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TREATED IN AN INTENSIVE CARE UNIT; HOW PATIENTS AND THEIR FAMILIES EXPERIENCE AND MANAGE THEIR SITUATION

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Treated in an intensive care unit – how patients and their families experience and manage their situation

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By

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To all patients and family members, thank you for your trust and for sharing your experiences so open-mindedly and powerfully!
God, grant me the serenity
To accept the things I cannot change,
The courage to change the things I can,
and
The wisdom to know the difference.

(Reinhold Niebuhr, 1951)
Background: An intensive care unit (ICU) is a high technological ward with specialist educated physicians, nurses, assistant nurses, and physiotherapists, treating patients in a life-threatening condition. It is common for patients to be treated with mechanical ventilation, pain relief and sedatives, which, together with the severity of illness, make them unable to communicate. Thus, they are totally dependent on the environment and the actions of those in the unit. During the treatment, patients can suffer from different mental and physical complications related to their illness and treatment. Hence, this means a traumatic experience for the patient and his or her family, with a lot of stress, anxiety, fear, worry and uncertainty. Survival and homecoming entail new challenges. A significant proportion of patients and their families suffer from the long-term impact on their mental and/or physical health, which reduces their well-being. Often, patients experience strange and scary memories or nightmares from the intensive care unit, called delusional memories, which can remain even after homecoming.

Method: This thesis includes four scientific studies that describe the patients’ health, explains their experiences as well as how patients and family members manage this process, from the time the patient becomes critically ill until recovery/everyday life at home. The four studies comprise one study with statistical calculation of patients’ experienced health and how it affects their life. The other three studies are based on interviews and observations.

Findings: Intensive care patients estimate their health as being worse than the general population one year after critical illness. During their stay in the ICU, patients could experience delusional memories with unpleasant content, often related to death, which could have a lasting impact on them long after the ICU care. But it seems for the patients that experiences of critical illness and intensive care had a greater influence in their lives. For patients and even for the family members, critical illness, and treatment in the ICU is an emotionally stressful experience with long-lasting impact on their well-being. Patients and their family members manage the process from when the patient becomes critically ill until everyday life home in different ways. However, the overall aim was to regain control of their life, which could be a lengthy and strenuous process. Processing and adapting to sometimes new prerequisites can be facilitated by seeking and obtaining support from other individuals; being able to make decisions; acting on issues related to oneself; finding explanations for the illness, events, and experiences; and by maintaining hope. Trust in other individuals is a property which promote the processing and humour and dispel thoughts through activities increases well-being. Those strategies help to leave the traumatic experiences and its consequences behind, not to forget but to relate to prerequisites in life. Processing takes time; however, for some, it becomes overwhelming.
ABSTRACT

Background: Critical illness and treatment in an intensive care unit (ICU) is a traumatic event for patients and their families, which involves stress, anxiety, fear, worry and uncertainty. Survival and homecoming entail new challenges, and a significant proportion of patients and their families suffer from the long-term impact on their mental and/or physical health, termed post intensive care syndrome (PICS). In addition, patients can suffer from delusional memories, which are associated with discomfort and fear.

Overall aim: The overall aim of the current thesis was to explore experiences and patterns of behaviours in critically ill patients and their family members, addressing the period from when the patient becomes critically ill until recovery/ everyday life at home.

Methods: Four studies resulted in four papers. Data collection was performed with both quantitative and qualitative methods at five different ICUs in Sweden, consisting of university hospital, county hospital and district hospital. Study I was a prospective cohort study which aimed to describe and analyse factors associated with a health-related quality (HRQoL) of life 3, 6 and 12 months after discharge from a general surgical ICU. Included were 276 (62%) patients treated ≥ 96 hours in the ICU. For data collection, we used the Short Form Health Survey (SF-36). To analyse changes over time, a linear mixed model was used. To compare the results from the 12-months, with a gender and age matched reference of a Swedish population, a Wilcoxon Signed Rank Test was used. Furthermore, a linear regression analysis was performed to explore the impact of the background variables on HRQoL. In Study II, we used a classic grounded theory methodology to explore the main concerns of patients cared for in an ICU. Data were collected at three different general ICUs in Sweden. Thirteen interviews initiated, with one open-ended question and seven observations of other patients in the ICU were performed and analysed. The aim of Study III was to explore delusional memories, and how they were managed by COVID-19 patients treated in an ICU. Data were collected at one medical intensive care unit in Sweden, through sixteen interviews, with three open-ended questions and one additional question on how the patient experienced being treated by health care professionals wearing protective equipment. The analysis was performed with thematic analysis. In Study IV, we used classic grounded theory methodology to explore the main concerns of family members of critically ill patients cared for in an ICU, from when the patient became critically ill until everyday life at home. Data were collected from three different general ICUs in Sweden. Fourteen interviews initiated with one open-ended question, and observations of eight other participants during the patient's ICU stay were analysed.

Findings: Patients’ HRQoL improves over time but is still affected one year after the ICU care. During their stay in the ICU, patients could experience delusional memories with unpleasant content often related to death, which could have a long-lasting impact even after discharge from the ICU. However, the experiences of critical illness and intensive care had a greater influence in patients’ lives. For patients and even for the family members, critical illness and treatment in the ICU is an extremely emotional and stressful experience, with
long-lasting impact on well-being and sense of losing control. Patients and their family members have different strategies to deal with critical illness, treatment in ICU, and complications of critical illness to regain control. Regaining control can be facilitated by patterns of behaviours to achieve social support, maintain autonomy, find explanations, and maintain hope, which can be promoted by having trust in other individuals. Strategies such as humour and activities can help to dispel thoughts and increase well-being. Strategies used in a constructive way could facilitate ability to leaving behind, not to forget but to relate to prerequisites in life. However, processing takes time; moreover, for some, it becomes overwhelming.

**Conclusion:** Intensive care patients and their families can find themselves in a vulnerable state. Their experiences and strategies used to manage the process from critical illness until recovery/everyday life at home vary, but it is a traumatic experience for everyone involved. This highlights the need for a more holistic thinking during care and follow-up, which involves the whole family, and everyone’s needs.
SAMMANFATTNING (SUMMARY IN SWEDISH)


Övergripande syfte: Det övergripande syftet med denna avhandling var att undersöka upplevelser och beteende mönster hos svår kritiskt sjuka patienter och deras familjemedlemmar, från det att patienten insjuknar i svår kritisk sjukdom till återhämtningen/vardagslivet hemma.


Resultat: Patienternas HRQoL förbättras över tid men är fortfarande påverkad ett år efter IVA-vård. Under vårdtiden på IVA kan de uppleva overkliga minnen som oftast har ett obehagligt innehåll relaterat till döden. Dessa minnen kan påverka dem även efter utskrivningen från IVA. Trots obehaget från overkliga minnen påverkar upplevelsen av svår kritisk sjukdom och IVA-vård patienten i större utsträckning. För patienterna och deras familjemedlemmar är svår kritisk sjukdom och vård på IVA en extremt stressfylld emotionell
upplevelse som påverkar deras välbefinnande och känsla av kontroll. Processandet för att återfå kontroll underlättas av strategier för att få social support, upprätthålla autonomi, hitta förklaringar och att upprätthålla hopp. Dessa beteenden främjas av förtroende för andra individer. Strategier såsom humor och egna aktiviteter kan skingra tankarna vilket ökar välbefinnandet. Om strategierna används konstruktivt underlättar de förmågan att lämna händelsen bakom sig. Inte att glömma men att förhålla sig till de förutsättningar man har i livet. Denna process tar tid och för vissa blir det överväldigande.

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<tr>
<td>ICU</td>
<td>Intensive care unit</td>
</tr>
<tr>
<td>IVA</td>
<td>Intensivvårdsavdelning</td>
</tr>
<tr>
<td>CGT</td>
<td>Classic Grounded theory</td>
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<tr>
<td>GT</td>
<td>Grounded theory</td>
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<tr>
<td>HRQoL</td>
<td>Health-related quality of life</td>
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<tr>
<td>SF-36</td>
<td>36-Item Short Form Health Survey</td>
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<td>PF</td>
<td>Physical functioning Physical</td>
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<td>RP</td>
<td>Role Functioning</td>
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<td>BP</td>
<td>Bodily pain</td>
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<td>GH</td>
<td>General Health</td>
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<td>VT</td>
<td>Vitality</td>
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<td>SF</td>
<td>Social Functioning</td>
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<td>RE</td>
<td>Emotional Role Functioning</td>
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<td>MH</td>
<td>Mental Health</td>
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<td>ICU-AW</td>
<td>ICU-acquired weakness</td>
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<td>PTSD</td>
<td>Post-traumatic stress disorder</td>
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<tr>
<td>LoS</td>
<td>Length of stay</td>
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<tr>
<td>APACHE II</td>
<td>Acute Physiology And Chronic Health Evaluation II</td>
</tr>
<tr>
<td>PICS</td>
<td>Post intensive care syndrome</td>
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<tr>
<td>PICS-F</td>
<td>Post intensive care syndrome – Family</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
<tr>
<td>ARDS</td>
<td>Acute Respiratory Distress Syndrome</td>
</tr>
<tr>
<td>COVID-19</td>
<td>Coronavirus disease 2019</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence Interval</td>
</tr>
<tr>
<td>SIR</td>
<td>Svenskt Intensivvårdsregister</td>
</tr>
<tr>
<td>ABCDE-bundle</td>
<td>Evidence based tool for: Awakening and breathing coordination exercises, controlling daily sedation, and removing mechanical ventilation, the choice of analgesics and sedatives, the monitoring and control of delirium, and mobilisation and early exercise</td>
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1 INTRODUCTION

My first experience of intensive care was in 1997, when my father was cared for in an intensive care unit. Some years later, I started my education to become an intensive care nurse. Hence, the care and the environment became familiar to me, but I still remember the feelings of fear and unreality from my first visit in one extremely scary environment. Intensive care is much more than advanced treatment, care and patient’s survival. It is also about consolation and mental and physical support. Moreover, ICU treatment raises questions relating to complicated ethical issues such as: ‘Is what we do, right?’ ‘Is our treatment meaningful?’ ‘Could we have done more?’ or ‘What prerequisites does the patient have to a life worth living?’ We take care of and treat the patient, but the whole family is included in our care.

Since long ago, I became interested in the human response to stressful experiences and stress management. Gradually, this interest formed the basis of the content in this thesis. At that time (2013), consequences of critical illness and intensive care were well explored in research. However, there was a lack of knowledge on how patients and their families manage their situation from critical illness until everyday life at home. I decided to explore this process from the patients’ and their family members’ perspective.

I had the opportunity to interview patients and family members in their everyday life after intensive care. During the interviews, patients and family members were very open-minded and told me in detail about how they managed the process from when the patient became critically ill until recovery and everyday life at home.

Critical illness and intensive care could never be free from discomfort for patients or their family members; it is a traumatic and strenuous life event for those involved. Therefore, my wish is that this thesis could contribute to ideas for interventions that improve their outcome.
2 LITERATURE REVIEW

2.1 INTENSIVE CARE

Intensive care means advanced diagnostics and treatment in a highly technological environment with especially trained physicians, nurses, and assistant nurses. The patient treated in the intensive care unit (ICU) is often in a life-threatening condition and needs continuous monitoring, advanced medical treatment, and technical equipment such as mechanical ventilation, renal replacement therapy and invasive monitoring.

2.1.1 Intensive care in Sweden

The first intensive care unit in Sweden started in 1952 at the Borås Hospital (1). Today, there are 84 intensive care units in Sweden, corresponding to 526 beds. Most of them are general ICUs (treating both medical-, surgical-, gynaecological-, orthopaedical- patients and sometimes, even children), but there are also intensive care units with specialist areas such as thorax, neurosurgical, burns, children, medical and extra corporeal membrane oxygenating (ECMO). During 2020, 35,624 patients were treated in ICUs in Sweden, out of which 62.2% were men (mean age 58.3 years) and 37.8% were women (mean age 55.6 years). The mortality rate at 30-days was 16.7% (2).

2.2 IMPACT ON PATIENTS TREATED IN THE ICU

The complexity of critical illness and ICU care cannot be underestimated. Patients in the ICU could suffer from complications related to severity of illness and ICU care, such as ICU delirium, delusional memories, ICU acquired weakness, pain, and sleep-disturbances.

2.2.1 Concepts of health and well-being

Health and well-being are common concepts used in this thesis. Definition of health is ‘A state of complete physical, mental and social well-being, not merely the absence of disease or infirmity’ (3). Well-being is a multidimension concept and could be defined as an individual’s mental, physical, social and environmental status, interaction between the aspects and in which each aspect has a different meaning and impact for each individual (4).

2.2.2 ICU delirium/hallucination

ICU delirium is defined as an acute mental disorder with disturbances of the central nervous system function, usually reversible (5, 6). This state can fluctuate, where the patient can be either hyperactive, hypoactive, or both. Symptoms of hyperactive delirium are aggression, hallucinations, agitation and restlessness. In contrast, hypoactive symptoms present as motor slowness, lethargy and inattentiveness and, therefore, are more difficult to detect (7-9).
Previous research found ICU delirium to be associated with prolonged hospitalisation period, long-term cognitive impairment, increased mortality (6, 8, 10) and depression (11). Further, risk factors associated with delirium include higher age, prolonged mechanical ventilation, severe systemic disease, drugs (benzodiazepines, opioids and steroids and anticholinergic agents) and complicated surgery (5). ICU delirium is declared as a major problem, affecting about 80% of ICU treated patients (8). In contrast, Svenningsen et al and Wolters et al claim that patients with ICU delirium did not have worse health-related quality of life than other ICU patients afterwards (12, 13).

2.2.3 ICU acquired weakness

ICU acquired weakness (ICU-AW) can affect patients during their ICU stay (14-16). Different pathologies cause ICU-AW such as polyneuropathy, myopathy or a combination thereof (15). Symptoms manifest as weakness in limbs and respiratory muscles, often more proximal than distal, whereas facial and ocular muscles are not involved (17). Whereas sepsis, severity of illness and immobility are reported risk factors for ICU-AW (16, 18) there is still uncertainty as to its cause (19). It has been reported that ICU-AW has a prevalence of 40% in ICU patients (20).

2.2.4 Pain and sleep disturbances

Due to the nature of critical illness, treatment and bed-side care in the ICU experiences of pain and discomfort are common for the patient (21, 22). This, together with barriers for communication because of unconsciousness, sedation and mechanical ventilation, makes the patient vulnerable in this state (23, 24). Despite development in understanding and management of pain relief, there are still gaps in given treatment (25). Afterwards, ICU patients could still remember discomfort and pain (26, 27).

Since the environment in the ICU can be noisy with ongoing treatment and care around the clock, it could affect the quantity and quality of patients’ sleep (28, 29). Factors associated with sleep disturbance are disease related, or related to stress, pain and/or anxiety (29). In addition, poor sleep has been reported as a cause of ICU delirium (30, 31).

2.3 IMPACT ON THE PATIENT AFTER DISCHARGE FROM THE ICU

The presence of complications after the ICU care is common. The patient may have long-term impairments in cognitive, physical and social functions, which affect their health-related quality of life and well-being. This state of complications is referred to as post intensive care syndrome (PICS). Moreover, the patient may suffer from delusional memories.
2.3.1 Health-related quality of life

After discharge from ICU, impaired mental, physical and social functions could influence the patient’s health-related quality of life (HRQoL) (32, 33). HRQoL is a subjective concept, which relates to how health status affects the daily life and life satisfaction in physical, mental and social domains of life (34). Previous research on long-term outcomes in ICU patients’ HRQoL found improvement over time, but HRQoL was still affected long after the ICU discharge (35-37). A recent systematic review finds that improvement of HRQoL occurs during the first year after hospital discharge, with less improvement thereafter (33). Factors that affect HRQoL negatively are pre-existing disease (35, 38, 39) and severity of illness (36). Moreover, previous studies found contradictory evidence on having memories from the ICU, where they can have both a positive (40) or negative (41-43) impact on HRQoL.

2.3.2 Post intensive care syndrome

In a stakeholder conference in 2012, long-term consequences of intensive care were termed post intensive care syndrome (PICS) (44). PICS is a multidimensional concept, which comprises long-term impact on physical, mental and cognitive functions (44-48). Impairments related to PICS are physical: decreased activity, pulmonary deterioration and muscle weakness (49); mental: post-traumatic stress disorder (50); and cognitive: concentration and memory disturbances (48). A recent concept analysis adds impaired social reconstruction to PICS (51). Besides the impact on health status, PICS affects personal and socio-economic factors (52) and quality of life (48), in patients and their families (52). Symptoms of PICS could be deterioration of previous conditions or new impairments related to critical illness and treatment (48). It has been reported that PICS affects 25–80% of the patients, depending on variation of symptoms, and could last for more than five years (49). In addition, risk factors for suffering from PICS could be divided into personal factors such as previous health, personality or social-demographics, or ICU-related factors such as patient experience, treatment and severity of illness (49, 50).

2.3.2.1 Mental impairments

Anxiety and depressive symptoms occur in 25–46% of the patients (53). Symptoms may decline over time, but prolonged symptoms may be persistent (54). In addition, posttraumatic stress disorder (PTSD) can affect patients following ICU discharge (55). PTSD is defined as a serious psychiatric disorder which could occur after an experienced or witnessed traumatic event. A long-time after the event, the person could still experience flashbacks and/or disturbing memories from the traumatic event, which could have an impact on cognitive functions and cause mental problems (56). It has been reported that benzodiazepines, sedation, stressful experiences and ICU delirium during ICU stay (55) as well as delusional memories without factual memories afterwards increase the risk of PTSD (57-60). A recent review by Righy et al. summarises the prevalence of PTSD in 20% of the patients, first year after hospital discharge (61).
2.3.2.2 Physical impairments

Impairment in physical functions related to PICS includes muscle weakness, pulmonary deterioration and decreased activity (44-49). Predictors of physical consequences relate to previous conditions, gender, age, ICU-AW, length of stay (LoS) in hospital (62) and Acute Respiratory Distress Syndrome (ARDS) (63). Further complications include persistent pain, which is common after ICU discharge (64, 65). Valso et al. found pain to be present in 68% of the patients, which declined over time but was still moderate after 12 months (64). Moreover, a systematic review summarises persistent pain in 28–77% , which declines over time, but after two years, 36% of the patients were still affected (65). Choi et al. found a correlation between pain and sleep disturbance, physical weakness, and fatigue (66). Moreover, sleep disturbances cause anxiety and depression (67).

2.3.2.3 Cognitive impairments

Experienced cognitive symptoms could be difficulties in expressing feelings, recalling experiences from critical illness (68) and concentrating in daily activities (69). It has been reported that 35–73% of the patients have cognitive impairments post ICU (48), which is more common in patients treated for severe sepsis (70) and ARDS (71).

2.3.3 Delusional memories

There are experiences of delusional memories both during and after the ICU stay. Delusional memories refer to hallucinations, nightmares and unreal memories from ICU care (27, 72-74). For the patient, this experience could be frightening, while their memories can often be experienced as real but with absurd content (75, 76). However, previous studies are inconsistent on whether delusional memories have an impact on emotional outcome (73), but delirium during the ICU stay (77) and more severe illness (78) increase the risk of experiencing delusional memories.

2.3.4 Emotional experiences and processing

For the patient, critical illness means vulnerability and a loss of control (79, 80). Therefore, survival begins a long-term emotional process towards a life in control again (81, 82), with repeated crises and sometimes even devastation (82) to a life, post critical illness (81). This process has three critical junctures: ICU admission, discharge from ICU and coming home (83). However, the time for processing is very individual (81). Chahraoui et al. found coping strategies associated with well-being, such as humour, optimism, familial support, leisure activities and acceptance (80). In addition, Page et al. found sense-making as a strategy towards recovery (83).
2.4 INTERVENTIONS TO PREVENT COMPLICATIONS OF CRITICAL ILLNESS

The most commonly described preventive interventions to optimise ICU patients’ outcome are: ABCDE-bundle, ICU diaries and ICU follow-up clinics.

2.4.1 ABCDE-bundle

An evidence-based tool used to systematically provide best practice and to reduce risks caused by sedation, immobility and delirium in the ICU is the ABCDE-bundle (84, 85). The use of the ABCDE-bundle also aims to prevent PICS after ICU discharge (86). The following are specifically connected to this tool: interventions of spontaneous awakening trials, spontaneous breathing trials, choice of sedation, assessing and preventing delirium, and agitation and early mobilisation (87).

2.4.2 ICU diaries

The purpose of diaries, written by healthcare professionals to the patient in the ICU, is to fill memory gaps and promote psychological recovery (88-90), which promotes their HRQoL (39) and could reduce new onset of PTSD (88, 91). Written texts include reason for admission, daily status, treatment, and events during the day, where even photographs of the critically ill patient could be attached (90). In addition, diaries constitute a source of communication among family members, which helps to manage overwhelming experiences together (92).

2.4.3 ICU Follow-up clinics

The objective of ICU follow-up clinics is to optimise rehabilitation for patients and their families, and to be a source of knowledge for healthcare, which could generate modifications and improvements in care and treatment (47). The follow-up is voluntary, and patients have the opportunity to ask questions and revisit the ICU (93). Engström et al. explains that the ICU follow-up contributes to one’s sense of coherence (SOC) (94), which could reduce depressive symptoms (95) and incidence of PTSD (95, 96). In Sweden, the follow-up of patients could be on one occasion or more at 2–12 months after intensive care (93), but implementations of follow-up services differ in organisation and performance (97). In contrast, recent research found insufficient proof of its effect on PICS symptoms during the patient’s recovery (91, 96-98).

2.5 PATIENTS TREATED IN THE ICU FOR COVID-19

The first reported COVID-19 patient treated in an ICU in Sweden was on 6th March 2020. During the first year of the COVID-19 pandemic (2020), intensive care units in Sweden treated fewer patients than usual (in 2019, there were 37,212 patients treated in the ICU), but the care burden and patient’s length of stay (LoS) increased considerably. In periods, ICUs increased their capacity significantly. Here is a summary of ICU care during COVID-19: during 2020, 6,710 patients were treated for COVID-19 in ICUs in Sweden, of which 72.3%
were men (mean age 61.6 years) and 27.7% were women (mean age 59.8 years). The 30-days mortality rate was 22.6% (2).

During the COVID-19 pandemic, the need for treating patients in ICUs with severe acute respiratory infection dramatically increased worldwide (99, 100). A challenge for healthcare professionals was to humanise the care of the patients when workload was extreme, and patients remained isolated from other persons and family members. Further, the healthcare professional wore personal protective equipment, which is a hindrance in communicating with the patient (101). Additionally, social and emotional isolation, limited nursing and uncertainty of the global pandemic contributed to increased risk of ICU delirium, with subsequent PICS after ICU discharge were reported (102). It has been reported that there is an increased risk of acute and long-term brain dysfunction in ICU patients due to the body’s immune response to the infection, further prolonged mechanical ventilation, and impaired respiratory function thereafter, which contributes to this risk (103). One recent meta-analysis found that 58% of ICU treated COVID-19 patients reported poor quality of life in both mental and physical domains following their illness (104).

2.6 FAMILY MEMBERS AND THEIR EXPERIENCES OF CRITICAL ILLNESS

Family members are in an extremely stressful situation when a loved one becomes critically ill (105, 106), making them vulnerable and feel like they are out of control (107, 108). Furthermore, family members are a part of the team around the patient (107, 109, 110), and they struggle to contribute to the patients’ healing process (111, 112), which promotes the patient’s well-being (113-115). In addition, they become surrogate decision makers in the care and treatment of the patient as the patient is too ill to make his or her own decisions (116, 117). Since family members take responsibility for the patients’ recovery process to a large extent (118), the patient’s level of psychological stress after ICU discharge has an impact on the family members’ mental health (119). Pochard et al. found that prevalence of anxiety and depression symptoms among family members remains high when the patient was discharged from ICU (120), and that long-term consequences such as anxiety, depression and PTSD are common even among family members (121, 122). Needham et al. termed this post intensive care syndrome-family (PICS-F) (44). High stress level in the ICU, e.g. when the patient is at high risk of dying or becoming ill unexpectedly, increases the risk of PICS-F conditions (120).

2.6.2 Support for the family

Ability to get social support and persons to entrust during the ICU stay reduces family members’ control over their situation (109). It has been described that interventions such as optimising communication between healthcare professionals and family members (106) and having information brochures (123) had a lower impact on mental outcome. Moreover, structured family conferences, including both nurses and physicians, may reduce minor symptoms of anxiety during the ICU stay (124). However, family members’ PTSD symptoms
could be reduced when writing in one’s own diaries for the patient, but this action had no effect on other mental symptoms (125). Also, rehabilitations programmes (119, 126) and education programmes for psychological distress (127) had no effect on PICS-F (119, 126, 127). Nonetheless, participation in follow-up visits could raise awareness on what had happened and why during the treatment in ICU, which could strengthen both the patient and his or her family (128).
3 RESEARCH AIMS

The overall aim of the current thesis was to explore experiences and patterns of behaviours in critically ill patients and their family members, addressing the period from when the patient became critically ill until recovery and everyday life at home.

Specific aims of the included studies were:

I. To describe and analyse factors associated with health-related quality of life 3, 6 and 12 months after discharge from a general surgical intensive care unit.

II. To develop an explanatory theory of patients’ patterns of behaviours from becoming critically ill until recovery at home.

III. To explore delusional memories and how they are managed by COVID-19 patients who have been treated in an intensive care unit.

IV. To develop an explanatory theory of family members’ patterns of behaviours from the patient becoming critically ill until recovery at home.
4 MATERIALS AND METHODS

The thesis compromises four clinical studies that resulted in four papers, where both quantitative and qualitative approaches were used. Study I was a prospective cohort study, performed in a general surgical intensive care unit in Stockholm County, Sweden. Studies II and IV were interview and observation studies with a qualitative approach and performed in four different ICUs in Sweden, consisting of one university hospital, two county hospitals and one district hospital. Study III was an interview study with a qualitative approach, performed in one county hospital in Stockholm County, Sweden. See table 1 for an overview of study design, setting, study and participants.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>Population</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study I</td>
<td>Prospective cohort study, Questionnaire of self-reported HRQoL, (SF-36), 3, 6 and 12 months after ICU-discharge.</td>
<td>One general surgical intensive care unit</td>
<td>Patients ≥18 years, ICU-stay ≥96 hours.</td>
<td>276</td>
</tr>
<tr>
<td>Study II</td>
<td>Qualitative interviews and observations. Classic grounded theory methodology</td>
<td>Three general intensive care units</td>
<td>Patients ≥18 years, treated in ICU. Ability to understand Swedish and absence of cognitive disorder.</td>
<td>20 (13 Interviews 7 Observations)</td>
</tr>
<tr>
<td>Study III</td>
<td>Qualitative interviews, Thematic analysis</td>
<td>One medical intensive care unit</td>
<td>Patients ≥18 years, admitted to the ICU due to Covid-19. Ability to understand Swedish and absence of cognitive disorder.</td>
<td>16</td>
</tr>
<tr>
<td>Study IV</td>
<td>Qualitative interviews and observations. Classic grounded theory methodology</td>
<td>Three general intensive care units</td>
<td>Family members, of patients treated in the ICU, ≥18 years. Ability to understand Swedish and absence of cognitive disorder.</td>
<td>19 (14 Interviews 5 Observations)</td>
</tr>
</tbody>
</table>
4.1 DESIGN

Study I

Study I was a quantitative survey study. For data collection, we used 36-Item Short Form Health Survey (SF-36), a generic self-reported survey of patient HRQoL, which includes 36 items. This instrument has been tested for reliability and validity in a Swedish general population. The items are answered by using Likert scales and summarised using the Likert method of summated ratings. The scores are summarised from 0–100, where a higher score indicates a better estimated health. HRQoL is measured in eight domains: Physical functioning (PF), nine items; Physical Role Functioning (RP), four items; Bodily pain (BP), two items; General Health (GH), five items; Vitality (VT) four items; Social Functioning (SF) two items; Emotional Role Functioning (RE), three items and Mental Health (MH), five items. In addition, there is one general item about perceived health and one item about reported health transition (129).

Study II/IV

In Studies II and IV, we used classic grounded theory (CGT) as a research method. CGT was developed by Glaser and Strauss in the mid-1960s (130). It is a general methodology, in which both qualitative and quantitative data could be used (Glaser and Holton, 2004). In classic grounded theory, human behaviours are conceptualised to generate a theory of the processing of the participant’s main concern. Pattern of behaviours are categorised and generated into concepts, which are related to each other in a theoretical explanation of a substantive area (131, 132) The method does not adhere to any theoretical perspective, and the research process does not start with a preconceived or predetermined problem. A grounded theory is abstract in time, place and people (131). We used Developing a Guideline for Reporting and Evaluating Grounded Theory Research Studies (GUREGT) in both studies (133).

Study III

To explore the experiences and management of delusional memories in COVID-19 patients, a qualitative study design with semi-structured interviews was used. Specifically, the consolidated criteria for reporting qualitative studies (COREQ), a 32-item checklist for qualitative studies, was used in this study (134).

4.2 SETTING

Data were collected from 2005 to 2021. All the studies were performed in ICUs in different parts of Sweden, comprising one university hospital- Karolinska Solna, Stockholm; one county hospital- Hudiksvalls sjukhus Hudiksvall; and two district hospitals- Södersjukhuset, Stockholm (two intensive care units) and Södertälje sjukhus, Södertälje.
4.3 PARTICIPANTS

All four studies included adult participants who were: ≥18 years of age, cared for in ICUs or family member to a patient cared for in an ICU, able to understand Swedish language and did not have any cognitive disorders. Quantitative data were collected from one ICU follow-up clinic from participants with a LoS ≥96 hours. Participants for interviews were recruited until saturation was reached, in collaboration with ICU follow-up clinics at each hospital. Furthermore, participants for observations were recruited in collaboration with the nurse responsible for the patient during his or her stay in the ICU.

Study I

Recruitment for the survey was at an ICU follow-up clinic in one district hospital at 3, 6 and 12 months after the patients’ discharge from one general surgical ICU. The patient was contacted by phone and given an invitation to the follow-up clinic and asked about participation in the study. The 36-Item Short Form Health Survey (SF-36) questionnaire was sent by mail, together with an informed consent form. The patient filled in the SF-36 at home and brought it to the visit at the follow-up clinic. Background data including age, gender, pre-existing diseases, and marital state together with ICU related data, including diagnosis at admission to the ICU, severity of illness measured by Acute Physiology and Chronic Health Evaluation II (APACHE II), if mechanical ventilation was used, LoS in the ICU and type of surgery were also recorded. For the inclusion process, see Figure 1, Study flow diagram.
Figure 1. Study Flow Diagram

Study Flow Diagram

Adult patients treated ≥ 96h at ICU during 2004-2012
N = 668

Excluded (n=221)
- Cognitive impairment (n=21)
- Not able to speak Swedish (n=20)
- ID missing (n=3)
- Died before the first visit (n=177)

Invited to follow-up (n = 447)

3 Months after ICU
- Missing (total n=242)
  - No need from patient (n=19)
  - Not want/could come or be reached (n=111)
  - Hospitalized or too sick to come (n=60)
  - Follow up at other ICU or lack of resources at follow-up clinic (n=6)
  - Did not answer SF-36 (n=2)
  - No reason (n=32)

6 Months after ICU
- Missing (total n=259)
  - No need from patient (n=59)
  - Not want/could come or be reached (n=112)
  - Hospitalized or too sick to come (n=57)
  - Follow up at other ICU (n=9)
  - Cognitive impairment between the first and second visit (n=7)
  - No reason (n=31)
  - Died between the first and second visit (n=9)

12 Months after ICU
- Missing (total n=263)
  - No need from patient (n=51)
  - Not want/could come or be reached (n=107)
  - Hospitalized or too sick to come (n=36)
  - Follow up at other ICU (n=4)
  - Cognitive impairment between the first and third visit (n=4)
  - Did not answer SF-36 (n=5)
  - No reason (n=36)
  - Died between the first and third visit (n=7)

Included in analysis
3 Months after ICU
n=205

Included in analysis
6 Months after ICU
n=197

Included in analysis
12 Months after ICU
n=184

Visiting at least one follow-up
Total n=276
- One visit (n=77)
- Two visits (n=68)
- Three visits (n=111)

Acta Anaesthesiologica Scandinavica (138).
Studies II–IV

Recruitment of participants was in collaboration with ICU follow-up clinics (interviews). The nurses at the follow-up clinics chose eligible participants (patients/family members) and informed the first author, who contacted the participant and informed about the study. If they agreed to participate, written information and consent were sent. For observations (studies II and IV), participants were chosen through theoretical sampling in collaboration with the ICU nurses in the ward during their treatment. All participants were informed of the study. If they agreed to participate, then written information and a consent form were provided. Participants were interviewed or observed on one occasion. The participants in the interviews were not the same as those observed. The participants were theoretically sampled, which means that the analysis guided for further questions and variation in choice of participants in order to saturate concepts, according to the Classic Grounded Theory methodology (132).

4.4 DATA COLLECTION

Study I

Data were collected from 2005 to 2012, on three occasions, 3, 6 and 12 months after the ICU stay. Patients brought their completed questionnaire, SF-36, to the ICU follow-up clinic, and the nurse in charge checked the form and asked if the patient had any additional questions. All data and clinical characteristics were registered in SPSS by the first author. Comparison of characteristics for finally study population, see Table 2.
Table 2. Comparison of characteristics for finally study population, (patients who answered SF-36 at least once), patients who died and those excluded or lost to follow up.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Final study population (n=276)</th>
<th>Died before first visit (n=177)</th>
<th>Excluded or lost to follow up (n=215)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>182 (65.9)</td>
<td>117 (66.1)</td>
<td>118 (54.9)</td>
<td>0.03**</td>
</tr>
<tr>
<td>Female</td>
<td>94 (34.1)</td>
<td>60 (33.9)</td>
<td>98 (45.7)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td></td>
<td>1 (0.4)</td>
<td></td>
</tr>
<tr>
<td>Age, median (IQR)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-64 years, n (%)</td>
<td>66 (43.5)</td>
<td>73 (65-80)</td>
<td>67 (56-78)</td>
<td>0.00**</td>
</tr>
<tr>
<td>65-74 years, n (%)</td>
<td>88 (51.9)</td>
<td>57 (52.2)</td>
<td>51 (26.2)</td>
<td></td>
</tr>
<tr>
<td>≥75, n (%)</td>
<td>68 (24.6)</td>
<td>79 (45.0)</td>
<td>70 (32.3)</td>
<td></td>
</tr>
<tr>
<td>Days in ICU, median (IQR)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4-7 days, n (%)</td>
<td>9 (6-17)</td>
<td>9 (6-15)</td>
<td>8 (6-15)</td>
<td>0.05</td>
</tr>
<tr>
<td>8-14 days, n (%)</td>
<td>101 (66.6)</td>
<td>68 (88.4)</td>
<td>97 (45.2)</td>
<td></td>
</tr>
<tr>
<td>≥15 days, n (%)</td>
<td>89 (29.0)</td>
<td>58 (28.8)</td>
<td>76 (35.4)</td>
<td></td>
</tr>
<tr>
<td>≥15 days, n (%)</td>
<td>25 (29.4)</td>
<td>51 (28.8)</td>
<td>42 (19.5)</td>
<td></td>
</tr>
<tr>
<td>APACHE II score, median (IQR)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-5, n (%)</td>
<td>21 (16-25)</td>
<td>27 (24-31)</td>
<td>22 (19-27)</td>
<td>0.00**</td>
</tr>
<tr>
<td>26-62, n (%)</td>
<td>179 (64.8)</td>
<td>35 (20.0)</td>
<td>57 (26.5)</td>
<td></td>
</tr>
<tr>
<td>Missing, n (%)</td>
<td>38 (13.9)</td>
<td>83 (47.0)</td>
<td>38 (63.3)</td>
<td></td>
</tr>
<tr>
<td>Mechanical ventilation, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>201 (72.8)</td>
<td>150 (89.3)</td>
<td>162 (75.4)</td>
<td>0.00**</td>
</tr>
<tr>
<td>No</td>
<td>75 (27.2)</td>
<td>19 (10.7)</td>
<td>52 (24.2)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td></td>
<td>1 (0.4)</td>
<td></td>
</tr>
<tr>
<td>Diagnoses at admission to ICU, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal surgery</td>
<td>96 (34.8)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Sepsis/infection</td>
<td>48 (17.4)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Vascular surgery</td>
<td>44 (15.9)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Respiratory failure</td>
<td>45 (15.6)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Bleeding/hypovolemia</td>
<td>20 (7.2)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Medical admission**</td>
<td>15 (4.7)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Trauma</td>
<td>9 (3.3)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Obstetric complication</td>
<td>3 (1.1)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Surgery, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute surgery</td>
<td>179 (64.9)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Elective surgery</td>
<td>56 (20.3)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>No surgery</td>
<td>41 (14.8)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Preexisting diseases</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. of diseases, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>60 (21.7)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>149 (54.0)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>2-3</td>
<td>67 (24.3)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Marital status, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>104 (87.7)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Married/living with partner</td>
<td>167 (60.5)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>5 (1.8)</td>
<td>N/A***</td>
<td>N/A***</td>
<td></td>
</tr>
</tbody>
</table>

* p-value <0.05 considered statistically significant
** Renal failure, heart failure, cardiac arrest, AMI, intoxication
***Not available
Study II

Data were collected from December 2014 to June 2018. Thirteen formal interviews were conducted with patients cared for in one intensive care unit with a variety of diagnoses, including nine men and four women, aged 22–82 (median 50) years old. The patients informed that their LoS in the ICU was between two and 28 days (median 11 days). The location for the interviews was either in the patient’s home or in a room at the hospital. All interviews started with one open-ended question, lasted about 1 to 1.5 hours, were audio recorded and transcribed verbatim. Details on interactions, the physical environment and non-verbal behaviours were written down in field notes.

Seven patients with a variety of diagnoses, who were awake, were observed. They included two women and five men, aged 19–85 (median 74) years old. Their behaviours and social interaction with others were observed and written down in field notes. Each of the observations lasted 4 to 6 hours.

Study III

Data were collected from November 2020 to January 2021. Sixteen individual interviews were conducted with patients treated for COVID-19 in one ICU. Five women and eleven men aged 18–85 (median 51) years old, with a LoS between 5–32 (median 17) days in the ICU were included. The interviews were conducted via video (two participants) or in a room at the hospital (fourteen participants). Data were collected through three open-ended questions: their experiences of delusional memories, how they felt, and how they managed this experience. One additional question was asked regarding their experience of being treated by healthcare professionals in protective equipment. All interviews were audio recorded, transcribed verbatim and lasted 22 minutes to 1 hour.

Study IV

Data were collected from February 2019 to June 2021. Fourteen formal interviews were conducted with family members of critically ill patients, treated for a variety of diagnoses in the ICU. Nine women and five men aged 36–79 (median 56) years old, were included. The relationships of these participants to the patient were two daughters, one son, three siblings, three husbands and five wives. The location for the interviews was either in the family members’ home or in a room at the hospital. All interviews started with one open-ended question and lasted 30 minutes to 1.5 hours. All interviews were audio recorded and transcribed verbatim. Details on interactions, the physical environment and non-verbal behaviours were written down in field notes.

Observations of eight family members were conducted in the patient’s room at the ICU. The five women and three men were one father, two sons, four wives and one granddaughter, aged 35–79 (median 49) years old. Their behaviours and social interaction with others were observed and written down in field notes. Each of the observations lasted 1–3 hours.
4.5 DATA ANALYSIS

Statistics (Study I)

In this study, we used Kruskal Wallis test and Chi-square test to evaluate differences in background characteristics. Missing data was an issue; therefore, we chose a mixed-effect model, which can accommodate missing data. A linear mixed model was performed to measure changes over time between 3, 6 and 12 months after the ICU stay, using time as a covariate. We assessed normality of the residuals in graphs and used the restricted maximum likelihood as our model estimation method. In all dimensions, an unstructured fixed model for time was significantly better than a random effect model. The estimated fixed effects as 95% confidence intervals (CI) and their significance are presented. For comparing the 12-months result with a Swedish reference population, we performed a Wilcoxon Signed Rank test. To explore the impact on HROoL from background variables and ICU-related variables, univariable and multivariable general linear regression analyses were used. The IBM Statistical Package for the Social Sciences (SPSS) version 22.0 (IBM Corp., Armonk, NY, USA) was used for all statistical analyses.

Classic grounded theory (Studies II and IV)

The analyses started immediately after the first interview with open coding (Glaser 1998). In open coding, patterns of behaviours were identified and coded. All data were coded line by line by using constant comparative analysis. Patterns of behaviours began to emerge and were grouped into codes and then into concepts. During the analysis, memos were written, which led to abstraction and ideas about further data collection. Memos are theorising write up-ideas of codes and their relationships (131). The core category emerged by constant comparative analysis: Stabilising life, (study II) and Shifting focus (study IV). The core category explains how the participants’ deal with their main concern and is the concept to which all other concepts relate. When saturation was reached, theoretical coding started. Memos were sorted, and memos on memos were written to increase the level of abstraction and to clarify the hypothesis relating to the concepts and their interconnection with each other. Finally, a literature review was performed to saturate the meaning of the concept and the generated theory.

Thematic analysis (Study III)

Thematic analysis is a method that enables a rich and detailed analysis of participants’ perspectives and a method for identifying, analysing and reporting patterns (themes) within data (135). The analysis process can be carried out in the following six steps: 1) All interviews were transcribed verbatim by the first researcher. Transcribed interviews and field notes were read and reread. 2) Thereafter, we coded the text into codes, which generated 82 initial codes. Detected codes were compared from various participants and listed together with meanings units. 3) In the next step, we compared codes and grouped them into potential themes in a thematic map. 4) Data were analysed to define and refine each theme and compare them with participants’ narratives. 5) The identified themes were compared with our
research questions and theoretical assumptions, and we defined and named the themes, which resulted in three main themes and 14 subthemes. For each theme, we conducted and wrote a detailed analysis. 6) In the last step, we generated and reported our findings. During the whole analysis, three of the researchers, experienced in qualitative method, participated in, and discussed each step.

5  ETHICAL CONSIDERATIONS

All studies included in this thesis were planned in line with the World Medical Association (WMA) Helsinki declaration (136). The overall research project was approved by the Ethical Review board in Stockholm. Considerations were taken about protecting participants’ health, well-being, privacy, and dignity in planning during and after the studies (136, 137).

Being a patient or family member to a person treated in the ICU puts one in a vulnerable situation. During the planning of the studies, we identified and discussed potential risks of participating in the studies. Participants could react negatively during the interviews due to the risk of reliving traumatic memories from retelling their experiences. We also discussed debt of gratitude, integrity and vulnerability, as two of the researchers work as intensive care nurses in one ICU. Therefore, we chose to include participants from other ICUs in Sweden, so that none of the researchers had a previous professional relationship with the participants. Moreover, we discussed risks and benefits with observations in depth and decided to only observe awake patients who could be informed about and decide on whether the researcher should be included.

At least one week before the interviews, the researcher thoroughly informed participants verbally and sent them a written consent with contact details to the researcher. Also included was information about the purpose of the study and its benefits and risks, and participants’ ability to withdraw their approval at any time without any explanation. The written consent also offered support from the follow-up clinic or a counsellor if the need were to arise for patients or family members. During the data-collection, the participants were treated with respect, and their well-being was prioritised before the research. A lot of participants cried during the interviews; they were once again offered additional professional support. All transcribed interviews and observations were de-identified, and all research material which could relate to a person was stored in a locked cabinet at the research centre. All data were presented so that no data could be traced to any individual.
6 RESULTS

Presented below are the summaries of the findings.

6.1 HEALTH-RELATED QUALITY OF LIFE AFTER GENERAL SURGICAL INTENSIVE CARE (STUDY I)

Study I described and analysed factors associated with HRQoL after critical illness and treatment in a general surgical intensive care unit. During the period from 2005 to 2012, 276 (62%) of the eligible patients completed SF-36 at least once.

An improvement was found between 3–12 months, but HRQoL was still significantly lower in all domains compared to the general population, see Table 3. Between 3–12 months, improvement in HRQoL was significant in the study-population but not in bodily pain (BP) (P = .24), general health (GH) (P = .15) and mental health (MH) (P = .09), see Table 4.

Factors that were associated with lower HRQoL were: female gender; BP (P = .03); role emotional (RE), (P = .04) and MH (P = .01); age 65–74 years; physical functioning (PF), (P = .00) and MH (P = .04); single living patients PF (P=.01) and patients with ICU length of stay > 14 days PF (P = .01). See table 5 for univariable analysis and table 6 for multivariate analysis.

Table 3. Reported values of the eight domains of SF-36 at 3 and 12 months for the study population and an age and gender matched reference population in Sweden.

<table>
<thead>
<tr>
<th>SF-36 domain</th>
<th>3 Months median (IQR)</th>
<th>12 Months median (IQR)</th>
<th>Age and gender matched reference population in Sweden median (IQR)</th>
<th>Difference 12 Months – reference population</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>45 (20–79)</td>
<td>45 (25–79)</td>
<td>35 (25–80)</td>
<td>35 (25–80)</td>
<td>0.00*</td>
</tr>
<tr>
<td>BP</td>
<td>0 (0–25)</td>
<td>0 (0–25)</td>
<td>0 (0–25)</td>
<td>0 (0–25)</td>
<td>0.00*</td>
</tr>
<tr>
<td>GH</td>
<td>30 (25–82)</td>
<td>25 (20–75)</td>
<td>32 (25–72)</td>
<td>28 (23–72)</td>
<td>0.00*</td>
</tr>
<tr>
<td>VT</td>
<td>40 (35–55)</td>
<td>35 (30–50)</td>
<td>41 (35–60)</td>
<td>37 (30–60)</td>
<td>0.00*</td>
</tr>
<tr>
<td>RE</td>
<td>10 (0–100)</td>
<td>10 (0–100)</td>
<td>10 (0–100)</td>
<td>10 (0–100)</td>
<td>0.00*</td>
</tr>
<tr>
<td>MH</td>
<td>48 (43–58)</td>
<td>48 (43–58)</td>
<td>49 (43–58)</td>
<td>49 (43–58)</td>
<td>0.00*</td>
</tr>
</tbody>
</table>

PF= Physical functioning, BP= Bodily pain, GH= General health, VT= Vitality, SF=Social functioning, RE= Emotional role functioning, MH=Mental health

* = p-value < 0.05
Table 4. Estimates of changes over time of HRQoL from 3 and 12 months after ICU-stay, linear mixed model, unstructured.

<table>
<thead>
<tr>
<th>SF-36 Dimension</th>
<th>3-months (intercept)</th>
<th>95% CI</th>
<th>Change at 12-months</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>43.93</td>
<td>40.21-47.75</td>
<td>9.36</td>
<td>5.55-13.17</td>
<td>0.00*</td>
</tr>
<tr>
<td>RP</td>
<td>18.72</td>
<td>13.95-23.49</td>
<td>14.08</td>
<td>7.75-20.41</td>
<td>0.00*</td>
</tr>
<tr>
<td>BP</td>
<td>52.46</td>
<td>48.54-56.38</td>
<td>2.27</td>
<td>-1.78 to 6.32</td>
<td>0.24</td>
</tr>
<tr>
<td>GH</td>
<td>51.18</td>
<td>48.40-53.93</td>
<td>2.79</td>
<td>0.10 to 5.68</td>
<td>0.15</td>
</tr>
<tr>
<td>VT</td>
<td>40.47</td>
<td>37.48-43.45</td>
<td>8.71</td>
<td>5.33-12.10</td>
<td>0.00*</td>
</tr>
<tr>
<td>SF</td>
<td>53.77</td>
<td>49.62-57.92</td>
<td>10.15</td>
<td>5.63-14.61</td>
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</tr>
<tr>
<td>RE</td>
<td>42.62</td>
<td>36.61-48.62</td>
<td>9.63</td>
<td>5.26-13.91</td>
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</tr>
<tr>
<td>MH</td>
<td>63.74</td>
<td>60.70-66.78</td>
<td>3.31</td>
<td>2.05-4.58</td>
<td>0.009</td>
</tr>
</tbody>
</table>


* p-value < 0.05

Table 5. Univariable linear regression analyses regarding impact of background and ICU-related factors on health-related quality of life at 12 months after discharge from ICU.

<table>
<thead>
<tr>
<th>Variables</th>
<th>PF</th>
<th>RF</th>
<th>SF</th>
<th>RE</th>
<th>MH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (yrs)</td>
<td>50.0 (15.0)</td>
<td>50.0 (15.0)</td>
<td>50.0 (15.0)</td>
<td>50.0 (15.0)</td>
<td>50.0 (15.0)</td>
</tr>
<tr>
<td>Acute surgery (n=135)</td>
<td>66 (48%)</td>
<td>66 (48%)</td>
<td>66 (48%)</td>
<td>66 (48%)</td>
<td>0.001</td>
</tr>
<tr>
<td>Severe injury (n=19)</td>
<td>19 (100%)</td>
<td>19 (100%)</td>
<td>19 (100%)</td>
<td>19 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. complications (n=168)</td>
<td>168 (100%)</td>
<td>168 (100%)</td>
<td>168 (100%)</td>
<td>168 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>Mortality (n=10)</td>
<td>10 (100%)</td>
<td>10 (100%)</td>
<td>10 (100%)</td>
<td>10 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. redistribution of organs (n=15)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. sepsis (n=15)</td>
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<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. ventilator days (n=15)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. propofol (n=15)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. propofol (n=15)</td>
<td>15 (100%)</td>
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<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
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<td>15 (100%)</td>
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<td>0.001</td>
</tr>
<tr>
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<td>15 (100%)</td>
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<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. propofol (n=15)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
</tbody>
</table>


Acta Anaesthesiologica Scandinavica (138).

Table 6. Multivariable linear regression analysis regarding impact of background and ICU-related factors on health-related quality of life at 12 months after discharge from ICU.

<table>
<thead>
<tr>
<th>Variables</th>
<th>PF</th>
<th>BP</th>
<th>SF</th>
<th>RE</th>
<th>MH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (yrs)</td>
<td>50.0 (15.0)</td>
<td>50.0 (15.0)</td>
<td>50.0 (15.0)</td>
<td>50.0 (15.0)</td>
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<td>0.001</td>
</tr>
<tr>
<td>Severe injury (n=19)</td>
<td>19 (100%)</td>
<td>19 (100%)</td>
<td>19 (100%)</td>
<td>19 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. complications (n=168)</td>
<td>168 (100%)</td>
<td>168 (100%)</td>
<td>168 (100%)</td>
<td>168 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>Mortality (n=10)</td>
<td>10 (100%)</td>
<td>10 (100%)</td>
<td>10 (100%)</td>
<td>10 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. redistribution of organs (n=15)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. sepsis (n=15)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. ventilator days (n=15)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. propofol (n=15)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. propofol (n=15)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. propofol (n=15)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. propofol (n=15)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
<tr>
<td>No. propofol (n=15)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>15 (100%)</td>
<td>0.001</td>
</tr>
</tbody>
</table>


** p-value < 0.05

Acta Anaesthesiologica Scandinavica (138).
6.2 STABILIZING LIFE: A GROUNDED THEORY OF SURVIVING CRITICAL ILLNESS (STUDY II)

Being out of control emerged as the main concern for intensive care patients, from the time of becoming critically ill until recovery at home. This means having a lack of control over one’s life and living, including the body, mind, and environment. For the patient, this is enormously stressful and can be perceived as a fight against physical and mental obstacles. Stabilizing life is the core category, which is pattern of behaviours used by the patients to manage their main concern. This is a process which consists of three categories: the two phases Recapturing life, Recoding life and the ongoing strategy Emotional balancing. The process could be linear, but patients could move back and forward through the process and/or within the phases, depending on triggers such as physical and emotional setbacks or lack of social support. Longing to come home could be a trigger to moving forward in Recapturing life. A factor that has an impact on the theory and its outcome is a fighting spirit, supported by stubbornness, which could promote recovery. Experiences of difficulties in life and higher age can facilitate accepting permanent changes in life. The experience of critical illness could affect a person’s view of life and living, and their ways of thinking and their identity could be partially or totally changed from before falling ill. See Figure 2, An overview of the theory Stabilizing life.

Figure 2. An overview of the theory Stabilizing life Strategies in the two phases: Recapturing life and Recoding life, and Emotional balancing used as a strategy throughout the whole process.

<table>
<thead>
<tr>
<th>Stabilizing life</th>
<th>Recoding life</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Recapturing life</strong></td>
<td><strong>Recoding life</strong></td>
</tr>
<tr>
<td>Seeking interaction</td>
<td>Sense-making</td>
</tr>
<tr>
<td>Regaining control</td>
<td>Managing fear</td>
</tr>
<tr>
<td>Being connected to reality</td>
<td>Adapting to new life conditions</td>
</tr>
<tr>
<td>Balancing independence</td>
<td>Relying on others</td>
</tr>
<tr>
<td></td>
<td>Holding back</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emotional balancing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional strengthening</td>
</tr>
<tr>
<td>Emotional holding</td>
</tr>
<tr>
<td>Emotional shielding</td>
</tr>
</tbody>
</table>
6.2.1 Recapturing life

Strategies used in this phase are more common during the hospitalisation period. This phase starts when the patient becomes critically ill. Initially, the patient is more dependent on other people’s ability to interpret their needs. Recapturing life means managing the frightening and often unknown situation of being critically ill, surviving and then becoming more autonomous and self-determined. Experiences of feeling safe in this situation is dependent on trust, which is a result of successful interactions with others in the environment. Having family members close by helps to reduce the stress for the patient; if family members are not nearby, daydreaming about them and keeping them in their thoughts are ways to control the mind. For the patient, critical illness means that their integrity and autonomy are affected, caused by a loss of control over his or her body and self-determination. When one depends on other people to manage the day, asserting self-determination is used. Even if it results in setbacks, this strategy could increase self-esteem. Since the visit to the ICU and being in the ward is a disturbed reality for the patient, the connection to reality and the normal life and living outside contribute to the feeling of being a person and not an object. In various hospital contexts, expectations on the patient could differ, which could be a challenge for the patient to discover. Therefore, support from family members could be necessary for the patient to be more self-assertive and independent in actions and decisions. Self-assertion and independency promote the patient’s self-esteem.

6.2.2 Recoding life

Strategies used during the second phase are more common during recovery. In Recoding life, the patient processes consequences and traumatic experiences of being critically ill. To better understand the impact of illness, fragmentary memories are linked to reality, and facts communicating with professionals, family members and reading diaries are used. Using diaries was found to be an important source for making sense of fragmentary memories; pictures in the diaries, in particular, increase the understanding. Delusional memories from the ICU are common and could sometimes appear afterwards, especially in the evening. This fear could be managed by communicating them with others and accepting them as unreal. Another fear could be to fall critically ill again, where symptoms of a slightest cold could be frightening. This fear could be managed through new positive experiences where it ends well. Critical illness could result in changes in physical and mental conditions, compared with life before illness. By modifying life in a positive way and using small step-by-step goals in recovery, the adaption could be managed in a favourable way. For many patients, physical and emotional support from others must be accepted to manage everyday life, but to be dependent on others could be strenuous; therefore, a two-way communication which requires empathy and attention from others was vital. Hindrance for processing is a guilty conscience toward the other person and what one exposed them for through becoming critically ill. This feeling could be a hindrance for communicating experiences from critical illness, which could have a negative impact on the relation.
6.2.3 Emotional balancing

Emotional balancing is an ongoing strategy throughout the whole process. This strategy is dependent on personality, previous experiences and mood of the day, which have an impact on strategies used to balance hope and fear. Maintain hope reduces stress and fatigue as well as being supported by others. Furthermore, autonomy and ability to think promote emotional well-being positively. Emotional imbalance may be a result of exhaustion and despair when emotional burdens feel overwhelming. Holding back emotions could be a reaction of burden, which depends on the specific day and setbacks. If negative emotions progress, it could result in emotional shielding, which is a reaction to being out of control. This could be a way to protect oneself from an overload of emotions but also a hindrance for stabilising life.
6.3 THE DELUSIONAL MEMORY EXPERIENCES OF PATIENTS TREATED IN ICU DURING THE COVID-19 PANDEMIC: A QUALITATIVE STUDY (STUDY III)

This paper explores experiences of delusional memories, in patients treated for COVID-19, in one ICU as well as how these patients manage this experience. Three main themes: Distorted truth, Captive and Managing delusional memories, explore this aim. For an overview of themes and sub-themes, see Figure 3.
6.3.1 Distorted truth

Patients’ description of the content of delusional memories were like a real experience with unreal and often scary content. This was very clear and retold in detail. The most common experience was to face death in different ways and contexts. These memories included noisy and often messy environments with strange people and events in recognised but distorted environments, in sometimes well-known places from everyday life and/or the hospital environment. People in the surroundings were familiar but often acted strangely, having weird clothes or sometimes looking half like animals.

6.3.2 Captive

Experiences and feelings linked to delusional memories are explored in captive. Delusional memories are experienced as a threatening reality, where it could be difficult and time-consuming to process the discomfort caused to the person. Feelings such as helplessness, frustration and fear are common and linked to delusional memories, but some delusional memories could be experienced as pleasant and harmonic. During the pandemic, healthcare professional wore protective equipment. The experience linked to this was a distanced
feeling, but it felt safe. Persons with calm and caring behaviours promoted a feeling of safety, despite the unfamiliar and anonymous look. Participants learned to recognise people based on their specific behaviours, voices, and other small details in how they look. Furthermore, flashbacks and discomfort associated with delusional memories could return during the recovery.

6.3.3 Managing delusional memories

Strategies used to cope with delusional memories could be both problem-focused and emotion-focused. Finding explanations for delusional memories made it possible to process them. Retelling them to other persons who listened actively and understood the feeling or using humour and telling them in a funny way could be used as strategies for well-being. Some participants mentioned professional help, which could be a solution for processing the experience, but most often not a choice for processing delusional memories. Furthermore, crying is a strategy used to relieve pressure. Experiences and feelings related to delusional memories could fade over time; however, taking control over feelings and living here and now, instead of in the past, could facilitate moving on. Moreover, pleasant activities help to dispel thoughts and increase well-being.

6.4 SHIFTING FOCUS: A GROUNDED THEORY OF HOW FAMILY MEMBERS OF CRITICALLY ILL PATIENTS MANAGE THEIR SITUATION (STUDY IV)

In this paper, we explore patterns of behaviours of family members of critically ill patients from the time he or she became critically ill until everyday life at home. Living on hold emerged as the main concern for family members of critically ill patients, which means that their lives had been put on hold and they felt like they lost control over their situation. Shifting focus emerged as the core category and are pattern of behaviours used of family members to deal with their main concern, living on hold. Shifting focus means to move beyond one’s own needs and focusing on the patient’s needs, well-being, and survival. This is a process that involves the strategies: Decoding, Sheltering and Emotional processing. However, there are three different outcomes of the theory: Balancing focus, Emotional resigning and Remaining in focus. Personal factors, previous experiences of trauma and family construct could affect use of different strategies and the outcome.

6.4.1 Decoding

Decoding is a way to reduce uncertainty by trying to understand and predict what to expect now and in the future. By observing, seeking information, comparing given information, and comparing experiences with other persons, conclusions can be drawn about the meaning of the illness as well as events linked to the illness, but sometimes drawing one’s own conclusions could result in misunderstandings. Clear and honest information from healthcare professionals can facilitate decoding. This strategy is more often used during the hospitalisation period.
6.4.2 Sheltering
Sheltering means taking responsibility for the patients’ needs and well-being during the care and recovery. Sheltering involves protecting the patient and advocating for their rights, getting involved in treatment and care, and motivating and transferring strength to the patient to overcome adversities. The degree of control over the situation influences the intensity of using Sheltering. Lack of trust in the environment or the patient’s capacity to manage difficulties could result in overprotecting, which is a way to maintain control but can be a hindrance for a balanced focus.

6.4.3 Emotional processing
Emotional processing means to reduce emotional strain caused by uncertainty and helplessness. Maintaining hope is fundamental for managing emotional strain caused by the patient’s illness. Another strategy in emotional processing is to share experiences and responsibility with trustful persons, which means those who are confirmatory and who understand the emotional strain, often those in the same situation. Family members also use reflecting, which means processing events and feeling connected to the patient’s critical illness. The intensity of reflecting is individual, but some persons remain in ruminating which is a hindrance to progress, and a risk of suppressing emotions. Overwhelming feelings and thoughts can be managed by taking a break and engaging in one’s own activities; therefore, dispersed thoughts can be useful in the emotional process.

6.4.4 Three different outcomes
There are three different outcomes of the theory: Balancing focus, Emotional resigning and Remaining in focus.

6.4.5 Balancing focus
Balancing focus means adapting to changes in life caused of illness and is a strategy used to receive focus on everyone’s needs and well-being within the family. This is done through an increased awareness of one’s own needs and activities, and by setting boundaries for how much support you can give the other person without affecting your own health. Distancing oneself from experienced burdens and looking forward by planning for the future enable a balanced focus.

6.4.5 Emotional resigning
When giving up hope in the patient’s ability to change negative patterns of behaviours or improving for the better, Emotional resigning is the outcome. This means to leave the other person emotionally behind, but not always physically. However, this strategy has a negative impact on the relationship. A finding was that not sharing burdens, being stuck in ruminating and/or suppressing feelings have an impact on this outcome.
6.4.6 Remaining in focus

By disregarding one’s own feelings and continuing to focus on the other persons’ needs could result in abandonment and fatigue. Decoding and sheltering are used to a higher degree and emotional processing to a lower degree in this outcome.

7 DISCUSSION

The main findings in this thesis were that critical illness is a traumatic experience for those involved, which means a loss of control, as well as health and well-being being affected, both for the patients and their families. This entails an emotionally strenuous process, which involves discomfort, vulnerability, consequences on health, hindrance, strengths and opportunities. However, patients and their family members experience this emotional strain from different perspectives and use different strategies to manage their situation. Common strategies used, which are strengthening when used in a constructive way, include: seeking and getting social support; maintaining hope; seeking explanations on how, when, and why; and preserving autonomy. Moreover, trust in other individuals promotes processing, and humour and engaging in activities helps to dispel negative thoughts, which together increase well-being.

7.1 HEALTH-RELATED QUALITY OF LIFE AFTER INTENSIVE CARE

In our first study, we analysed factors associated with HRQoL after discharge from the intensive care unit. This study indicated an impact on several factors of HRQoL and a worse outcome one year after intensive care compared with a Swedish reference population (138). The impact on patients’ HRQoL after ICU discharge is well studied in previous research (38, 139-144); however, it would be interesting to understand how their HRQoL was before the illness to compare if it is worse or better. Hofhuis et al. measured HRQoL before ICU admission (by proxies) until 5 years after ICU stay and found that HRQoL was affected but improves over time. However, five years after ICU discharge, the impact of ICU admission on HRQoL had declined (145). Sjoberg et al. found that the final outcome of HRQoL is more related to previous comorbidity and chronical conditions than to critical illness itself (139). In our study, HRQoL improved over time but was still affected one year after discharge from the ICU, but causes are unknown.

7.2 MANAGING LIFE DURING INTENSIVE CARE

In the ICU, the patient could be totally dependent on other individuals’ behaviour, both physical and mental, which means being out of control. Losing a sense of control has been explained in previous studies of intensive care patients (79, 80, 110, 146). The loss of control starts a process of using strategies such as interacting with other individuals, seeking or getting social support to become more independent and regaining control. Strategies used in a
constructive way promote a sense of feeling safe and well-being. In an integrative review of intensive care patients’ experiences of well-being, the authors found feeling safe, being cared for, security and tenderness as facilitators of well-being (147). Other research explains trust as essential for feeling safe (148, 149). Our findings were that people who communicate clearly and honestly, behave calmly, are respectful, and supportive promote the feeling of trust and feeling safe. During the hospital stay, family members’ presence, physical or in mind, is stress reducing for the patient, which also has been found in previous research on ICU patients and their families (110). This, together with being treated as an individual and not an object, contributes to regaining control (150).

Another finding was that when the patient becomes critically ill, family members put themselves and their own needs aside (151). One strategy used during the ICU stay is to try to figure out the meaning and possible outcome of critical illness and treatment by searching for information from different sources. This is in addition to family members doing their best to influence the patient’s outcome by getting involved in care, decisions, and supporting the patient. Those strategies have been explained in previous grounded theories (GT) in studies on family members of intensive care patients (107, 152). Trust towards healthcare professionals and sharing burdens with trustful persons alleviate some of the burdens. Also, maintaining hope is a perquisite for not giving up. Since it is difficult for the healthcare professionals to predict the outcome for the patient, promises cannot be made; therefore, it can be difficult to mediate hope. However, healthcare professionals can communicate clearly and honestly with promise to do their best for the patients’ survival, which mediates hope (150). Change of care level from the ICU to the general ward means a major change for family members, which could result in uncertainty and increased need to protect the patient (151). Page et al. found this change to be one of the critical junctures for patients and their family (83).

7.3 MANAGING LIFE AT HOME

For the patient, returning home means dealing with adversities and new perquisites in life temporarily or permanently (81, 150, 153). Kean et al. term this condition survivorship, which is a process to manage a different self (81). Strategies used in this phase include: raising awareness of fragmentary memories, confronting fear, adapting to changes in life and accepting support from others (150). Being vulnerable represents patients’ PICS experiences (154).

For family members, the patients’ return home means having to face new adversities and new routines in everyday life, temporarily or permanently. Processing events, emotional strain, guilt and adapting to changes caused by the illness facilitate leaving emotional strain behind. Besides focusing on one’s own needs and activities, setting boundaries for how much one can support the other person, focusing on abilities and providing new positive experiences together are strategies used which promote a more balanced focus within the family (151).
7.4 MANAGING HINDRANCES

7.4.1 Finding explanations and communicating

Finding out facts, what happened, when and why, are strategies used by both patients and their families to remain in or regain control (150, 151, 155). Since there are differences in experiences between patients and their families, they use different strategies to find out facts. Patients have more fragmented memories from the ICU stay; hence, they need to fill in gaps and sort memories (sense-making). Family members must process all the overwhelming memories and events they have been through (reflecting). In a previous study of ICU patients and their families, sense-making was a strategy used by all involved. However, access to information is central, which was in line with our findings (156). Finding explanations could be time-consuming but seems to be necessary for progress and well-being. The intensity of using the strategy might depend on personality and the personal meaning of the traumatic event. Some people get stuck in the ruminating stage. Ruminating could be necessary for understanding what one has been through, but it could also be a hindrance to progress and being able to adapt to the new situation. In addition, our finding was that using ICU diaries was an important source for providing clarity, which is congruent with previous research (157, 158). Furthermore, using ICU diaries is an intervention to prevent or relieve anxiety, depression (159), PTSD post-ICU (88, 160) and has a positive effect on HRQoL (39). ICU follow-up clinics were another resource for sense-making, which had been attested in previous research (94, 128).

Brittain et al. analysed health and communication and found trust as a prerequisite for effective communication (161). This was also our finding; in addition, however, we found that communication with other persons involved during the process helps to alleviate burdens. People who have been able to listen actively, are non-judgmental and understand the meaning of what one has experienced inspires trust, which contributes to constructive communication. A trustworthy person does not always have to be a close family member. However, relationships with people who are self-focused and ‘energy thieves’ were often interrupted or ended to save energy for their own well-being (150, 151).

7.4.2 Hope

Hope enables well-being and health (162, 163), but the meaning of the concept depends on the setting (164). Reduced sense of hope in family members is associated with anxiety, stress and depression during the patient’s hospitalisation period (165). In our studies, hope is an emotional process associated with the patients’ survival and progress, acceptance, and a functioning future within the family. Hope is fundamental for not giving up. Bygstad-Landro et al. explain that hope and endurance are fundamental in the process during a depression; hope helps one to endure and increased hope lessens having to endure (166). Our finding was that maintaining hope is vital to being able to move forward in processing adversities. Negative messages or setbacks in the patients’ condition affect hope in patients and their family, but even small signs of progressions help to maintain hope. Healthcare professionals
could support the experience of hope by providing distinct and honest information and engaging in professional and confidence-inspiring behaviours.

7.4.3 Relationships and social support

A well-functioning relationship within the family and ability to communicate and support each other are strengths that promote recovery and well-being. Patients and family members have different needs, which can affect their relationship (150, 151). Patients could suppress their emotions in order not to burden their family. Suppressing emotions and thoughts could be a hindrance for communication within the family (150). In contrast, family members could have a bad conscience for making wrong decisions during the patient’s illness or not being able to address their own needs, and therefore overprotect (sheltering) the patient, which have an impact on their own well-being and being able to move forward in the process (150).

During the recovery, some patients require a lot of support in everyday life, which could be difficult for their family to accommodate. Setting boundaries could be an obstacle for the family without knowing what expectations there might be from the patient. Carr et al. argue that patients need information on realistic expectations, in terms of health after severe critical illness, which facilitates them to adjust their expectations, thus maybe reducing the impact of disease in their lives (167).

Being able to receive emotional and social support as well as sharing experiences with and responsibility for the patient with others, often family members or close friends, alleviates the burden on family members. Positive effects of social support between family members have been described in previous research (107, 109). Wong et al. explain how family members’ support to each other during the ICU stay contributes to regaining control, but interactions with other families in the same situation could cause secondary stress reactions (109). Vandall-Walker et al. state that nurses could support the family during the ICU stay, especially when other social support was insufficient (107). Emotional social support received from family members and friends is a prerequisite for patients’ emotional balance, which is in line with previous research by Kang et al. (82). However, emotional support must sometimes be offered by others, as it could be difficult for persons to seek support. Our finding was that interaction between individuals be promoted of confirming and respectful behaviours from others.

7.4.4 Autonomy

Autonomy is a multidimensional concept, which refers to a person’s ability to make decisions and act on issues related to oneself (168). In the ICU, the patients’ autonomy could be affected due to severe illness, sedation and/or mechanical ventilation (150, 168), which makes them vulnerable and dependent on other persons’ behaviours (169). In our study, autonomy was fundamental for the patient in emotional balancing, which can be promoted by being treated like a person, not an object and to be self-determinate in actions even if it requires an effort. Kang et al. found self-efficacy to be a coping strategy to mobilise internal
resources (82). Mental and physical dependence on others could be a hindrance for recovery (110), which is in line with our findings.

7.4.5 Humour

Humour has positive effects on emotional well-being and relationships (170) as well as a health strategy to replace discomfort with positive emotions (80, 171, 172). In studies II–IV, (150, 151, 155) humour was used to alleviate burdens and as a strategy to connect with each other, which increased the sense of well-being within the family. Even during the ICU stay, humour was of importance for well-being. Although humour increases well-being, it could also be a challenge to use humour; it could be used incorrectly or at the wrong time and therefore have a negative impact on individuals (172).

7.4.6 Dispel thoughts

We found engagement in one’s own activities to dispel thoughts was a strategy used by both patients and family members to gather energy. Activities mentioned were physical training, meeting friends, engaging in hobbies and working. Chahraoui et al. found leisure activities as a coping strategy (80), but other strategies for dispelling thoughts have not been defined in previous research.

7.4.7 Experience and managing delusional memories

Delusional memories occur during the ICU stay. This is one fear that must be managed even after home coming. Our finding was that the content in delusional memories could be a long-lasting scary experience of a distorted reality, associated with discomfort, which has been confirmed in earlier studies (5, 58, 74, 155, 156, 173-175). During the interviews, patients could retell their delusional memories in great detail even if time had passed, which could confirm its impact on the person. Previous studies describe an increased risk for PTSD symptoms (57, 176), anxiety and depression in those affected with delusional memories (53, 74), but it also means discomfort and flashbacks afterwards (155). We interviewed COVID-19 patients treated in an ICU after hospital discharge and were told of the different strategies used to manage this experience. Strategies used could be both emotion-focused and problem-focused (177). In our study, strategies such as finding explanations, communication, using humour and laughing together, crying, and taking control over one’s thoughts to reduce impact of discomfort were used (155) Our findings was that delusional memories are only part of the patients’ stressful experiences associated with critical illness. We had an additional question in the interviews, namely ‘what were the patients’ experiences of being treated by professionals in protective equipment’. This question was related to previous research, which indicates that this experience could contribute to social isolation and feeling of loneliness (102, 103), as well as our own thoughts based on experiences as ICU nurses. As nurses working in ICU, we thought our appearance could scare the patients, whereas patients in our study experienced nurses’ appearance in full protective gear as a distant feeling. During their ICU stay, they learned to recognise persons through other details in their looks and
behaviours. However, the most important for the patients was nurses’ behaviour and their ability to provide good care and convey a sense of security.

7.4.8 Overwhelming adversities

Hindrances for patients to regain control could be a lack of autonomy, distancing themselves from others, lack of social support, lack of hope, not finding explanations, acting defensively and holding back emotions. Moreover, emotions of guilt and shame towards the family could have a negative impact within the family relationship (150, 155).

To be caught in ruminating, suppressing one’s feelings, lack of hope, lack of social support and remaining focused on the other individual were hindrances for family members and for them to have a balanced focus on everyone’s needs within the family. Imbalance within the family could result in exhaustion for family members and/or broken relationships (151).

7.5 METHOD DISCUSSION

7.5.1 Validity and reliability (study I)

In paper I, the study population, intensive care patients, admitted into ICU ≥96 hours, were consecutively included by the follow-up clinic at the hospital. This was a heterogenous population, where 32% were excluded/lost to follow-up. Moreover, as there was a significant difference between gender in excluded/lost to follow-up, and study population there are risks for selection bias. In our study, health-related quality of life was measured with SF-36, a generic instrument for measuring HRQoL, validity and reliability, tested for the Swedish population, which is a strength. A limitation is that we did not control for HRQoL before critical illness, therefore, we cannot estimate whether there was an improvement or deterioration from before the illness. Regardless of the cause, a statistically significant impact on HRQoL was found 12 months after ICU discharge, with an improvement over time from 3–12 months. The results of this study might not be generalisable to other ICU populations because this study population consisted of predominantly surgical patients, and the proportion of those excluded/lost to follow-up was large.

7.5.2 Fit, relevance, workability, modifiability (studies III and IV)

Rigour in CGT is established through fit, work, relevance and modifiability (132). Fit is another word for the concept of validity. All concepts in data emerged from collected data, both observations and interviews. During the analysis, memos were written, which are conceptual notes of relationships between events in the concept and between concepts and the core category. During the analysis, first and last author continuously discussed codes and concepts derived from the data, and the last author has extensive experience in CGT. Furthermore, all authors participated in discussions on the concepts. Relevance: data were captured from participants’ concerns in the area studied and were collected and coded until no new data emerged. Workability: during the analysis, our focus was to find the core
category with as much variation as possible to cover and to explain participants’ main concern with as much variation as possible. **Modifiability:** both the theories follow the data and are modifiable as reality changes.

### 7.5.3 Trustworthiness (Study III)

In study III, trustworthiness was maintained through credibility, transferability, dependability, confirmability and reflexivity (178). **Creditability** was established through rich data from a variety of participants until saturation was reached. During the analysis, three of the researchers, experienced in the qualitative method and from different professions, read all interviews and discussed themes and sub-themes continuously to ensure the truth of the findings; thereafter, all authors participated in discussions of the findings. **Transferability** was obtained by a rich description of participants’ experiences in their own context and might be transferable to another context. **Dependability and confirmability** were addressed by following a strict analysis process in six phases (135), illustrating themes and sub-themes grounded in data, and providing quotations from participants. This was done to cover relevant topics and to have a transparent description. **Reflexibility**, where reflexive notes were written during and after interviews and during the analysis to provide self-awareness of one’s own role in the research process.

### 7.5.4 Strengths and limitations

The strengths and limitation in our first study are described above. The results in our first study in this thesis were the basis for planning research questions and methods for the following three studies.

When using classic grounded theory (studies II and IV), the researcher has no predetermined research question and does not know what is relevant (Glaser, 1998). An example which illustrates its openness is: when starting the first interview of intensive care patients, the study aimed to look at patterns of behaviours used during the patient’s ICU-stay. The ICU stay was not the most important for the patients interviewed; they talked about the whole process from becoming critically ill until recovery at home without or with a few additional questions. Therefore, study II explores this process. The researcher is an intensive care nurse and, as such, had preconceptions in the research area. This must not be a hindrance in CGT; instead, it could create a specific motivation. This can be achieved by interviewing oneself before start of data collection and adding this interview to the other interviews in the analysis (132). This was performed, and during the analysis, patterns of behaviours emerged that were not recognised by the researcher before. Only concepts related to each other, and which emerge from data, are included in both theories. This choice of method gave insight into processes with both less favourable and constructive patterns of behaviours.

Studies II and IV explain patterns of behaviours in substantive areas; however, there might be a variety of behaviours in other contexts and cultures. Children ≤ 18 years were not included in our studies, and they are part of the family and might have different patterns of behaviours.
Study III came into being during the ongoing doctoral studies. At first, this aimed to be a grounded theory of healthcare professionals’ main concerns when caring for intensive care patients. During the data collection, several participants talked about their delusional memories as a very stressful and scary experience. We had common discussions in the research group and found this to be an interesting topic, so we decided to deepen our knowledge in this area. During this planning, the COVID-19 pandemic affected the world, and, in our ICU, we saw patients experiencing more hallucinations and being more terrified than usual. We therefore decided to choose this patient-group after common discussions. The choice of method was also discussed, and we decided to use a thematic analysis, as it is a flexible method well suited for our research questions. Even in this interview study, we received rich material with only a few additional questions to the pre-determined questions. During the interviews, a lot of participants were emotional when they shared their traumatic experiences; although they were offered support verbally, no one accepted the offer. Instead, they expressed the feeling of relief to be able to tell their story. Many of them even expressed an enormous gratitude for the care and treatment received, and they stated that this was an opportunity to deliver something back to healthcare.

A limitation in this study is that there might be differences in delusional memories related to anxiety, depression or PTSD, but our study was not designed to explore this.

Critical illness and its consequences are complex. To study different aspects of this complexity with different approaches, quantitative and qualitative, could result in a better insight and understanding of how consequences of critical illness and patterns of behaviours used relate to each other, which is a strength of this thesis.

8 CONCLUSIONS

To become critically ill and be cared for in an intensive care unit means being in a state of vulnerability and experiencing emotional strain in the long-term, impacting not only the patient’s health and well-being but also that of the whole family. Although patients and family members use different strategies to manage the process, this could both separate and bring them closer together. After discharge from the ICU, a long-term strenuous journey begins by processing the traumatic event and often having to adapt to new conditions. Furthermore, the patient’s return home is a critical point within the family, and strategies used could both support and have a negative impact on the family and everyone’s well-being. Strategies used to strengthen this process include: maintaining hope, regaining or preserving autonomy, finding explanations, seeking and getting social support, engaging in pleasure and relaxing activities and humour. Trust in other individuals facilitates this process.

There are previous studies that theoretically explain the process that patients and family members undergo from the time when the patient becomes critically ill until recovery/everyday life at home (81, 107-110, 152, 156, 179, 180) or during the recovery (82).
However, our research contributes to an explanation of how different patterns of behaviours are intertwined.

Intensive care patients and their families are a population in need of extended support from professionals. Both an individual and holistic view of patients’ and their families’ needs are required. For high quality intensive care and follow-up after intensive care, healthcare professionals must be aware of the whole process from when the patient becomes critically ill until recovery at home, for both patients and their families.

9 CLINICAL IMPLICATIONS

Intensive care means treatment of a critically ill patient, but it also means caring for and supporting a whole family. Due to different experiences of the same event, how one processes such an event and their needs during the event differ from each other. Intensive care is not only care in the ICU, but it is also a long-lasting process in which patterns of behaviours are influenced by each other. The findings in this thesis add knowledge about experiences and patterns of behaviours used during the whole process from the time of critical illness until recovery/everyday life at home, for patients and their families.

In intensive care, this knowledge could be used by healthcare professionals to better support the whole family during the ICU stay and to prepare them for the next transition in the process, with a change in the level of care and home coming.

Awareness of the whole process and strengthening strategies could result in a better understanding of and response to patients and their families’ needs in the general ward, which could also prepare them better for home coming.

During follow-up, this thesis could be used as a basis for interventions that are targeted for the whole family, which could make it easier for members of the family to support each other but also take care of themselves.

The results in this thesis could also be used by healthcare professionals to identify persons with an increased need for support.

Moreover, patients and their relatives could use this thesis to get an awareness of common experiences and patterns of behaviours. Awareness increases a sense of control, which could help them to process this traumatic event.
10 FUTURE RESEARCH

It can be of value to capture persons at risk, both patients and family members. There seems to be patterns of behaviours that increase the risk for a worse outcome. Perhaps personality and lack of social support from family and friends could indicate who might be at a higher risk of facing adversities. This could be a future perspective for research.

Critical illness is a traumatic experience for all involved as well as a long-lasting process. It is interesting that some individuals with major changes in their life are able to find new opportunities, and others with minor changes have difficulty to move forward and become stuck in the ruminating stage. By learning from them, we might be able to find those who are at higher risk of facing adversities. More research on persons that manage the process in a healthy way could indicate useful strategies and interventions for well-being.

The discharge from the intensive care unit to the general ward is a difficult adjustment especially for family members. There seems to be a lack of knowledge on what type of information and support patients and family members need before transition to the general ward. Additionally, there is a lack of knowledge on how healthcare professionals in the general ward could support and inform family members and patients to alleviate their burdens. Hence, more research is needed in this area.

There seems to be a lack of knowledge on patients and their families regarding realistic expectations when coming home after critical illness. By gaining information from them, interventions based on their needs could be improved.
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