

**From breaking point to breakthrough during the ICU stay: A qualitative study of family members' experiences of long-term intensive care patients' pathways towards survival**

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Review

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3 **From breaking point to breakthrough during the ICU stay: A qualitative study of**  
4 **family members' experiences of long-term intensive care patients' pathways towards**  
5 **survival**  
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7 **[Red coloured text: means new text**  
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10 **Abstract**  
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12 **Aims and objectives.** To explore family members' experiences of long-term intensive care  
13 unit (ICU) patients' pathways towards survival and to highlight family members' efforts to  
14 promote the patient's health during the ICU stay.  
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18 **Background:** Although considerable research has been devoted to the **substantial** burden of  
19 long-term ICU patients, less attention has been paid to health promoting factors that facilitate  
20 patients' health and survival during ICU stays. Support from family members can improve  
21 patient outcome. However, there is little knowledge of the specific contributions provided by  
22 family members.  
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29 **Design.** A hermeneutic phenomenological approach, within the context of Antonovsky's  
30 salutogenic theory and Merleau-Ponty's phenomenology of the body, **involving the body as**  
31 **the fundament of experience and understanding.**  
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36 **Methods.** In-depth qualitative interviews. Thirteen family members of long-term ICU  
37 patients were interviewed once, at six to 18 months after ICU discharge. **The consolidated**  
38 **criteria for reporting qualitative research were used.**  
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43 **Results.** Three themes were identified: (1) A body at a breaking point; (2) Family members'  
44 presence and; (3) Breaking through. In the perspective of the family members, their beloved  
45 ones were at a breaking point between life and death. The family's presence was significantly  
46 health promoting, demonstrating and communicating love and sensitivity. Moreover, family  
47 members' understanding of the patient's unique characteristics and personality was crucial to  
48 the patient's experience of being understood, recognized and acknowledged. Inner strength  
49 represented a life force capable of moving the patient from **the** breaking point towards a  
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3 breakthrough towards life. Family members purposely used their knowledge about the patient  
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5 to trigger, nurture and release the patient's inner strength.  
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8 **Conclusions.** Family presence helps to trigger, arouse and release a patient's inner strength,  
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10 representing important health promoting factors facilitating patients' health and survival  
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12 during an ICU stay.  
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15 **Relevance to clinical practice.** Insights into t The unique and vital health promoting  
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17 influence of family participation indicate the responsibility of the ICU team to provide  
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19 support for families.  
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24 **Key words.** critical care, critical care nursing, family, health promotion, intensive care,  
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26 intensive care units, nursing, patients, qualitative research, salutogenesis  
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## Introduction

Due to advances in medical treatment, the number of patients surviving an episode of critical illness is increasing. The medical treatment and the healing process represent a substantial burden on the patient and her/his family, clinicians, and society (Kean & Smith, 2013; Lone et al., 2016). A study from New Zealand suggested that the proportion of patients spending more than seven days in the ICU represents approximately 10% of the ICU population and accounts for 40 to 50% of the total ICU costs (Carden, Graham, McLennan, & Celi, 2008). Accordingly, knowledge about this specific group of ICU patients is highly warranted.

ICUs are dominated by advanced medicine; the main focus is on survival and medical treatment, which is necessary and beneficial. Nevertheless, the medically oriented attentiveness and atmosphere might cause stress for the patients and their families (Samuelson, 2011).

The ICU patient's existential threat has been expressed as a fear of death, as well as a threshold between life and death (Egerod et al., 2015). The importance of *getting through* the illness trajectory is thus not only associated with the struggle to survive serious illness, but also to retain the existential will to keep on living (Haugdahl, Dahlberg, Klepstad, & Storli, 2017). Therefore, a more holistic approach along with a particular focus on stressors and coping resources should be the basis of long-term ICU patient care (Fok, Chair, & Lopez, 2005).

## Background

Antonovsky (1979) developed the salutogenic theory of health, representing a holistic approach to recovery, health and well-being. Sense of coherence (SOC) was coined by Antonovsky (1979; 1987) as the core concept of his salutogenic model to explain the origins of health. SOC refers to a global orientation to view one's internal and external environments as comprehensible, manageable and meaningful. A positive relation between SOC and

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3 perceived health has been confirmed by a number of studies included in a systematic review  
4 (Eriksson & Lindström, 2006), and the concept has been applied in several settings such as in  
5 mental rehabilitation (Griffiths, 2009; Langeland & Wahl, 2009) and among older people  
6 (Tan, Vehvilainen-Julkunen, & Chan, 2014). SOC is found to be a health promoting resource  
7 strongly related to coping, representing resilience and a positive state of health (Eriksson &  
8 Lindstrom, 2005; Griffiths, 2009; Langeland & Wahl, 2009; Tan, Vehvilainen-Julkunen, &  
9 Chan, 2014).

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18 In the context of long-term ICU patients, a salutogenic perspective implies a search  
19 for elements in life supporting ICU patients' survival, recovery and health. Exposed to a life-  
20 threatening crisis, ICU patients might experience powerlessness and vulnerability  
21 characterized by losing one's "self," along with feelings of shame, fear, and distrust (Yang,  
22 2016). Although considerable research has been devoted to the substantial burden of long-  
23 term ICU patients (Parker et al., 2015), less attention has been paid to the health promoting  
24 factors that facilitate patients' health and survival during an ICU stay (Al-Mutair, Plummer,  
25 O'Brien, & Clerehan, 2013; Eriksson & Lindstrom, 2006).

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35 Family members' support is vital to the ICU patient's healing process (Egerod et al.,  
36 2015; McAdam, Arai, & Puntillo, 2008; Wassenaar, Schouten, & Schoonhoven, 2014),  
37 signifying crucial help and encouragement during the patient's recovery (Agard, Egerod,  
38 Tonnesen, & Lomborg, 2012; Alpers, Helseth, & Bergbom, 2012). The ICU patient's critical  
39 health state represents a burden for the family, involving emotional pain, anxiety and  
40 worrying. Simultaneously, family members make a great effort to support the patient's  
41 healing process (Blom, Gustavsson, & Sundler, 2013). Guidelines for family centered care in  
42 ICUs highlight that support from family caregivers can improve patient outcome and  
43 consequently reduce the length of the ICU stay (Davidson et al., 2017). However, details of  
44 the specific contributions of family members are not included in this particular guideline, and  
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3 research based on the family perspective is scarce (Davidson et al., 2017). In this study, the  
4 aim was to explore family members' experiences of long-term ICU patients' pathway  
5 towards survival and to elucidate how their efforts benefit the patient's healing process. The  
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7 research question addressed was: What are family members' experiences of factors of  
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12 significance in promoting long-term ICU patients' pathways towards survival in the ICU?  
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### 14 15 **Design and methods**

16 In order to explore family members' experiences of how to support long-term ICU patients'  
17 survival as well as to understand how their efforts might benefit the patient's recovery  
18 process, a hermeneutic phenomenological approach was used. This approach aims at  
19 illuminating the meaning embraced in people's experiences and their expressions (Dahlberg,  
20 Dahlberg, & Nyström, 2008; Van Manen, 1990). This study intended to investigate the  
21 beneficial influence of family members' presence on the healing process during the ICU stay.  
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23 The present data were therefore analyzed within the context of Antonovsky's (1996)  
24 salutogenic theory and Merleau-Ponty's (1994) phenomenology of the body, involving the  
25 body as the fundament of experience and understanding.  
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### 37 **Setting and sample**

38 A purposive sample of ICU patients' family members was recruited from the ICU database in  
39 a university teaching hospital in Norway. Inclusion criteria were (1) family member of a  
40 patient mechanically ventilated  $\geq 7$  days, (2) Norwegian speaking, (3) visited the patient  
41 regularly, (4)  $\geq 18$  years of age, and (5) any gender. An invitation to participate was sent to 32  
42 family members by the research coordinators (RE, IA), and 13 consented to participate.  
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50 The ICU had ten beds, a one to one nurse:patient ratio and treated all patient  
51 categories except cardiac surgery and transplant patients. The unit had two rooms dedicated  
52 to family members for retreatment and rest. There were no age restrictions on visitors, while  
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3 visiting hours were mainly limited to 10.00-14.30, 16.30-18.30 and 20.00-21.30. In the  
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5 Norwegian context, ICU patient care is performed by nurses. Family members are considered  
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7 as visitors and not routinely involved in patient care.  
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### 10 **Characteristics of the researchers**

11 All authors are ICU nurses, with competence in teaching, clinical practice and research, while  
12  
13 the last author is widely experienced in health promotion research.  
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### 16 **Data collection**

17 The data were collected by in-depth interviews between August and November 2016. A semi-  
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19 structured interview guide with open-ended questions was used. Thirteen participants were  
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21 interviewed once, six to 18 months after the patient's ICU discharge. At the participants'  
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23 choice, the interviews were performed at home or in a university/hospital office. The  
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25 researcher introduced the interviews with a short briefing of the purpose, followed by some  
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27 open questions; "Can you tell me about your relationship to the patient, and why she/he was  
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29 in the ICU?" and "What are your experiences of significant factors that promoted the  
30  
31 patient's survival?". The emphasis was on narratives of concrete situations during the ICU  
32  
33 stay. The interviewer facilitated an open dialogue including sequences of questions (Dahlberg  
34  
35 et al., 2008): "Can you tell me about significant factors related to the  
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37 staff/environment/yourself/your family?", and "Can you give an example/tell me more about  
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39 ...?" Interviews were audio recorded and transcribed verbatim, and lasted from 35 to 60  
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41 minutes.  
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### 46 **Data analysis**

47 Initially, the first and second authors read the transcripts to gain an overall impression,  
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49 including writing a reflection note for each transcript. Second, a structured coding of each  
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51 transcript (using NVIVO qualitative data analysis software; QSR International Pty Ltd, 2014)  
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53 was performed, leading to preliminary aggregated coding groups. Each transcript was closely  
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3 analyzed on its own terms, i.e. a thorough reading and systematic structuring of the data using  
4 tables, extracting statements and searching for essential clusters of meaning within and across  
5 the interviews (Van Manen, 1990). Third, a reflective discussion guided the preliminary  
6 development of themes. The analysis was guided by the question: How do the participants  
7 describe their experiences of factors that contributed to ICU patient's survival? Parallel to the  
8 discussion, the reading of literature in the life-world field of research and on salutogenesis  
9 inspired further interpretation of the data. Fourth, the analysis continued through an iterative  
10 process of moving back and forth between the separated meaning units and their meaning  
11 structure. A thematic structure was developed, portraying the participants' descriptions as  
12 closely as possible to the native data, yet also revealing meaning beyond those descriptions.  
13 Fifth, themes of meaning were derived, representing the essence of the phenomenon.  
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### 26 27 **Rigor**

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29 Rigor in the analysis was assured through a series of steps inspired by Morse (2015); (1) the  
30 research group developed a common understanding of the research question and relevant  
31 follow-up questions; (2) the interviews were reviewed by all authors to ensure rich data and  
32 to discuss the subsequent interpretations and analysis; (3) the first and second authors  
33 developed a thematic structure; (4) all the researchers discussed and collectively verified that  
34 the analysis was a representation of the interviews; (5) openness was achieved by  
35 documenting the reflexive process in a diary and provided a clear audit trail of all decisions;  
36 and (6) concreteness was demonstrated by describing context and the use of quotes. The  
37 consolidated criteria for reporting qualitative research (COREQ) were used (Tong, Sainsbury,  
38 & Craig, 2007).  
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### 51 **Ethical considerations**

52 The interviewer was aware of the participants' vulnerability related to opening up and sharing  
53 details about such a stressful life event. The interviewer therefore intended to communicate  
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3 empathically, acknowledging the participant's emotions and reactions. The study was  
4 approved by the Regional Committee for Medical Research Ethics (REK – 2015/2311).  
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## 8 9 **Results**

### 10 **Participant characteristics**

11 The present sample consisted of thirteen family members: two men and eleven women. Ages  
12 ranged between 26 and 72 years (median 45). Among these 13 informants, in four cases the  
13 patient passed away during the ICU stay. Table 1 lists the sample characteristics.  
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### 23 **ICU patients' pathways toward survival - essential meaning and themes**

24 The starting point of the long-term ICU patient's pathway toward survival was the beloved  
25 one at a breaking point between life and death. At this stage, intensive care made life still  
26 possible, yet the outcome was uncertain. The participants described how their presence made  
27 a significant contribution to the ICU patient's pathway, from being at a "breaking point"  
28 between life and death, towards "breaking through" back to life. Family members' presence  
29 at the bedside was crucial in communicating love and caring. Moreover, they assisted the  
30 professionals in understanding the patient's unique characteristics and personality, and in  
31 interpreting the patient's attempt to communicate with the professionals. Family members  
32 deliberately used their knowledge about the patient as a unique person to trigger, nurture and  
33 release the patient's inner strength, involving a life force capable of moving the patient from a  
34 "breaking point" towards a "breakthrough" to survival and thus to life. Three main themes  
35 emerged from the data: (1) A body at a breaking point; (2) Family members' presence, and  
36 (3) Breaking through (Table 2).  
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### 56 **A body at a breaking point**

### *Between life and death*

Witnessing the “struggling between life and death” and perceiving the patient's body to be at a breaking point, family members experienced significant uncertainty and stress:

First he got pneumonia, meningitis, and fungal infections. There was no light in the tunnel ... In one and a half weeks he had surgery three times. ... They told me the bacteria had entered his brain and gnawed holes in it (id\_3).

When the patient’s survival was ensured, family concerns were linked to possible loss of functions, personality changes or that the patient was giving up. One of the spouses heard the patient saying:

I can't put up with any more! I just can't, I'm going to die (id\_4).

### *No response - an empty gaze*

Family members considered the period when the patient was sedated and mechanically ventilated to be beneficial for the patient:

Then his body could work to get healthy again instead of spending its energy on breathing (id\_10).

Phases when the patient ‘disappeared’ into himself without giving any response were experienced as some of the worst situations:

When he was lying there, we realized he was seriously ill. But when he woke up and sort of just glanced at you so emptily ... no content in his eyes: "Don't you recognize me, don't you know who I am?" It was tough, because he didn't give any response. ... it was like a stranger lying there (id\_3).

### **Family members' presence**

#### *Sitting by the bed*

Most relatives visited the patient daily, feeling that they were welcome to stay by the patient as much as they wanted. Sitting at the bedside, they observed that the staff talked to the patient explaining what they were doing, even if he was sleeping due to sedation. The staff's

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3 way of responding and treating the patient during times when he was struggling and stressed  
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5 reassured family members that the staff knew what they were doing:  
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8 It was a quiet atmosphere in the room. Dad had a single room, and although there were alarms, the staff was  
9  
10 very quiet. And I think that was good for him of course, and also helped me to relax. I think it was positive for  
11  
12 my Dad that what they did helped *me*. For me, that was interconnected (id\_6).  
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14 Some family members stayed from the morning until night, watching for the patient to wake  
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16 up:  
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19 What if he woke up!? Actually, I knew that he wouldn't, because of those medicines that made him sleep, but I  
20  
21 just felt I had to be there. To see what happened and to look after him (id\_10).  
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24 Many families made shift arrangements, while others organized a closed Facebook group in  
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26 order to inform relatives and friends about the patient's condition.  
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28 The family members held the patient's hand, stroked gently her/his cheek and  
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30 explained what they were doing at home. They told the patient that they loved him and  
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32 encouraged him to fight:  
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35 You can make it! ... We didn't talk much about what had happened really. It wasn't natural. It was here and  
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37 now (id\_11).  
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### 39 *Trying to understand*

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41 In the first phase of ventilator treatment, family members experienced little or no contact.  
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43 Talking to the patient was difficult. However, relatives felt, or thought they felt, that the  
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45 patient gave them a weak touch when holding their hand. When they observed rapid  
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47 breathing and altered facial expressions, some perceived the patient to be stressed. Some  
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49 noticed a specific position in bed that made the patient uncomfortable or recognized an  
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51 increased pulse rate while they talked about things that they knew were of significance to the  
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3 patient. Others wondered whether the higher pulse was a sign that the patient felt the presence  
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5 of family members.

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7 Further, when the patient eventually was able to shake his head and nod, it was  
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9 difficult to interpret whether the patient understood what was said or not. At the same time, it  
10  
11 was hard to get any sense of what the patient was trying to express:  
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14 It's very unnatural to talk to a person who doesn't speak back. ... When she woke up, she began to nod and shake  
15  
16 her head and tried to write a little. I believe it was good that I was there, as no one except me would have  
17  
18 understood her handwriting (id\_7).  
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21 Family members noticed that the experience of not being understood made the patient upset.  
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23 Consequently, family presence was important for deciphering and understanding what the  
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25 patient tried to communicate or wanted help for, such as turning off a radio with music he did  
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27 not want to listen to, or help with anything that was uncomfortable.  
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### 30 31 **Breaking through**

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33 When the sedatives were reduced or discontinued, patients needed varying lengths of time  
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35 before being fully awake. At this point of the pathway, family members described various  
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37 signs of breakthrough:  
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41 One day I was sitting there he seemed better, and then we had eye contact. First, it was wonderful that he saw  
42  
43 me, and seemed happy to see me as well. For me that meant a lot, but he doesn't remember anything of that  
44  
45 moment himself (id\_11).

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47 The first time she opened her eyes was in relation to care ... they had helped her at the bedside ... (id\_1)  
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### 49 *Facilitating hope*

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51 Family members focused on the things that they knew meant a lot to the patient, rather than  
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53 the state of illness. Telling stories about what was going on at home, a football game, cycling,  
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55 etc. seemed vital to motivate the patient's efforts for survival. Using such particular personal  
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3 insights, family members encouraged the patient's spirit, helping her/him to look forward  
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5 towards good life experiences. They reassured the patient that she/he was not alone,  
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7 emphasizing that this was something they would succeed in together:  
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10 It was important to be there, look ahead, and reassure: "We're going to solve this together". We tried to mobilize  
11 his resources: "You sure love exercise ... and you'll be okay". I tried not to be too concerned when I was there.  
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13 Tried not to talk about just what was wrong, but rather look ahead (id\_11).  
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16 Physical activity with guidance and development of short-term goals helped the patient  
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18 ahead, and promoted a sense of hope. During the recovery phase, it was crucial to include the  
19  
20 patient in decisions as well as performing different tasks and actions based on respect and  
21  
22 collaboration. If the patient was asked, he could figure out how to arrange a planned activity,  
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24 and be able to take more responsibility for his progress:  
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28 He was determined to exercise. His body looked as if he was 80-90 years old, the muscles were gone, only skin  
29  
30 and bones were left. It was just terrifying the first time they took him out of bed and we got to see what he  
31  
32 looked like! But eventually he borrowed mother's weights. I don't know how many 100 grams they were, but he  
33  
34 was exercising - he was determined to get up on his feet again! (id\_10).  
35

36 Hope was an essential part of getting through the ICU stay. Hope was linked to trust and  
37  
38 confidence in the idea of "I will get well, I will recover", and was conveyed by both health  
39  
40 professionals and relatives. Some patients became tired during visits by children or friends.  
41  
42 For others, visits by young children seemed to be a bright spot and motivating factor:  
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45 He wanted to give up, but the day he woke up, he was told that he'd become a grandfather. The next day he saw  
46  
47 the baby. I believe that moment perhaps helped him to grasp the future (id\_4).  
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### 50 *Knowing the patient*

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52 A kind of breakthrough was also related to the staff actively making efforts to get to know  
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54 and acknowledge the patient as a unique person:  
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3 When they got to know him, I realized that they did what they could to bring out a smile in him. ... The person  
4 who was there (the nurse) was really interested in getting to know the individual lying there (id\_6).  
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7 Furthermore, having family members who cooperated with staff in order to motivate, support  
8 and push during physical therapy was beneficial:  
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12 When we were going to leave, the physical therapist said: "you should be here". I saw that my Dad looked at me  
13 and I said to him: "Now you have to continue". He rolled his eyes and I replied: "If you're going to get out of  
14 here, you have to get through this work, even if it is tough". I think my presence was positive. Not only what the  
15 physical therapist did, but the combination of the professional contribution and family presence was helpful  
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19 (id\_6).  
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### 22 *The patient's inner strength*

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24 Family members described the patient in terms of positive characteristics, such as mental and  
25 physical strength, and the will to exercise and never give up:  
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29 He has a strong will. When he's sick and needs help, he never surrenders. He has tremendous patience (id\_10).  
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32 A sense of humor and being curious by nature were highlighted as representing a kind of  
33 inherent power:  
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37 He's a fighter. He's so kind, he has a sense of humor and everyone thinks it's fun being with him (id\_4).  
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40 Some family members underlined the patient's will to survive and eagerness to exercise,  
41 whilst others emphasized the patient's ability to deliberately block negative thoughts.  
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### 44 *Facilitating well-being*

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46 The little extra, some sort of tailored care, was considered important. Nurses helped patients  
47 to experience well-being by means of e.g. a bed-bath, massage and shampooing:  
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52 At times he could be stressed ..., but they cared for him so well ... he calmed down (id\_13).  
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3 Individualized care, including facilitating well-being, helped to increase families' trust and  
4 confidence in the nursing care. Resulting from this trust and confidence, family members  
5 were able to entrust the patient to the nurses and thus take care of themselves by resting,  
6 going for a walk, etc.  
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## 11 12 13 **Discussion**

14 The aim of this study was to explore family members' experiences of long-term ICU patients'  
15 pathway towards survival during the ICU stay. Research on ICU family members has  
16 primarily focused on family needs, and less on family members' contribution to care  
17 (McAdam et al., 2008; Olding et al., 2016). The present study adds to the latter, revealing  
18 three main findings: First, the ICU patient was at a breaking point and family members'  
19 presence was important to acknowledge the patient's "self". Second, family members'  
20 presence and actions demonstrated health promotion care based on their knowledge of  
21 patients' unique characteristics, such as their personality, interests and values. Third, this  
22 knowledge seemed to be applied deliberately in order to trigger and release the patient's inner  
23 strength. Family presence based on their exclusive understanding of the patient as a unique  
24 person was revealed as a health promoting influence that pulled the patient towards the  
25 turning point of breaking through to life.  
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41 Our findings concur with a recent meta-synthesis of Nordic studies (Egerod et al.,  
42 2015), which demonstrated that patients with life-threatening illness descend into a liminal  
43 state, where they face the choice of life or death. However, in contrast to previous research  
44 (Egerod et al., 2015; Haugdahl et al., 2017), the ICU patients in our study who were at  
45 breaking point could not always be regarded as actively capable of "choosing" to consciously  
46 use their inner resources. The present study supports the idea that, in the notion of an ICU  
47 patient's *breakthrough* to life, two energies predominate: a force that pulls, and another that  
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3 pushes. First, the family members' presence has the potential to pull the patient to an  
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5 existential "here", in the direction of a breakthrough. Second, there is an inherent directional  
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7 vital force in life itself, pushing forward the breakthrough process (Rogers, 1995) (Figure 1).  
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10 FIGURE 1 ABOUT HERE  
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### 12 **Acknowledging the patient's self**

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15 When the patient is "at breaking point" between life and death, the relationship between  
16  
17 family members and patient helps to pull the patient towards the existential moment of "here  
18  
19 and now". This study shows that interaction based in attunement and sensing can help to  
20  
21 understand the patient's situation, by recognizing the patient through eye contact, gentle  
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23 touching and telling news from home. Knowing the patient was important to understand what  
24  
25 she/he was trying to express.  
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29 A key concept in phenomenology refers to the relationship between consciousness  
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31 and the world; intentionality implies that consciousness is always directed toward *something*  
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33 (Merleau-Ponty, 1994). What appears as something (e.g. family members' voices and touch)  
34  
35 appears to someone (a bodily subject), and it appears as part of a context. Therefore, the ICU  
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37 patient's bodily experiences involve a dimension of meaning that involves the person's life  
38  
39 story and past memories. This means that the body, including the body at a breaking point, no  
40  
41 longer can be understood as a passive object of consciousness, but is itself interpretive and  
42  
43 meaningful. Hence, nurse-patient or family-patient interaction acknowledging the patient's  
44  
45 experiences, supporting a sense of comprehensibility, manageability and meaning (SOC)  
46  
47 seems relevant even if the ICU patient is cognitively unconscious.  
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51 Delusional memories or chaotic experiences of being somewhere else are common  
52  
53 among ICU patients (Storli, Lindseth, & Asplund, 2007), including experiences of a floating  
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55 bodily existence (Haugdahl et al., 2017). The "salutogenic key" to this state is to find ways of  
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3 preserving the “self”. Family members were attentive to bodily expressions and sought for  
4 signs of whether the patient could sense their presence. Even if a patient is not fully awake,  
5 she/he has the ability to hear and sense, as often interpreted by family members as a weak  
6 confirmatory touch when holding their hand. A study exploring exposure to threats and the  
7 effect of handholding (measured by neural responses by brain imaging), demonstrated that  
8 spousal handholding had a powerful and specific effect that distinguished it from stranger  
9 handholding (Charuvastra & Cloitre, 2008). One possible explanation for this difference  
10 might be found in the phenomenological perspective; here, memories of bodily sensations  
11 might be invoked and recognized beyond control of the mind (Maurice Merleau-Ponty,  
12 1964).

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Family members’ presence and actions (as a pulling force) seem to support the  
“indwelling directional vital force” (as a pushing force). Viewed from the perspective of the  
body as interpretive and meaningful in itself, also at the breaking point between life and  
death, the ICU patient might sense the situation to be more comprehensible, manageable and  
meaningful (SOC) due to the family presence. In this way, family presence seems to make  
the patient’s critical situation bearable and thus have significance for preserving the self and  
supporting the inner strength, both of which are seen to be health promoting.

### **Triggering, arousing and releasing the patient's inner strength**

The present study illuminates how family members are a key to the patient’s breakthrough  
because their actions are tailored to the patient’s specific personality as well as the patient’s  
life world. Patients’ breakthroughs become visible in different and individual ways; some  
appeared suddenly in relation to caring procedures such as bed bathing or placing in an  
upright position, while others emerged gradually. Patient eye contact and the first smile of  
recognition were found to be important confirmations of the patient’s awakening and a sign

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3 of progress. Conversely, a gradual loss of eye contact where the patient was perceived to be  
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5 in a state of existential withdrawal was an extremely tough experience for family members.  
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7         Meaning represents a fundamental aspect of SOC (Antonovsky, 1996), and is seen to  
8  
9 provide a framework for coping with illness, losses, loneliness, perceived burdens, despair  
10  
11 and anxiety about death (Dwyer, Nordenfelt, & Ternstedt, 2008; Knestruck & Lohri-Posey,  
12  
13 2005; Thomas, Burton, Griffin, & Fitzpatrick, 2010). But how can we understand the concept  
14  
15 of “meaning” in a context of critical illness, characterized by extreme bodily and mental  
16  
17 stress? The nursing theorist Janice Morse (Morse, 1997) defined comfort as a state of well-  
18  
19 being that eases, relieves, and assists the patient to endure. Morse argued that facilitation of  
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21 comforting (well-being and relief) is an important factor in the disease course (Morse, 1997).  
22  
23 In light of the salutogenic perspective of health (Antonovsky, 1996), comfort can be  
24  
25 understood to be a health promoting asset. Consequently, since family presence appeared to  
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27 be comforting, this presence acted as a health promoting resource during the ICU stay.  
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31         Evidence on the impact of tactile touch given to ICU patients is scarce. However, one  
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33 intervention study from 2008 demonstrated that ICU patients enjoyed tactile touch and  
34  
35 experienced comfort from this (Henricson, Ersson, Maatta, Segesten, & Berglund, 2008).  
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37 Although the impact on stress parameters was limited, except for the level of anxiety which  
38  
39 declined significantly (Henricson et al., 2008), a comforting presence might help the patient  
40  
41 to gradual realization and discovery of meaning in life and be considered as a health  
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43 promoting asset (Yang, 2016). Furthermore, a qualitative study demonstrated that caring  
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45 touch made patients feel present and anchored and seemed to create a caring space where the  
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47 patients became receptive to care (Ozolins, Horberg, & Dahlberg, 2015). Moreover, touch is  
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49 not only a physical quality; people do also touch each other emotionally and spiritually, by  
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51 their presence along with a sense of human contact. Health promoting influences of nurse-  
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53 patient interaction among nursing home patients have been demonstrated, revealing a  
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3 significant effect of such interaction on patients' perceived meaning, hope and self-  
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5 transcendence (Haugan, 2014a). This idea can probably be transferred to the ICU context.  
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7 Comforting interaction, whether between nurse and patient or family and patient, is stress  
8  
9 reducing and health promoting, supporting patients' perceived meaning (Haugan, 2014b).  
10  
11 Hence, the concept of "meaning" in a context of critical illness might be related to moments  
12  
13 of comfort, well-being and hope, all of which were supported by family connectedness and  
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15 presence in the present study.  
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18         Comforting also includes challenging the patient; however, empirical research on this  
19  
20 issue is limited (Morse, 1997). The present results respond to the idea of Morse that family  
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22 members' exclusive understanding of the patient as a unique person benefited the  
23  
24 physiotherapy. They knew exactly how they could best challenge the patient and thus how to  
25  
26 helpfully push him forward, in the right direction. The pushing and encouraging of the ICU  
27  
28 patient was based on triggering the patient's "inner strength", which is a central salutogenic  
29  
30 term and phenomenon (Antonovsky, 1996), as well as a salutogenic resource.  
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33         Recent ICU research also indicates the importance of support from family members  
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35 (Agard, Egerod, Tonnesen, & Lomborg, 2015; Egerod et al., 2015; Storli et al., 2007;  
36  
37 Wassenaar et al., 2014). However, in order to understand the complex person-environment  
38  
39 interactions that underscore resilient adaptation to stress, there is a great need for more  
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41 knowledge (Bowes & Jaffee, 2013). The recently established cross-disciplinary field of  
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43 psycho-neuro-endocrino-immunology can provide further insight, suggesting that variability  
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45 in response to stressful exposures is an interplay between genetic, biological processes and  
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47 environmental factors (Bowes & Jaffee, 2013; Feder, Nestler, & Charney, 2009). Evidence  
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49 shows that close relationships have an impact on health through inflammatory responses  
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51 (Kiecolt-Glaser, Gouin, & Hantsoo, 2010), and people with stronger social relationships have  
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3 a 50% greater likelihood of survival than those with weaker social relationships (Holt-  
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5 Lunstad, Smith, & Layton, 2010).

6  
7 Considering the positive impact of close relationships on health (Holt-Lunstad et al.,  
8  
9 2010; Kiecolt-Glaser et al., 2010), the present study demonstrates that family members'  
10  
11 presence acts as a health promoting resource, supporting the medical treatment and ICU  
12  
13 nursing in enhancing the healing processes towards survival and recovery. These insights into  
14  
15 the unique and vital influence of family participation in the ICU are important for clinical  
16  
17 ICU practice and point to the responsibility of the health care team to provide support for  
18  
19 families of critically ill patients. The present study expands on previous research (Linnarsson,  
20  
21 Bubini, & Perseus, 2010; Davidson et al., 2017), adding valuable insights of family  
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23 members' experiences of what is of significance during the patient's pathway to breakthrough  
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25 in the ICU, informing further development of ICU clinical guidelines.  
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### 29 30 **Strengths and limitations**

31 Although considerable research has been devoted to ICU patients (Parker et al., 2015), less  
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33 attention has been paid to health promoting factors that facilitate patients' health and survival  
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35 during an ICU stay (Eriksson & Lindstrom, 2006). Insight into the phenomenon of family  
36  
37 members' experiences of long-term ICU patients' pathways to survival represents a crucial  
38  
39 contribution to the body of knowledge on vital aspects of ICU nursing. It would seem  
40  
41 imperative to find beneficial ways of including and supporting family members in ICU care.  
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45 There are potential limitations to this qualitative study. First, the study participants  
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47 were recruited from one hospital. However, some of the ICU patients were transferred to the  
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49 ICU at their local hospital for further treatment after being stabilized. This means that the  
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51 participants may have experiences from different ICUs, including university and local  
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53 hospitals. Second, the study participants were family members of patients who had been  
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55 intubated and spent seven days or more in the ICU. Other ICU patients who are less critically  
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3 ill, without intubation and with shorter stays, were excluded. Consequently, findings cannot  
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5 be transferred to the general population of ICU patients' families. Third, the high staffing  
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7 ratio (1:1), compared to other non-Scandinavian countries (Egerod, Albarran, Ring, &  
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9 Blackwood, 2013), coupled with liberal visiting policies, may not reflect family members'  
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11 experiences during the ICU stay in other countries (Liu, Read, Scruth, & Cheng, 2013;  
12  
13 McAdam & Puntillo, 2013). Nevertheless, staying close to a family member who is critically  
14  
15 ill is a basic human trait. Fourth, the length of time between the ICU visits and the interview  
16  
17 varied, and a long interval may have affected the memories of the ICU experiences.  
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19 However, the narratives were rich and detailed, and seemed to be independent of the interval  
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21 since the ICU stay, possibly because such existential experiences are bodily grounded and  
22  
23 can therefore be aroused and narrated despite a long time span (Storli et al., 2008).

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26 Fifth, the researchers interviewing the present informants were ICU nurses and  
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28 university teachers in nursing, representing a pre-understanding based in the perspective of  
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30 professional health care, which in many ways differs from family members' life world.  
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32 Hence, the professional ICU nursing perspective along with a scientific viewpoint might have  
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34 influenced the interview dialogue in a certain direction and therefore the content of the  
35  
36 empirical data. Nevertheless, the informants honestly and with great willingness shared their  
37  
38 experiences. In fact, they stated that speaking with professionals about these experiences was  
39  
40 health promoting, indicating that they were able to share what was important to them.  
41  
42 Researchers' pre-understanding has a significant role in the interpretation of qualitative data.  
43  
44 The theoretical perspective of this study comprised the salutogenic health theory  
45  
46 (Antonovsky, 1996) and the phenomenology of the body (Mearleau-Ponty, 1994),  
47  
48 representing new ideas brought into the ICU field. This is a strength. However, these  
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50 perspectives might not fully enlighten the present empirical data. Using other theories might  
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52 well have brought other dimensions of the present data into light.  
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## Conclusions and relevance to clinical practice

Understanding family members' experiences of long-term ICU patients' pathways towards survival in the ICU is important for fully understanding the complexity of intensive nursing care. The family members in this study provided detail and context in this respect. By using a health promotion perspective and concepts from phenomenology of the body, the study highlights the body as interpretive and meaningful, also at the breaking point between life and death. Family presence helped to trigger, arouse and release patients' inner strength, which was an important factor to promote patients' health and survival during the ICU stay.

### Relevance to clinical practice

Clinical ICU nurses may have a *feeling* of the importance of including family members in patient care. However, it is difficult to ascertain the significance of this feeling. By using the hermeneutic phenomenological approach, this study provides new knowledge of family members' experiences of significant factors that promote long-term ICU patients' pathways towards survival in the ICU. Furthermore, this study involves the recently established cross-disciplinary field of psycho-neuro-endocrine-immunology (Bowes & Jaffee, 2013; Feder, Nestler, & Charney, 2009) adding new insight to ICU research and care. We suggest that future research may benefit from a more comprehensive approach (phenomenology and natural science), which may enhance understanding of human health processes elucidated by connections between lived experiences and biological processes in ICU patients' pathways towards survival.

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

- Family support has been found to be important to ICU patients' healing process.

However, details of the specific contributions of family members are insufficiently described in international guidelines.

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- This study provides new insight into how family members' presence acts as a health promoting resource, helping to trigger, arouse and release the patient's inner strength, representing crucial vitality for the movement towards a turning point and breakthrough to life.
  - The exploration of health promoting factors based on family members' experiences can guide health professionals in improving ICU care by including additional health promoting resources in ICU long-term care.
  - Insights into the unique and vital influence of family participation and presence highlight the responsibility of the ICU team to provide support for families.



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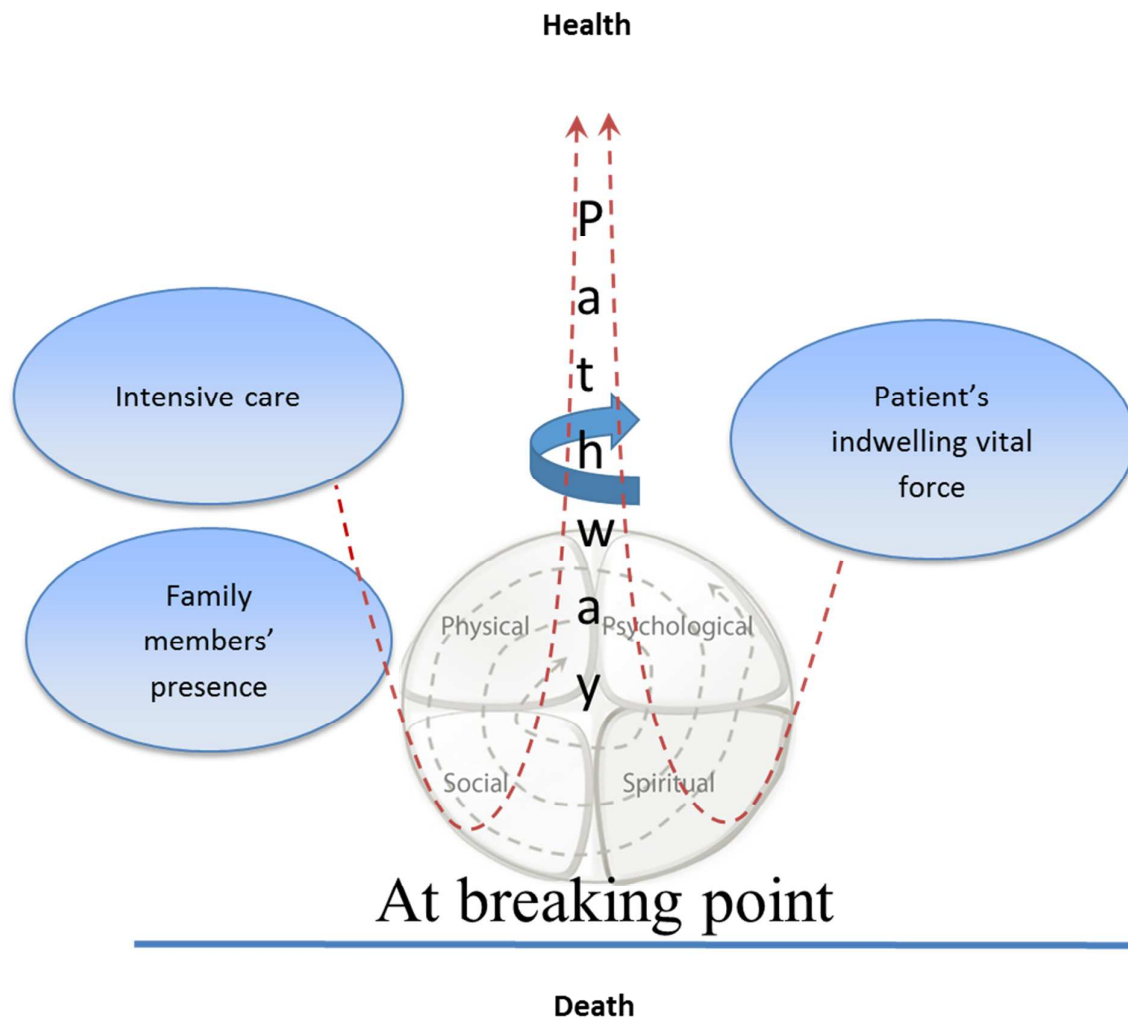
**Table 1** Demographics of family members and patients

<b>Id</b>	<b>FM</b>	<b>Gender FM</b>	<b>Daily visit</b>	<b>LOS ICU</b>	<b>Patient diagnose</b>	<b>Death at ICU</b>
1	Son	M	Yes	7	Respiratory	Yes
2	Spouse	F	Yes	9	Sepsis	No
3	Spouse	F	Yes	8	Infection	No
4	Spouse	F	Yes	12	Infection	No
5	Spouse	F	Yes	47	Renal	Yes
6	Daughter	F	Almost	39	Gastro	Yes
7	Son	M	Yes	11	Hearth	No
8	Daughter	F	Yes	12	CNS	No
9	Spouse	F	Yes	12	Trauma	No
10	Spouse	F	Yes	9	Gastro	No
11	Sister	F	Almost	12	Trauma	No
12	Daughter	F	Yes	10	Circulatory	No
13	Spouse	F	Yes	11	Respiratory	Yes

*FM* family member, *LOS* length of stay, *ICU* intensive care unit

**Table 2** Family members' experiences of long-term ICU patient's survival

<b>Themes</b>	<b>Subthemes</b>
<b>A body at a breaking point</b>	Between life and death No responding-an empty gaze
<b>Family members' presence</b>	Sitting by the bed Trying to understand
<b>Breaking through</b>	Facilitating hope Knowing the patient The patient's inner strength Facilitating well being



36  
37 **Figure 1** The long-term intensive care patient's pathway to survival.

38 The patient survival at breaking point is dependent on intensive care as well as an indwelling vital force. Family  
39 members' presence has the potential to support the patient on her/his pathway towards a turning point breaking  
40 through to life.

41 *Intensive care:* including medical treatment and nursing care

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