015). This salutogenic perspective of dreams and delusions providing a healing potential represents a complementary view to the pathogenic perspective interpreting delusional experiences as a symptom of ICU delirium (Barr et al., 2013). A number of risks for ICU delirium are listed, for example, interactions of pain, sleep deprivation, noise, sedatives and severe illness, resulting in pathogenic brain processes (Reade & Finfer, 2014).

This study found that the feeling of being valuable to others influenced on ICU patients' willpower positively. In accordance with Haugdahl et al. (2018), a sense of being valued and important to others, particularly one's relatives, seemed to act as a positive force, which activated and nurtured patients' inner strength and willpower. Furthermore, our study revealed that bad messages concerning limited possibilities for recovery might be used for motivation. A poor prognosis might well provoke the individuals to fight against what they perceived as a doctor's pessimistic view. This resilient way of responding is often interpreted by ICU health workers as a kind of denial or repression (Bonanno, 2004), indicating the need for a realistic reorientation. According to Bonanno (2004), health workers in the Western world generally understand reactions from potentially traumatic events in the light of grief work (Stroebe & Stroebe, 1991), which at the ICU results in a neglect, overlook and thus a misinterpretation of ICU patient's hopes, beliefs and coping strategies. Instead of perceiving an excessive will to go on fighting for recovery as a health-promoting resource, ICU professionals often interpret patients' "unrealistic" expressions as defence mechanisms. Bonanno and Diminich (2013) presented the minimal-impact resilience trajectory as the most common outcome from potentially traumatic events. This implies that ICU patients may show a healthy adjustment to the situation without occasioning distinct grief work, although a mild and transient disruption in functioning might occur. Lack of support for and understanding of this health-promoting force might inhibit patients' inner strength and willpower.

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According to Bonanno and Diminich (2013), personality is one among several fundamental variables that may influence an individual's resilience. Nevertheless, Bonanno and Diminich (2013) refer to a growing number of studies that support the importance of personality traits, such as low negative affectivity, ruminative response style and a self-enhancement trait. These personality traits were also seen in the present study, exemplified by descriptions of how the patients uplifted and boosted themselves by self-enhancement.

Inspiration to compose music when listening to the rhythmic sound of the infusion pumps was an uplifting and creative way of coping seen in the present study. Making "infusion pumps music" followed by future planning might be a meaning-making act and thus a health-promoting strategy in this difficult life situation (Antonovsky, 1996). Perceived meaning-in-life probably relieves physical and emotional stresses, supporting inner strength. Perceived "meaning-in-life" is found to positively affect nursing home patients' wellbeing, in physical, emotional, social and functional ways (Haugan, 2014a). Moreover, significant associations between meaning-in-life and physical symptoms, such as pain, fatigue, nausea and vomiting, insomnia and dyspnoea, have been shown (Haugan, 2014b). Patients with high scores on meaning-in-life displayed a significantly lower perceived symptom burden and better physical and emotional functioning, compared to those experiencing low meaning (Haugan, 2014a, 2014b). These findings are probably transferable to longterm ICU patients who suffer from similar symptoms.

# 5.2 | Challenges to ICU patients' inner strength and willpower

Repeating medical complications, including both physical and mental issues, led to a negative state of tapping the willpower, along with exhaustion and decreased inner strength. Delusional memories experienced as "horror movies," involving chaotic and frightening experiences, led to exhaustion. According to Henden (2008), the willpower in many ways works like a muscle: if overused for too long, this resource will simply burn out. This picture fits well with the long-term ICU patients' expressions of finding no available willpower to engage in one's recovery. The present study revealed states of exhaustion from heavy symptom burdens. Nonetheless, all participates survived their serious illness, which supports the idea of willpower as an energy resource mobilised by the patient's inner strength or by health-promoting relationships.

## 5.3 | Strengths and limitations

A limitation of this study arises from all informants being recruited from one ICU in one of the largest university hospitals in Norway. However, this university hospital serves a large part of Norway, meaning that a great number of the present informants after some time were transferred to ICUs in local hospitals for further treatment. This implies that the experiences shared in this study involve different ICU units, including a large university hospital and various local hospitals.

Furthermore, the present data were collected 6–20 months after the patients left the ICU, representing a diversity concerning the time perspective. Reflecting upon one's ICU stay 6 months after might indicate more clear memories compared to looking 20 months backward; the more distance in time the more might one's memories be processed as well as faded to some extent. Nevertheless, Zetterlund, Plos, Bergbom, and Ringdal (2012) compared ICU patients' memories after one and 5 years past their ICU stay, showing that their memories were stable over time (Zetterlund et al. (2012)). In the present study, the vivid and detailed narratives experienced during their ICU stay still represented vivid experiences in their daily lifeworld, despite the passage of 6–20 months.

ICU patients staying a shorter period in the ICU encountered different challenges compared to the long-term ICU patients (Moitra et al., 2016). Hence, the present findings might have less significance to the care of patients having shorter stays at the ICU.

The actual ICU involved in this study had a liberal visiting time for relatives and a staff ratio of 1:1, which is quite high compared to non-Scandinavian countries (Egerod, Albarran, Ring, & Blackwood, 2013). These aspects might influence long-term ICU patients' experiences of support and care along their recovery trajectory. Being the exclusive patient receiving attention from one nurse might facilitate more individualised care than when the nurse must care for several patients at a time. The present findings should be interpreted in the light of this.

All authors participated in conducting the interviews and the transcription, which is a strength of this study. The researchers' consciousness about their prejudgement is important during the interviews and the interpretation of qualitative data (Corbin & Strauss, 2008). The researchers' prejudgements involved their experience as ICU nurses as well as teaching graduate and postgraduate nursing students. The salutogenic health perspective (Antonovsky, 1996) was well known among the authors. The theories of Antonovsky (Antonovsky, 2012) and Lazarus and Folkman (1984), along with literature on inner strength and willpower (Bonanno, 2004; Bonanno & Diminich, 2013; Henden, 2008; Holton, 2003; Karp et al., 2014; Smith et al., 2018), have shed light on the present data. Nonetheless, other theories might have provided other fruitful perspectives. The salutogenic resources of inner strength and willpower represent a new perspective and a health-promoting approach to ICU nursing. This study provides insights about the phenomenon of "inner strength and willpower" among long-term ICU patients.

The fact that the informants had survived the severe illness during their ICU stay might indicate that these individuals represent the most resourceful patients. The experiences of ICU patients who did not survive remain silent.

## 6 | CONCLUSION

This study provides expanded insights into what promotes and what challenges the inner strength and willpower of long-term ICU patients. A variety of coping strategies are demonstrated. This study also exposes comprehensive challenges due to the long-term ICU patient's demanding situation. By means of a health-promoting perspective, this study highlights long-term ICU patients' personal

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experiences of inner strength and willpower. To nurture inner strength and trigger ICU patients' willpower, it seems fundamental that ICU nurses understand these patients' personal experiences. However, the experiences among the "silent group" of long-term ICU patients who were unable to survive are lacking.

# 7 | RELEVANCE TO CLINICAL PRACTICE

Knowledge about the great variety of long-term ICU patients' coping strategies, as well as their hopes, beliefs and positive attitudes towards recovery, is important. To support and nurture ICU patients' inner strength and willpower, insights about how positive dreams and terrifying delusions influence the patients, are essential. Furthermore, ICU nursing students are eager to learn essential knowledge in natural sciences, which is vital. However, knowledge about and understanding of long-term ICU patients' personal experiences, that is their subjective lifeworld, as well as potential post-traumatic events, are essential to care quality, efficiency in promoting health and well-being. Implementation of the knowledge provided in this study might help reduce long-term ICU patients' negative experiences and thus facilitate their well-being during the recovery journey back to life. In doing so, the length of the ICU stays will be reduced, which is beneficial for the patients and their families as well as to the society in general.

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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, BS, RE, HSH, TEP, SBL and GH. First coding of the data: IA and BS; the rest of the authors in collaboration validated the data analyses and interpretations. Revisit of the manuscript for important intellectual content: IA, BS, RE, HSH, SBL, TEP and GH. All authors approved the final version of this publication.

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#### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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