

Being cared for in an Intensive Care Unit – family functioning and support

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Cover Design: Picture taken by uncle Rune Olofsson of my beloved parents Sonja and Gösta Olofsson, Söderköpings järnvägsstation, 1964.

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To my beloved family and all families in the studies!
My family is my world, it is not perfect and has its flaws and imperfection,
but I would be nothing without my family.

Människors möte
Om i ödslig skog
ångest dig betog
kunde ett flyktigt möte
vara befriande nog.

Giva om vägen besked,
därpå skiljas ifred:
sådant var främlingars möte
enligt uråldrig sed.

Byta ett ord eller två
gjorde det lätt att gå.
Alla människors möte
borde vara så.

Hjalmar Gullberg (1898–1961)

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PREFACE

When I started out as a newly examined intensive care nurse in 2011, there was a vacancy in the follow-up clinic, and I was invited to seek the position. A colleague asked me to participate in a study, having group conversations with intensive cared patients and their family members. The study with family members was published in 2015 and it made me more interested in how to help and involve the family of intensive cared patients in the follow-up clinic.

During the years of my work in the follow-up clinic, I have asked the patients and family members what they would like to have altered and what we could improve. One of the issues is that the patients and family members would like to talk to groups of people that have similar experiences of intensive care. Family members of intensive cared patients needed support even when the patients were too sick to attend the follow-up clinic. These meetings would give them the opportunity to be able to talk and listen to others and share experiences. Therefore, the research has been a product of the wishes of former patients and their families, with both an individual and systems perspective.

In 2016, I was asked to be a doctoral student and to find out more about follow-up after intensive care with family health conversations. I was uncertain of my ability at first. I asked my family to support me, and in 2017 I was enrolled as a doctoral student.

Given this opportunity to be involved in this field of research my wish was to make families more involved in the follow-up clinic. I found out that there was a lack of research on how family functioning was affected by intensive care, and this area needed to be more examined to find an intervention to improve the families' follow-up. You need to start with the small to be able to make a change.

Mona Ahlberg

ABSTRACT

When COVID-19 came as an uninvited guest into our everyday lives, nursing in intensive care was affected and thus the studies contain data from both before and during the COVID-19 pandemic.

Before the pandemic, most intensive care units, which care for patients with critical illness in a technical setting, allowed family members to visit the patient 24 hours a day. The intensive care unit is a stressful and frightening environment for both the patient and their family. They can be affected both mentally and physically, showing symptoms such as difficulty sleeping, stress and depression. The intensive cared patient often does not remember anything from the time they were cared for in the intensive care unit, and the family needs to explain and recount this unconscious time. During the pandemic, this changed, with restrictions and limited opportunities to visit the hospital and patient due to virus outbreaks. Family members received information about the patient's medical condition by phone from a physician.

The overall aim of this thesis was to explore and conceptualise the family functioning of families with a family member treated in the intensive care unit. There was also an intention to describe and evaluate how an intervention affects the family and individual family members in families where a family member received intensive care.

In these studies, qualitative, quantitative, as well as mixed methods were utilised. Participants were adult intensive cared patients from seven intensive care clinics, and their families. The results examined between families are based on the patient and family characteristics.

The results from study I show that families who have experienced COVID-19 and with a family member who was cared for in an intensive care unit, have existential thoughts.

Study II shows no major impact on family function between families, but the answers differ within the families who experienced intensive care.

In study III, concerning families experiencing intensive care and attending family health conversations, there was an awareness of family function. The conversations brought the family closer together, through improved understanding of each other.

In study IV family functioning, hope and sense of coherence were compared among the participants in two intervention groups: Family health conversations and support group conversations. Family functioning and hope were higher in the group that participated in the family health conversations and comprehensibility, meaningfulness and vitality were higher among the participants in the support group conversation.

By exploring how family function affects the individual family member and the family as a unit during critical illness and intensive care, new ways of working can be strengthened in the care of patients and their families.

SVENSK SAMMANFATTNING

När COVID - 19 kom in som en objuden gäst i vår vardag, har omvårdnad inom intensivvården påverkats, och gjort att studierna innehåller data både före och under COVID-19 pandemin.

Före pandemin erbjöd de flesta intensivvårdsavdelningar, som tar hand om patienter med kritisk sjukdom i en teknisk miljö, familjemedlemmar att besöka patienten dygnet runt. Detta är en stressig och skrämmande miljö för både patienten och dennes familj. De kan påverkas mentalt och fysiskt med bland annat symptom som sömnsvårigheter, stress och depression. Intensivvårdspatienten kommer ofta inte ihåg något från tiden de vårdats på intensivvården och familjen behöver förklara och återberätta den förlorade tiden. Under pandemin förändrades detta, med restriktioner och begränsad möjlighet att besöka sjukhuset och patienten på grund av virusutbrott. Familjemedlemmar fick information om patientens sjukdomstillstånd, per telefon av en läkare.

Det övergripande syftet med denna avhandling var att undersöka familjefunktionen hos familjer med en familjemedlem som vårdats på intensivvårdsavdelning. Det fanns också en avsikt att beskriva och utvärdera hur en intervention påverkar familjen och enskilda familjemedlemmar i familjer där en familjemedlem fick intensivvård.

I dessa studier användes kvalitativa, kvantitativa och mixad metod. Deltagarna var vuxna intensivvårdspatienter från sju intensivvårdskliniker och deras familjer. Resultaten som undersöks mellan familjer baseras på patient- och familjekaraktäristika.

Resultatet i studie I, visar att familjer som erfarit COVID - 19 sjukdom och vårdats på intensivvårdsavdelning, har existentiella funderingar.

Studie II visar ingen större påverkan på familjefunktion mellan familjerna, men svaren skiljer sig inom familjen som erfarit intensivvård.

I studie III där familjer som upplever intensivvård och deltagit i hälsostödjande familjesamtal visar en medvetenhet om familjefunktion. Samtalen för familjen närmare varandra, genom förbättrad förståelse av varandra.

I studie IV jämfördes familjefunktion, hopp om framtiden och känsla av sammanhang bland deltagarna i två interventionsgrupper: Hälsostödjande

familjesamtal och stödgruppssamtal. Familjefunktion och hopp om framtiden var högre i gruppen som deltog i hälsostödjande familjesamtalen och begriplighet, meningsfullhet och vitalitet var högre bland deltagarna i stödgruppssamtalet.

Genom att utforska hur familjens funktion påverkar, den enskilde familjemedlemmen och familjen som enhet, av kritisk sjukdom och intensivvård kan nya arbetssätt stärkas i omvårdnaden av patienter och deras anhöriga.

LIST OF PAPERS

- I. Ahlberg, M., Berterö, C., & Ågren, S. (202X). Family functioning of families experiencing intensive care and the specific impact of the COVID - 19 -19 pandemic – a grounded theory study.
- II. Ahlberg, M., Persson, C., Berterö, C., & Ågren, S. (202X). Exploring family functioning and hardiness in families' experiencing adult intensive care – A cross-sectional study.
- III. Ahlberg, M., Hollman Frisman, G., Berterö, C., & Ågren, S. (2020). Family Health Conversations create awareness of family functioning. *Nursing in critical care*, 25(2), 102-108. [doi:10.1111/nicc.12454](https://doi.org/10.1111/nicc.12454)
- IV. Ahlberg, M., Persson, C., Berterö, C., & Ågren, S. (2021). Family health conversations versus support group conversations when a family member has been critically ill : A mixed methods study. *Families, Systems, & Health*, 39(2), 293-305. [doi:10.1037/fsh0000607](https://doi.org/10.1037/fsh0000607)

ABBREVIATIONS

BP	Body Pain
COVID – 19	COronaVirus Disease
FAD	Family Assessment Device
FamHC	Family Health Conversations
FCOS-S	Family Sense of Coherence Scale
FHI	Family Hardiness Index
GFS	General Functioning Subscale
GH	General Health
HHI	Herth Hope Index
ICU	Intensive Care Unit
MH	Mental Health
PF	Physical Function
RAND - 36	Research ANd Development
RF	Role Function
SF	Social Function
SF - 36	Medical outcome Short-Form health survey
SGC	Support Group Conversations
SPSS	Statistical Package for the Social Sciences
VT	ViTality

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INTRODUCTION

An intensive care unit (ICU) can be a stressful environment for both the patient and family, full of technical equipment for treatment and/or replace/support the function of vital organs (Martmaan-Moe et al., 2021; SIR, 2022; Ågård & Harder, 2007). The environment as well as the uncertain future for the patient affects the whole family's physical, psychological, and social functioning, which has been shown in studies both before the COVID-19 pandemic (Ågren et al., 2019; Alfheim et al., 2019; Smithburger et al., 2019) and during it (van Veenendaal et al., 2021).

The COVID-19 pandemic came to our knowledge in 2019 as an active respiratory infection, which is typically mild and may also lead to acute respiratory distress syndrome which can be lethal. The uncertainty about COVID-19, and that family members are not allowed to visit the patient, made family members worried (Kennedy et al., 2021).

Because all members of the family affect each other's lives and health, the family as a unit has importance and needs to be addressed. The idea of these studies was to see if family functioning is affected by critical illness, and to compare and contrast two interventions.

A nurse-led intervention, putting the family in focus, showed how the family use their experiences as a resource to identify and solve issues that affect family functioning (Persson & Benzein, 2014). There is international consensus concerning the need for ICU follow-up, including informing the families for increased quality of health, for both the patient and their family, and family functioning (Jonasdottir et al., 2018; Rosa et al., 2019). But it has been hard to find a suitable intervention that shows significant effects of mental health interventions (Cherak et al., 2021). A systematic review reported positive intervention effects, to cover patient's basic needs in an intensive care context. The nurses' communication and psychosocial care were considered essential components of nursing interventions in the ICU (Larsen et al., 2022).

Knowledge of family functioning can be used to implement an intervention where the family of former ICU patients can be offered follow-up. The critically ill family member and the rest of the family might have diverse needs

for support. It is important to know about this and to address interventions to the family members in need of support.

BACKGROUND

There are international research articles published reporting the importance of follow-up for patients and their family after an ICU stay. Families have a significant role in the rehabilitation, mental and physical recovery for the former ICU patient. As family members affect each other, there is a need for more research so health professionals can help support the whole family. The priority in the ICU is the patient and because of staff workload, the family members may be set aside. Health professionals need to find a way of involving the family of the patient in the care and decisions, to give them support so they can help the patient.

Intensive care

ICU patients affected by critical illness, complications or severe trauma are cared for, and the level of care means close monitoring and advanced treatment. The aims of the treatment are preventing, further illness and injury, replacing or supporting the function of vital organs when these are insufficient to meet the patient's needs. Specialised health professionals work in teams to provide constant close monitoring and care for the ICU patient. Intensive care is high-tech, expensive and has an inherently high mortality rate because it cares for the most critically ill patients in healthcare (SIR, 2022).

The patients are connected to equipment with wires and tubes so it can be both unpleasant and intimidating for the patient as well for the family to visit the ICU and see the patient (SIR, 2022). The care is stressful for the patient (Maartmann-Moe et al., 2021) and there are repeated investigations/examinations made, with X-rays, and vital examinations by health professionals and nursing care. Health care professionals are always present next to the ICU patient. If there is a need for more specialist care at a higher level the patient is transferred to another hospital (SIR, 2022).

The ICU care mainly focuses on the seriously ill patient, on vital values and technical equipment. The ICU environment is impersonal and creates stress, as the patient's state of health is uncertain and the patient can suffer permanent injury and even die.

The ICU team need to take many quick decisions to prevent illness and death, and family members do not always follow and understand all information they are given. This creates an intense sense of death. Family members find it difficult to actively participate in the work around the patient, as the environment is so technical (Ervin et al., 2018). Visiting hours at the ICU are flexible (Jakab et al., 2019; SIR, 2022) at least they were before the COVID-19 pandemic. Due to all the specialised care and investigations/examinations, the family are often waiting in the waiting room for permission to visit the ICU patient. The waiting is suffering, and this is stressful for the family members (Björk et al., 2019).

Intensive cared patients

An ICU patient requires highly technological care. Planning of care is required to facilitate the work so that care can be directed towards the goals of treatment. The decisions on the care can change suddenly and various specialists with different medical specialties often make decisions about life-saving care (SIR, 2022).

The ICU patients are often critically ill, having memory loss. The first time in the ICU can be very scary: being critically ill, not being able to breathe, having severe pain etc. These memories are recalled when waking up and can become nightmares, even delirium (Rose et al., 2019; Boehm et al., 2021). These feelings are hard to communicate vocally during the ICU stay due to the patient's need for ventilation assistance. The vocal cords are blocked because of the tracheal respiratory tube.

Delirium appears with different degrees of irritability, anger, fear, anxiety, and perplexity and can be characterised as anxiety, depression, acute and post-traumatic stress (Rose et al., 2019). The delirium experience has emotional, cognitive, physical, relational, spiritual, and situational dimensions, and there are feelings and memories that often stay in the memory for a long time (Boehm et al., 2021). ICU patients report mental effects such as post-traumatic stress disorder (PTSD) symptoms. These occur in as many as one in five patients and are associated with worse health-related quality of life, 12 months post-ICU (Parker et al., 2015). ICU patients have a higher risk of developing chronic conditions (van Beusekom et al., 2019). Impaired quality of life is also shown for former ICU patients one year after care, as well as higher costs associated with an increased number of outpatient consultations (Kosilek et al., 2019).

The Swedish ICU patients are registered in the Swedish Intensive Care Registry (SIR) using a questionnaire, RAND-36, filled in by former ICU patients on three occasions after intensive care, at two, six and 12 months. Based on the World Health Organization (WHO) definition of health, the questionnaire provides a good picture of health-related quality of life in terms of physical, mental, and social ill health. The survey is reported to the SIR and compiled (SIR, 2022).

In 2019, when 83 out of 84 ICU clinics reported in the SIR there were \approx 40 000 ICU patients; 15% of these had a stay of 96h or more (some ICU registered patients with a shorter stay) and 580 out of the reported ICU patients were followed up three times. Out of these independently diagnosed patients, 36% needed more help and support in everyday life, two months after intensive care, and this need for help decreased over time. Follow-up of the patients' need for help and support in daily life was done by the patient, valuing their need before intensive care, and comparing it with after intensive care. A “typical” Swedish ICU patient had a mean age of almost 59 in 2019, and more than 57 % were men (SIR, 2022).

Family and family members of critical intensive cared patients

The frightening environment, the technology and seeing their family member fighting for their life is terrifying (Ågård & Harder, 2007). Standing at the bedside and seeing the patient with delirium, not being able to understand and comfort is a source of emotional, cognitive, physical, relational, spiritual, and situational distress for the family members (Boehm et al., 2021).

Family members of critically ill ICU patients showed a prevalence of anxiety between 15% and 24%, depression between almost 5% and more than 36% and PTSD between 35% and 57% six months after ICU discharge (van Beusekom et al., 2015). The family member experiencing the ICU might also develop lack of hope, a low sense of coherence and decreased health-related quality of life and the family might develop unhealthy family functioning and have a demanding time managing challenges on a systems level (Ågren et al., 2019; Alfheim et al., 2019; Smithburger et al., 2017; Zhang, 2018).

Family members of ICU patients are frightened and wish only to be part of the patient care, feel useful and get all the information about the outcome

for the patient (Jakab et al., 2019). Because the ICU patients often are not able to communicate during their care in ICU, the family members need to be the voice of the patients. The family are needed to inform the healthcare professionals about the patient's social, mental, and physical history, so the health professionals can make a complete, more patient safe care plan (Engström & Söderberg, 2007; Jakab et al., 2019).

The family are the main providers of care in the home, helping with rehabilitation and everyday life. They are the ones who talk about the care in the ICU as the patient does not remember. This makes it important to include them in the care with information and support. The importance of the family for the recovery of ICU patients is well documented (Alsharari, 2019; Davidson, 2009; Grant et al., 2020; Hupcey, 2001; Kiwanuka et al., 2019; Olding et al., 2016).

ICU follow-up

Different models of follow-up were identified in an integrative review in 2017, including several types of ICU-based follow-up clinics. The most reviewed are the ones in the United Kingdom where ICU follow-up was first implemented. Former ICU patients and their family appear to benefit from returning together to the ICU or participating in follow-up programmes. But there is variation in how these follow-ups should be performed (Svenningsen et al., 2017). In a systematic review and meta-analysis of effects of post-ICU follow-up on subject outcomes, 26 studies were included. The results show that ICU follow-up is associated with improved subject outcomes, such as depression symptoms, mental health-related quality of life and PTSD symptoms (Rosa et al., 2019).

Follow-up after ICU care started in Sweden in 2000. By the year 2010, 30–40% of the Swedish ICUs offered structured ICU follow-up, either with a nurse or a multidisciplinary team. Other units offer non-structured follow-up, often in conjunction with diary handover. The primary aim of follow-up was to aid rehabilitation, helping the patient come to terms with ICU experiences, fill in memory gaps, provide information and advice and identify patients needing more assistance. The nurse-led follow-up was supplied to former ICU patients that received care for a longer time. At first the nurse visited the patient one week after the ICU transfer, gave written information on the ICU and recovery, and had a dialogue with the patient on their experience of the ICU. Two to three months post-ICU care there was

a follow-up visit that had a different structure. The basic of the ICU follow-up was to hand over the ICU photo diary, written during the ICU care for the patients, by the ICU personnel and/or the family of the patient (Egerod et al., 2013). A photo diary is one way of giving the patient information regarding the time in the ICU. The photo diary has the goal to give information of the memory loss to patients and their family, through chronological, logical, and fact-based information (Nydahl, 2020). At the follow-up visit the nurse made a chart review and listened to the patient's narrative of the experience and memories before, during and after the ICU care. Patients are screened for well-being, memory, and discomfort in ICU, using different questionnaires. The Swedish Intensive Care Register recommends using SF-36 at three, six and 12 months. Some follow-up programmes provide a visit at the ICU with a focus on equipment, and others allow visiting the staff (Egerod et al., 2013).

In Sweden today, in 2022, there are still a variety of follow-ups at different clinics. The main purpose of follow-up clinics is still to give the ICU patient information, and to follow-up on the patient's experiences and well-being. A systematic follow-up, after an intensive care-demanding illness, is an important task for intensive care staff, and the SIR requests that it be performed. The follow-up could be via meetings, questionnaires, or photo diaries. The SIR informs that one way of following up is as follows: the former ICU patient is called to a meeting in a room close to the ICU to be informed and discuss their stay at the ICU with health care professionals from the ICU. The meeting is held approximately two months after discharge and the patient is recommended to ask a family member to join in and to bring the ICU photo diary. If the patient wishes, the follow-up meeting can be repeated at six and 12 months after the ICU stay. These follow-ups may occur in various forms and in some ICUs they do not occur at all (SIR, 2022).

There is diversity at ICUs and between countries regarding how follow-ups are performed and whether family members are invited (Jónasdóttir et al., 2016; Lasiter et al., 2016; Peskett & Gibb, 2009; SIR, 2022). There seems to be consensus on the need for ICU follow-up internationally, even though there is no consensus on the best model (Jonasdottir et al., 2018; Rosa et al., 2019; Schofield-Robinson et al., 2018; Svenningsen et al., 2017).

The family's opportunity to participate in the follow-up clinic after the ICU is still not made available everywhere. Various interventions for follow-up are reported to improve this, both in family-centred and family related

nursing. The intervention Family Health Conversations (FamHC) has been shown to put the family in focus; the family use their experiences as a resource to identify and solve issues that affect family functioning (Ågren et al., 2019), and this could be a way to have the family as a unit benefit from ICU follow-up. Sometimes the former ICU patients need more support and follow-up, and follow-ups with just former ICU patients gathering in a conversation group show that ICU patients benefit individually. Group conversations for former ICU patients gave strength to the participants by allowing them to share experiences and understand the process of survival after critical illness, and provided insight into other patients' experiences (Bäckman et al., 2018). When the former ICU patients need hospital care and rehabilitation for a longer time, they are unable to participate in an intervention. The family might still have need for a follow-up, discussing their feelings with persons having the same issues. An intervention to follow-up with just family members gathering for a group conversation, the family members gained confirmation and togetherness. In the group conversations, they shared experiences of being a family member with a next of kin being cared for in the ICU with other family members from various families experiencing ICU (Ahlberg et al., 2015).

COVID-19

At the end of 2019, a new coronavirus was identified which could infect humans. COVID-19 is the official name for the disease and stands for coronavirus disease 2019. The first confirmed case in Sweden was in January 2020 and by March there were confirmed cases in all regions (The Public Health Agency of Sweden, 2022).

A total of more than 4,000 COVID-19 patients were cared for in ICUs in 2020 in Sweden. The average age was 61 years and 71 % were men (The Public Health Agency of Sweden, 2022).

In 2021, fewer than 4,000 intensive care patients were reported with confirmed COVID-19, in Sweden. The average age was 60 years and 68 % were men (The Public Health Agency of Sweden, 2022).

The care for the COVID-19 infected patients was comprehensive, with a high technological and medical scope and a great need for health professionals. The regions and hospitals in Sweden all assisted with the care for these patients. Because of increased healthcare liability related to more seriously ill patients than normal, the patients were more likely to be transported to a different hospital for care. There were health professionals from

different clinics involved with the care for the COVID-19 patients. In the ICU, mostly personnel from the operation department were relocated to support (Bergman et al., 2021).

At one year after ICU treatment for COVID-19, physical symptoms were reported by more than 74% of patients, mental symptoms by 26%, and cognitive symptoms by 16% (Heesakkers et al., 2022).

Follow-up interviews of former COVID-19 patients cared for at the ICU showed the experience of being critically ill due to the virus as hard and stressful. The patients described a frightening unreality; they felt fear and loneliness (Engström et al., 2022). The mortality of COVID-19 ICU patients was reported in news media around the world to be higher than other ICU patients (Armstrong et al., 2020). The high risk of getting infected and the fear of being isolated, might have caused anxiety for both the patient and the family.

A higher risk at developing PTSD was also seen in family members of COVID-19 ICU patients (Azoulay et al., 2022). Three months after the patient's admission with COVID-19 to the ICU the family members with higher scores of PTSD described feelings of distrust and concern about the need to take clinicians' information at face value without being present to see for themselves how the patient was feeling and if the care was successful (Amass et al., 2022).

Family functioning

There are several types of definitions of family functioning. The definition used in my studies, which is suitable for measuring family functioning, is the family's ability to cope with the situation. The definition is also used in the questionnaire used in the study, the General Functioning Scale (Epstein et al., 1983).

The families' capability in problem-solving, how they communicate with each other and their experience of connection and control, defines family functioning. Family functioning can include both "good and bad", and the adaptation to change can either be good if they can maintain honest communication, or poor, for example, if the family's communication is lacking (Epstein et al., 1978).

Healthy family functioning is defined as a process of dynamically engaging with one another over time. If this is not the case, poor family functioning

is manifested in families with high levels of conflict, disorganisation, and poor affective and behavioural control (Epstein et al., 1978; Newman, 1999). The family members need to feel connected as a family. McGoldrick et al. (2013) state that the individual development of family functioning only takes place in the context of significant emotional relationships. The family's cultural and historical context, past and present, as well as their experiences, in this case the ICU, need to be understood and/or changed to be able to improve their family functioning (McGoldrick et al., 2013). By increasing the awareness of family functioning concerning the factors that have a supportive and encouraging function on family members, individually and as a family unit, families can contribute to and create their own family health (Wright & Leahey, 2013).

Family functioning in the context of illness defines how family members communicate with each other, how they fulfil family roles, accept family routines and procedures, cope with and adjust to family stress, and relate to each other (Zhang, 2018).

Family hardiness

Family hardiness, or the family's resilience, is described as the family's ability to change their patterns to recover from stressful events. How the family cope with this situation and obtains capacity to develop strengths to protect the family as a unit from major disruption. The individual perceptions of family stress resistance and adaptation resources affecting the family members' ability to work together and their confidence in handling problems. During periods of illness, families may develop strengths and capabilities or not and it is due to the family's ability to make this adaption related to the general atmosphere of interactions within the family (McCubbin et al., 1996).

Family hardiness is also a concept that has been used in one of the studies and are measured with the questionnaire family hardiness index (McCubbin et al., 1996).

THEORETICAL FRAMEWORK

Family systems nursing

This thesis focuses on family systems nursing which includes how the family and the nurse experience, perceive, and manage the nursing relationship.

Family systems nursing has salutogenes as one important foundation of the model (Benzein et al., 2008). The salutogenes perspective focuses more on what factors cause and perpetuate health, than on what causes disease (Antonovsky et al., 2005).

The theoretical basis is also system theory, constructivism, cybernetics, communication theory and theory of change (Wright & Bell, 2009; Wright & Leahey, 2013). A system is affected by all parts and the whole is greater than the parts (Bateson, 1998). Illness and ill health in one family member affect the other family members individually but also the whole family and vice versa (Benzein et al., 2008). A basic view of communication is that different people can differently perceive the same reality, i.e., if two people describe a situation in diverse ways, then both people's descriptions are equally true (Maturana (1988). The theory of change focuses on change from substance to form (Bateson, 1998), and how individuals interact with one another. All nonverbal communication is also meaningful. Being available for conversations is the foundation of communication, being present, engaged and listening without judgement (Watzlawick et al., 1996). Change can be in first and second order. First order of change is doing something that always has been done in a certain way. The theory of change is used in this thesis with the second order focusing on interaction, how the individual family members change and the way they look at the problem. This process of change affects the whole family, and the change can come stealthily or happen hastily, like a sudden awakening. The problem is tackled from a different perspective and solved in a new way (Watzlawick et al., 1996).

The model of the interventions used in the thesis emphasises mainly three areas. That is; human conceptions of reality, reflection as a path to a change of beliefs, and the relationship between family and nurse (Benzein et al., 2008).

Family systems nursing can be described in two ways: family-centred and family-related nursing.

Within family-centred nursing, the patient and other family members are seen as a whole, in other words the individual family members and the family are focused on at the same time. A systemic approach, wherein all members of the patient's family are building blocks who interact with one another, as a unit. Considered together, the whole forms a slightly larger entity than when each building block is considered separately. Interactions between the patient and their family members provide additional security or dysfunction if there is friction, for example in a disease context (Benzein et al., 2008; Wright & Leahey, 2013).

Family related nursing is when the focus is on the patient or family member, and the others form the context (Benzein et al., 2008; Wright & Leahey, 2013).

To focus on the family in family system nursing makes it possible to identify the strengths and resources of the family and individual family member to act on challenges and support the recovery process (Bell, 2013). Health professionals have a key role in making the family a part of planning and delivering nursing care (Saveman, 2010). The family as a unit is engaged with partnership, dignity and respect, information sharing, participation, and collaboration. The family are viewed as integral members of the health care team and the family is conceptualised as the unit of care (Bell, 2013).

Bell, 2013 believes the family systems nursing must be the way health professionals demonstrate confidence, knowledge and skills. The way health professionals communicate with the family is of importance, as is the way the staff talk to families, and how they welcome, include, and acknowledge families as partners. She goes as far as saying that there would be fewer errors made by health professionals and greater satisfaction with care reported by families if there was family systems nursing (Bell, 2013). Nurses educated in family systems nursing interventions can explore how illness has impacted the family's lives and relationships. They focus on what happens in the context of a nurse–family relationship enacted through family conversations (Bell, 2013; Wright & Leahey, 2013).

The family has importance for how critical illness is experienced/managed, by the individual patient and the family members. In the context of intensive care, family systems nursing can be lifesaving. The ICU patient often does not communicate due to illness or sedation, and their family are able to provide invaluable information to the health care professionals (Engström & Söderberg, 2007). During the COVID pandemic, it was difficult for

the family to visit the ICU and patient due to restrictions and social distancing. Finding alternative solutions to maintain family systems nursing is important. Hart et al., believe that it is more, not less, important during a pandemic to support family-centred inpatient care. The study shows that although the limited time healthcare professionals had, they made new strategies during the pandemic maintaining family-centred care. By internet-based solutions the routine and structured communication can facilitate family systems nursing (Hart et al., 2020).

Family

The family is important in family systems nursing. In order to provide the conditions for the family to be involved in their family members' care, the health care system should conduct more family-focused nursing. This means focusing on the family's importance for the family member's experience of ill health and illness, making room for the family to communicate and listen to each other and the health professionals. So, the family adapts to the new situation as well as the new mental and physical issues that might come (Wright & Leahey, 2013).

Family is a concept that has changed over time. In a hospital situation, one way of seeing it is that the family consists of those who the patient considers belong to the family (Whall, 1986). Family members are not limited by criteria of marriage, blood, or adoption. The family is more likely to be those who are strongly bound by emotional ties. A passion and sense of belonging wanting to be involved in each other (Wright & Bell, 2009). In this definition of family, you remain open to an individual choice of family (Wright & Leahey, 2013). This opens the possibility for different structures of family and means that traditional family members can even be excluded because of lack of trust, or disagreements related to earlier conflicts (Benzein et al., 2017). It is important for health professionals to help the family to be able to adapt or to support the family's adaptation, both during and after the ICU care.

The ICU patients participating in my studies chose those family members significant to their experience of health and illness.

RATIONALE

Since the ICU is a stressful environment for both the patient and their family, families need more information and support. Family members need to be acknowledged and confirmed in their knowledge and key role to support and comfort the ICU patient.

The family constitutes a system/unit, so the family members influence each other while the family as a unit also affects the individual family members. The family as a system/ unit are the main health provider in the post care after critical illness and ICU care. There are challenges for the health professionals to care for the family being cared for in the ICU, both individually and as a system /unit.

Family functioning is about how families as a system/unit communicate, fulfil family roles, and accept new family routines, and procedures. The way a family cope with and adjust to family stress and relate to each other, is family functioning.

Therefore, studies identifying, describing, and conceptualising as well as exploring family functioning in families experiencing ICU care are conducted in this thesis.

AIMS

The overall aim of this thesis was to explore and conceptualise the family functioning of families with a family member treated in the intensive care unit. There was also an intention to describe and evaluate how an intervention affects the family and individual family members in families where a family member received intensive care.

The specific aims of the studies are as follows:

Study I: The aim of this study was to identify, describe and conceptualise the family functioning of families where a formerly critically ill family member had stayed at the ICU, during the COVID–19 pandemic.

Study II: The aim of this study was to explore family functioning and family hardiness in families of intensive care patients.

Study III: The aim of this study was to identify which components of family function are affected when families participate in Family Health Conversations.

Study IV: The aim of this study was to compare and contrast the responses from two different types of follow-up interventions for families of critically ill persons, focusing on individual hopes, health-related quality of life, family functioning and ability to cope with challenges.

METHOD

Designs

Multiple designs have been used to capture the ICU family members' and families' experience of ICU care and follow-up interventions, both at an individual level and a group level. Quantitative methods (II) and qualitative methods (I, III) as well as mixed methods (IV) have been employed. The different aims of the studies guided the choice of design and method (Table 1) (Lincoln & Guba, 1985; Polit & Beck, 2006).

Family system nursing is applied in all my studies. Families are included in the sample for all studies and my choices of data collection and analysis methods are well adapted to process data individually and for family systems / units.

Table 1. An overview of the designs, methods, participants, and analysis in the four studies.

Study	Designs/ Methods	Participants and Sample size	Data Collection	Analysis
I	Grounded theory	A strategic sample of adult ICU cared person and their family at first and then theoretical sampling. 8 families, 20 persons	Family interviews – Data collected and analysed, through constant comparative. Analysis to generate categories and properties. When data saturation was achieved, a deeper and systematic analysis of the data was performed	Constant comparative analyses
II	Explorative cross-sectional study using descriptive quantitative design	A strategic sample of adult ICU cared patients and their family members, 145 participants, 60 families (60 patients and 85 family members)	Two questionnaires – the General Functioning Scale; GFS and Family Hardiness Indexes; FHI registered individual	Descriptive and analytic statistical methods
III	Secondary analysis using inductive qualitative design	A strategic sample of adult ICU cared patients and their families 7 families, 17 persons attended the intervention FamHC	Follow up family interviews – with open-ended questions, carried out on two occasions with the same participants	Narrative research analysis
IV	An interventional, mixed method study	A strategic sample of adult ICU cared patients and families in Family Health Conversations (FamHC), 17 persons Family members from various families (no ICU patients) in Support Group Conversations (SGC), 21 persons	Four questionnaires – *The General Functioning Scale (GFS), *Family Sense of Coherence (FSOC-S), *Herth Hope Index (HHI), *The Medical Outcome Short-Form health survey (SF-36) or Research AND Development (RAND-36)/ registered individual from all participants 17/21. Follow up group interviews – 7 family interviews in FamHC and 18 individual interviews, in SGC	Mixed methods. Combining narrative research analysis and statistics analysis

Interventions

I used the interventions *Family Health Conversations* (FamHC) and *Support Group Conversations* (SGC) in my studies. They are theoretically built on the Calgary Family Assessment and Intervention Models (Wright & Leahey, 2013) and particularly the Illness Beliefs Model (Wright & Bell, 2009). Wright and Leahey emphasise that each family is unique, and the intervention must be adjusted to fit every family (Wright & Leahey, 2013). FamHC is a family systems nursing intervention (Östlund et al., 2015). Family responses to family systems nursing interventions show improved understanding, capability, and enhanced coping. Family members care more about each other and the family, and there is improved individual and

family emotional well-being. Interventions with family system nursing improve the interactions within and outside the family, and the participants gain healthier individual behaviour (Östlund & Persson, 2014).

Family health conversations

Theoretically, FamHC rest on the so-called Calgary models, adapted to Swedish conditions (Benzein et al., 2008), which are based on a theoretical basis of constructivism, cybernetics and systems-, communication- and change theory (Wright & Leahey, 2013).

This theoretical basis is consistent with the definition of family functioning as a complex phenomenon that identifies families' problem areas by focusing on the entire system rather than on the individuals (Benzein et al., 2008).

The model has an underlying theory and definition of family systems nursing based on non-hierarchical relationships between the family and the professionals. The focus of the conversations is on the families' resources and on acknowledgement of each family member's experiences. Every family member is invited to tell their story and to listen to the other family members' stories (Benzein et al., 2008).

In order to achieve the purpose of FamHC, the nurse actively invites the family to take part in conversations, and strategically identifies, confirms and reinforces facilitating performances by asking circular and 'appropriately unusual' questions. The nurses ask the reflective questions to invite alternative ways of thinking about the family's situation (Benzein et al., 2008). The nurses' approach (based on the theoretical starting points) and the conversation structure, possibly induce the families and the individual family members to see the matter from a different viewpoint. By using four types of questions, we can move forward in the conversations. Strategic issues suggest options for changing the situation. Circular questions encourage the family to think for themselves, as participants in a dynamic pattern of human interactions. Reflective questions are slightly different questions that make the family member look at the situation in a new light. The nurses also used linear, straightforward questions about tasks and causes. These are used in a flow so that the conversation becomes challenging and non-confrontational. During the talks, both an internal and an external dialogue are ongoing. Parts of the internal dialogue can be communicated to the others in the conversations if the persons themselves decide to share.

The inner dialogue that the persons have is a prerequisite for the reflection to have the space it requires; therefore, it is important that the conversation leaders put in conscious pauses that stimulate family members to reflect so that they can have room to formulate new thoughts and beliefs (Andersen, 2011). In the process of further minimising the family's suffering, nurses confirm the healthy change to strengthen facilitating beliefs. A summary of and reflection of the process of change within the family, as the participating nurses perceived and interpreted the change, are presented to the family after each conversation (Benzein et al., 2008; Persson & Benzein, 2014).

Nurses take a university course on FamHC, with learning outcomes focused on family systems nursing theory and the development of conversation skills for planning and conducting the interventions. Two nurses conduct the intervention. One nurse takes the primary responsibility for the conversation while the other acts as a co-participator (Benzein et al., 2008; Östlund et al., 2015).

The structure of the FamHC has been evaluated in families living with chronic illness (Benzein et al., 2015). There is a structure when conducting the intervention, based on theoretical assumptions from 12 core components, identified as a frame for the conversation series, by Östlund et al., 2015:

- Jointly reflecting with the family on expectations of the conversation series.
- Exploring the family structure.
- Ensuring all family members are given space within the conversations and have the opportunity to narrate their experiences.
- Jointly prioritising which problem(s) most need to be discussed.
- Exploring significant parts of the family narratives.
- Using reflective questions.
- Using appropriately unusual questions and challenging family beliefs.
- Giving commendations and acknowledging suffering.
- Inviting family members to reflect on each other's narratives.
- Offering nurses' reflections.
- Asking what happened since the last conversation.
- Closing the conversation series (Östlund et al., 2015).

In summary, the FamHC intervention used in study III and IV, took the form of a series of three one-hour conversations held at two- to three-week intervals. During the first conversation, all family members were requested to tell their stories, to listen to each other's stories and to begin identifying problems. The second conversation was intended to focus on and explore the problems identified in the first conversation. The third conversation focused more on coping strategies and on the future. A few weeks after the last conversation, the family received a 'closing letter' as an additional way of concluding the conversation series.

The FamHC intervention started two months after ICU care. There were two to four family members in each group, and they did not all participate in all sessions (Figure 1).

Support group conversations

The SGC intervention was adapted to contain family members from various families and not the family member being cared for at the ICU. The purpose of the SGC was for the family members to get together and talk, and to hear about what other family members felt and experienced about having a critically ill family member staying at the ICU. The same 12 core components were used as a structure for the conversations (Östlund et al., 2015).

This intervention had a single one and a half to two-hour session, or in one case two sessions, and no closing letter. The conversation starting with all family members telling their stories, to listen to each other's stories and to begin identifying and explore the problems, and later to focus more on coping strategies and on the future. In the groups that had more than one conversation the second meeting focused on coping strategies and the future.

The SGC intervention started two months after ICU care. There were one to three family members from two to three various families participating in one session, and one group with three family members from two different families had two sessions, two weeks after the first conversation (Figure 1).

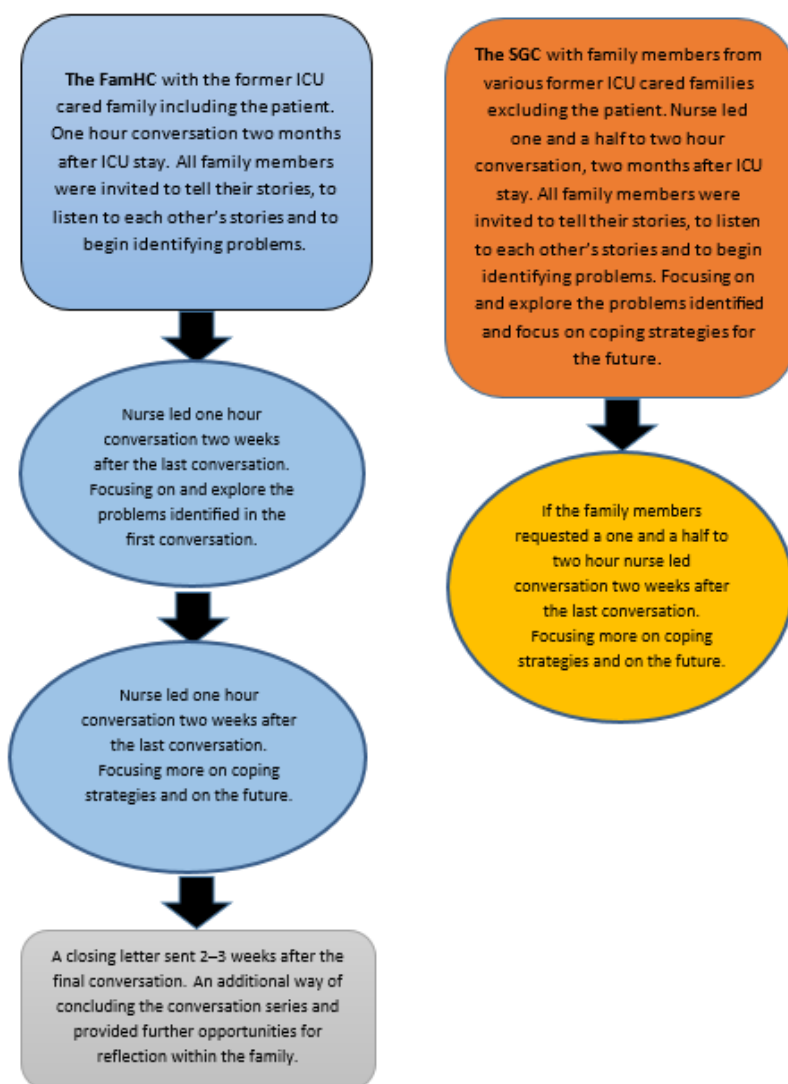


Figure 1. A flowchart showing the two interventions FamHC and SGC.

Settings

The settings were different general ICUs in different cities in Sweden. In all seven different clinics in the southeast region, three regional and four university hospitals, data collection took place. The ICUs care for patients of any age, who have had major or specialised surgery, respiratory failure, major trauma, sepsis, or post cardiac arrest.

Study I included former ICU patients and their family from one regional hospital and two university hospitals.

In study II, families from two regional hospitals and two university hospitals participated.

The participants from study III came from one university and one regional hospital.

In study IV, three hospitals were involved. In the FamHC intervention one regional -, and one university hospital and the participants in the SGC intervention had experience of another general ICU in a regional hospital.

Participants and procedures

There were in total 210 participants in this project: 75 former ICU patients and 135 family members. The participants were recruited in collaboration with ICU administrators.

The adult former ICU patients decided which adult family members should be involved in the study and gave their consent for whom to contact.

Study I

The participants were consecutively recruited, followed by theoretical sampling in the selection procedure. The inclusion criteria were patients cared for in ICUs for ≥ 24 hours and being diagnosed with COVID-19 and their family. I sent potential participants information on the study and a request to telephone or email me if interested in participation.

Eight families were included in the study (eight patients and 12 family members) (Table 2). One patient did not need any respirator care, the others three to 43 days requiring respiratory care. The patients had one to three family members attending the follow up interview. Most family members were living in the same household. Due to the pandemic COVID-19 restrictions concerning social distancing some interviews were conducted in person and some online.

Data was collected during June 2021- December 2021.

Table 2. Characteristics of the participating intensive cared patients

	patients age	patients gender	days in ICU
1	34	man	2
2	68	woman	6
3	75	woman	52
4	51	man	6
5	50	man	11
6	54	woman	13
7	64	woman	32
8	76	man	29

Study II

Former patients been cared for at ICUs for ≥ 96 hours and discharged from the ICU one to two months before the request to participate was sent out. Sampling was consecutive, and 390 patients fulfilling the inclusion criteria received a request to participate with an invitation by letter from me. There were no exclusion criteria, but the participants had to be able to understand and write in Swedish. After the former patient had decided which family members should be invited for participation, I sent the questionnaires.

In total, data from 60 families (60 patients and 85 family members) was received (Table 3).

Recruitment was ongoing between December 2017 and June 2019.

Table 3. Sample characteristics of the former 60 ICU cared patients and 85 family members (n=145).

	ICU cared patients	Family members
Age, years; mean \pm SD	64 \pm 14	55 \pm 17
Gender; female, N (%)	25 (42)	61 (72)
Days in the ICU; mean \pm SD	9/13 \pm 11	
Relation; N (%)		
Spouse/partner		47 (55)
child		22 (26)
sibling		9 (11)
friend		7 (8)

Study III

In this study, data was used which had already been collected by the research team. The selection criteria were former patients cared for at ICUs

for >72 hours. Purposeful sampling was used. Eight former ICU patients and their families participated in the FamHC intervention.

Data from 13 interviews (seven families; overall, 17 participants) was collected with qualitative follow-up family interviews, three and 12 months after they had participated in the FamHC intervention. The participants' mean age was 60 ± 19 years. The former critically ill patients had a mean stay in the ICU of 7.3 days.

Data collection between the years 2013 to 2016.

Study IV

In this study, participants involved in one of two interventions were included. A total of 38 family members took part in the interventions (Table 4). A purposeful sample was collected, from families that had a member who was critically ill and who had received ICU care.

Data collection took place during 2013-2016 with family follow-up interviews for the FamHC.

The data collection for the SGC was made during 2017-2019, with individual follow-up interviews.

The data collection for the two interventions was the same: first baseline quantitative data was collected before the interventions and then one follow-up interview was conducted and quantitative data obtained, three months after the end of the interventions.

Table 4. Characteristics of family members in the FamHC (patients excluded) and family members in the SGC.

	FamHC (family members – patient, n=10)	SGC family members, n=21)
Age, years (mean \pm SD)	53 \pm 18	59 \pm 14
Female gender, n (%)	7 (78)	12 (57)
Number of groups	7	7
Stay in the ICU for the patient in days (median/mean \pm SD)	8/7 \pm 4	13/15 \pm 18
Numbers of families participating	7	13

Data collection

Demographic data (studies I-IV)

Background data were collected using a self-administered questionnaire in studies II, III and IV asking for the sex, age, employment. The background data was obtained in person in study I, during the interviews. The ICU administrators at the different clinics informed me about the duration of the patients' stay in the ICU.

It was quite hard to recruit families in the studies. Clinics were interested in the interventions but there were limited possibilities to involve the personnel, due to lack of time and shortage of personnel.

Questionnaires (studies II & IV)

The questionnaires were sent once, to the persons that had signed the consent form, and there was no reminder. The participants were asked to complete them individually, regardless of focus level (individual or family/system) and send them back in a pre-paid addressed envelope.

In study IV, the participants were told they were going to receive an invitation to participate in a follow-up interview and there were questionnaires to be sent by mail three months after the intervention. There was just a small note attached to the questionnaires with the study title, in the form of a thank you for participating and giving my working mail address.

The questionnaires were positioned together starting with the background questionnaire, GFS and FHI, in study II. In study IV: the background questionnaire, GFS, FSOC-S, HHI and SF-36 or RAND-36, were put in the same order. So, it was intended that all the participants would be scoring the questionnaires in the same order.

Two self-reported questionnaires, GFS (Epstein et al., 1983; Bylund et al., 2016) and FHI (McCubbin et al., 1996; Persson et al., 2016) were used in study II.

In study IV, four self-reported questionnaires; GFS (Epstein et al., 1983; Bylund et al., 2016), FSOC-S (Antonovsky & Sourani, 1988; Möllerberg et al., 2019), HHI (Herth, 1992; Benzein & Berg, 2003), and SF-36 (Stewart, 1992; Sullivan et al., 1995) or RAND-36 (Hays et al., 1993; Orwelius et al., 2018) were used (Figure 2).

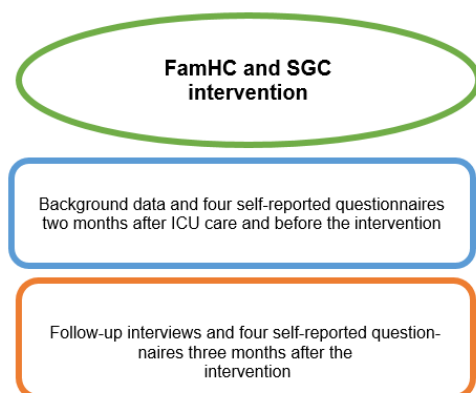


Figure 2. Data collection process.

The General Functioning Scale (studies II & IV)

The GFS is used to measure the overall family functioning, and to find patterns that can distinguish healthy from unhealthy family functioning (Epstein et al., 1983).

The GFS was developed from the Family Assessment Device, FAD. The scale is based on seven sub-scales: problem-solving, communication, roles, affective responsiveness, affective involvement, behaviour control and general functioning, with the last scale measuring the overall health of the family. An equal number of items describe healthy and unhealthy functioning for each dimension (Epstein et al., 1983).

The GFS is a 12-item rating scale, measuring interaction within the family (Epstein et al., 1983). The questionnaire was composed to assess family members' individual perceptions of the family's ability to function, including six aspects focusing on the emotional and physical health or problems of family members: problem-solving, communication, roles, affective responsiveness, affective involvement, and behaviour control.

It is a summative scale, where the score is the mean of all items, ranging from 1 to 4, with a cut-off score of 2. Higher scores indicate unhealthier family functioning.

The Swedish version showed good reliability when tested in the context of participants who had undergone gastric bypass surgery (ordinal alpha = 0.9) (Bylund et al., 2016).

The Family Hardiness Index (study II)

The FHI was used to measure family hardiness (McCubbin et al., 1996).

The FHI is a 20-question Likert-type scale that measures family members' individual perceptions of family stress resistance and adaptation resources affecting the family members' ability to work together and their confidence in handling problems. In addition, the family members' approach and attitude towards new experiences and the sense of being in control of family life are measured (McCubbin et al., 1996).

The questionnaire is scored on a four-point scale, false = 0 – true = 3. Four sub-scales constitute the questionnaire: commitment, confidence, challenge, and control. The total score ranges between 0 and 60, with a higher score reflecting higher family hardiness (McCubbin et al., 1996).

The Swedish-translated instrument showed good reliability, $\alpha = 0.8$, tested in the context of family members of persons with cognitive dysfunctions (Persson et al., 2016). A study collecting FHI with comparison of family stresses, strengths, and outcomes after trauma and surgery, showed $\alpha=0.7$ in reliability (Leske, 2003).

The Family Sense of Coherence Scale (IV)

The FSOC-S assess family sense of coherence and involves the extent to which the world is seen as comprehensible, manageable, and meaningful, and focuses on the family (Antonovsky & Sourani, 1988).

The FSOC-S consists of 12 estimation questions. The highest score is 12, with a cut-off score of 4, where higher scores indicate a stronger sense of coherence (Antonovsky & Sourani, 1988).

The reliability of the Swedish version of FSOC-S is $\alpha = 0.91$ was tested in the context of families living with cancer (Möllerberg et al., 2019).

The Herth Hope Index (study IV)

The HHI used to measure hope was developed by Herth (Herth, 1992).

The Swedish version of HHI has been used to validate the hopes of people with cancer in palliative care on an individual level (Benzein & Berg, 2003).

This HHI has 12 items with a 4-point Likert scale which measures levels of agreement. Higher scores (range 12–48), indicate higher levels of hope. The reliability is α 0.88 (Benzein & Berg, 2003).

The Medical Outcome Short-Form health survey (SF-36) or the Research and Development (RAND-36) scale (study IV)

The RAND-36 is used for entering ICU patients onto SIR, which previously used the SF-36, an equivalent questionnaire (SIR, 2022).

We used both of these questionnaires as we collected data during different years.

The SF-36 for the evaluation of health-related quality of life is a generic 36-item scale. The eight dimensions are weighed together in two consecutive indexes, a physical component score made up of four dimensions: physical functioning, physical role functioning, bodily pain, and general health. Then there is a mental component score consisting of four dimensions: vitality, social functioning, emotional role functioning, and mental health (Sullivan et al., 1995).

The scores on all sub-scales are transformed to a scale from 0 to 100, where a higher score indicates better perceived health.

The SF-36 has been translated and validated into Swedish in a representative sample of the population (Sullivan et al., 1995).

The RAND-36 scale is used to measure health-related quality of life. RAND-36 measures self-rated, health-related quality of life at the level of the individual and uses the World Health Organisation's definition of health. RAND-36 assesses eight health concepts (the number of questions per dimension varies between two and 10) on a multi-item scale (35 items). In turn, these can be divided into two main domains: physical health and mental health. An additional, single item assesses change in perceived health during the last 12 months (Hays et al., 1993; Stewart, 1992).

Scores range from 0 to 100, where higher scores indicate better health-related quality of life (Hays et al., 1993; Stewart, 1992).

The Swedish-language version of RAND-36 has been validated, with reliability of α 0.86-0.97 (Orwelius et al., 2018).

The eight dimensions in RAND-36 and SF-36 were used to enable proper analysis of the data, as SF-36 questions were used in the FamHC intervention, and the RAND-36 scale was used in the SGC study.

Individual and family interviews (studies I, III & IV)

Interviews were conducted in three of the four studies. All interviews took place at a time and place the participants chose. Participants were contacted by telephone, by the interviewer, to schedule the time for the interview.

The interview started with some small talk, and the participant was given brief information about the purpose of the study and had the opportunity to ask questions. This was not recorded. The interview also ended with some small talk; the interviewer asked if the participant wanted to continue the study.

Family interviews were conducted in study I, with an inductive approach using iterative data collection. The interviews were conducted by me, directed by an interview guide at the first interview. According to the method, interview questions could be added, and the interviews were changed/developed during the interviews, depending on the previous interview:

- Tell me what kind of family you were before the intensive care.
- How does it work/look in the family now?
- Has the family been affected by the length of care?
 - Tell me in what way.
 - During the period of care.
 - After the period of care.
- Do you have any thoughts on what the future holds?
- What does the future look like? (From a family perspective).

Throughout the interview, I used follow-up and in-depth questions, allowed silences, repeated what the person said before a period of silence or in case of ambiguity. Examples of questions are:

- Can you tell me more about that?
- What happens then?
- What do you do in such a situation?

In study III, follow-up family interview was used for the intervention FamHC collected for another study and in study IV individual interviews were made for the participants in the intervention SGC. A semi structured

interview guide was used, and the interviews involved open-ended questions focusing on family members' experiences of the interventions. The families were asked to narrate as freely as possible their reflections and the significance of the conversations to family functioning and well-being. The following questions were used to guide the interview:

- Would you please tell me how you experienced the FamHC?
- Have the conversations influenced you?
 - If so, how?
- What meaning did the conversations have for your family?
- Was there anything specific in the conversations that was of noteworthy value for you?
- What in the conversations had greatest meaning for you?

Probing questions (e.g., “Would you please tell me more about that?” “What do you think?”) were used when suitable.

All family interviews were conducted in person, on two occasions. These interviews were not conducted by me. The designed was a secondary analysis using a narrative research approach made by me and the research team.

Study IV used follow-up family interviews from the FamHC intervention, from three months after the intervention and individual follow-up interviews with family members attending the SGC intervention. I conducted the SGC intervention, which is why the follow-up interviews were performed by the research team, by telephone or through video calls.

The follow-up interview was conducted once, three months after the interventions (Figure 2).

The same semi structured interview guide developed by the research team was used in studies III and IV.

Data analysis

Qualitative methods (studies I, III-IV)

Several qualitative methods were used to explore the family functioning of families with a family member treated in the ICU and to describe and evaluate how an intervention affects the family and individual family members in families where a family member received intensive care.

Grounded Theory was used in study I, to facilitate understanding of how people manage social processes, such as family functioning (Glaser & Strauss, 1967).

In study III, secondary analysis exploited existing data, not collected by me, but by a member of the research team. Secondary analysis was conducted by a researcher not involved with the collecting of the data, with a new aim not proposed by the primary researcher. The primary data had the aim of identifying and describing the outcomes of a nurse-led intervention, regarding family functioning and well-being in families with a member who was critically ill. The original data contained much information to answer my study aim.

This data from follow-up interviews on the FamHC intervention was analysed with narrative research analysis using holistic content, with a focus on family functioning and on family members' experiences of the interventions in study IV. Quantitative and qualitative data from two different interventions were compared and contrasted with follow-up interviews using secondary analysis from follow-up family interviews after the FamHC intervention and follow-up individual interviews after the SGC.

The narrative research demonstrates how the families make sense of and interpret their life world, by discourse or by exemplifying it as presenting a connected succession of happenings (Lieblich et al., 1998).

Grounded Theory (study I)

The data was collected and analysed using Grounded Theory (GT) in study I. There are several types of GT, and the most appropriate method for this study and aim was classic GT by Glaser.

The findings in GT emerge through open coding, theoretical sampling, and constant comparison. Using the constant comparison method gets the analyst to the desired conceptual power. Categories emerge upon comparison, and properties emerge upon more comparison (Glaser, 2005).

I listened to the interviews and transcribed them verbatim. There was parallel data collection and analysis. The first interview was analysed before the next interview was conducted and so on. Data from the verbatim interviews were read several times and open coding made line by line, and notes made in the margin. Memos were written continuously, to develop ideas about the concepts that would be included in the theoretical construction. Analysis was performed line by line with an open mind, and substantive codes were generated. The codes were labelled with origin words from the data. Substantive codes were compared with previous data, and similarities and differences were noted while categories were identified and conceptualisation of the phenomena was conducted. Data were examined several times with constant comparison. The categories were modified and constantly refitted to represent and conceptualise the family functioning of the family having a former critical ill family member staying at the ICU. The gathering of data and analysis continued until a saturation 'point' was reached and then three more interviews were conducted.

One of these interviews was conducted with a former ICU patient that had good knowledge about ICU care. The patient had worked as an ICU nurse for a long time. The time since he/she had been cared for was longer than the other participants. This so-called extreme case was used to strengthen or reject the theoretical construction. The interview strengthened the results and no new data was revealed from this extreme.

The final level is identifying a core category. A core category is the category that is imbued with data from all categories and raw data. Categories are related to each other and to the core category and are scrutinised to verify their relevance (figure 3). The findings were discussed and compared within the research team during the entire process. The members of the team had good knowledge of GT (Glaser & Strauss, 1967; Glaser, 1978, 1998, 2002, 2007).

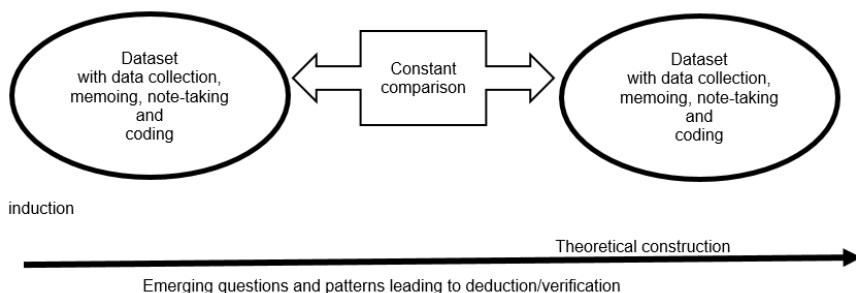


Figure 3. GT with constant comparison of the interview data, codes, categories leading to a final level, identifying a theoretical construction, a core category.

Narrative research (studies III-IV)

In studies III and IV, narrative research analysis of the data by Lieblich was used. The analysis was based on the transcribed interviews. The transcription was done by a retired administrator with long experience transcribing text.

I listened to and read the transcript at the same time to check that it was correct.

Lieblich (1998), points out two dimensions of narrative research: holistic versus categorical and content versus form. The analysis focused on wholeness, as well as the content of the interviews, in order to interpret what the families said about family functioning directly and indirectly. Holistic analysis is a narrative research approach that gives the opportunity to learn about variations in the data structure and content and thereby understand the interviewee's revolutionary life experiences. The analysis was thereby focused on wholeness as well as the content of the interviews in order to interpret what the families expressed about family function directly and indirectly (Lieblich et al., 1998).

Lieblich et al. suggest five steps for the analysis. First, the transcribed data were read multiple times; then, separately, I wrote down a resume. Verses in the interview text were marked in different colours and read separately and repeatedly. Words that had close associations in meaning were grouped. After this was carried out, these words were grouped to form a label. Later, the labels were combined to form a theme. This was performed by me separately, and then the research team discussed their analysis several times and came to a consensus (Lieblich et al., 1998) (Figure 4).

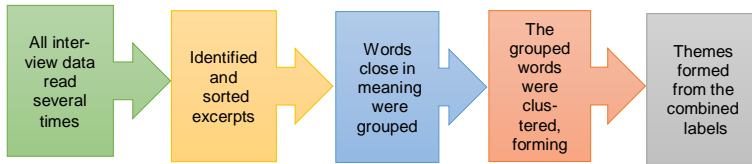


Figure 4. The analytical narrative research process.

Quantitative methods (studies II & IV)

Statistics

Analyses of the data conducted in the Statistical Package for the Social Sciences Version 25.

I conducted the analysis in cooperation with a statistician who guided me and gave suggestions to improve the analysis.

The level for statistical significance was set at $p \leq 0.05$. I used univariate methods to describe the sample. Cronbach α coefficients were calculated for all scales to evaluate internal consistency reliability (Altman, 1991). Cronbach α was > 0.8 for all scales. Continuous variables were expressed as mean \pm SD. No corrections were made for missing data. The power of the sample size was determined prior to the collection of data. Power calculation is based on data from a previous study using an unpaired t-test. The calculation is based on a medium power size ($ES = 0.6$, $\alpha = 0.05$; $1 - \beta = 0.8$).

In study II, scale values from the two questionnaires were accounted for, both family wise and between the patients and family members. The FHI questionnaire had no standard cut-off; we used one SD as the cut-off as recommended by Altman, (1991). The GFS questionnaire standard cut-off is ≤ 2 , for healthy family functioning (Epstein et al., 1983).

Univariate methods were used to describe the characteristics, shown in a tables and in the text within this manuscript. Statistical analyses were conducted using a T-test to compare the means (or averages) among ICU patients, family members and families to see if the groups differed, and an analysis of variance (ANOVA) was performed to explore family functioning and family hardiness in families of intensive care patients, based on the GFS and FHI questionnaire data.

The power of the sample in this study was determined at 104 participants. Due to sending out information and requests to include the participants to

different clinics and at different times the sample was 145, 41 over previously determined power of sample size. To comply with ethical guidelines all participants that answered and wanted to participate were included (Altman, 1991; Field, 2018).

In study IV an independent t-test and one-way ANOVA were used to compare background variables within the two intervention groups. Both descriptive and analytical statistical methods were used to analyse the data. Univariate methods were employed to describe the sample. For comparisons of background variables between the two interventions, an independent t-test, one-way ANOVA, repeated measures ANOVA, and chi2 -tests were used. To compare the two intervention groups, the patients were removed from the final analysis. For normally distributed data, because of intra family correlations, the base 10 logarithm function was utilised (Altman, 1991).

To adjust for the covariance structure of the data, the difference between three months and baseline was calculated and then analysed using the linear mixed-effects model (Field, 2018).

Mixed methods (IV)

A mixed methods study design (Creswell & Creswell, 2017; Tashakkori & Teddlie, 2021) including data from interviews and questionnaires, was used to explore and compare the two interventions in study IV (Figure 5).

The quantitative and qualitative results were integrated using mixed methods and are shown according to the purpose of interjections between methods: recasting the results of qualitative narrative research analysis in the FamHC with quantitative results, looking for contradictions and/or new perspectives. The results from the SGC data were analysed in the same way. The total results from the FamHC data were then cross-validated with those from the SGC data (Greene et al., 1989; Tashakkori & Teddlie, 2021).

A triangulation process was applied to describe corroboration between the two sets of findings and to describe the process of studying the problem using different methods to gain a more complete picture. A triangulation was conducted with the purpose of providing a fuller, more complex picture, instead of mainly validating results (Creswell & Creswell, 2017; Tashakkori & Teddlie, 2010, 2021).

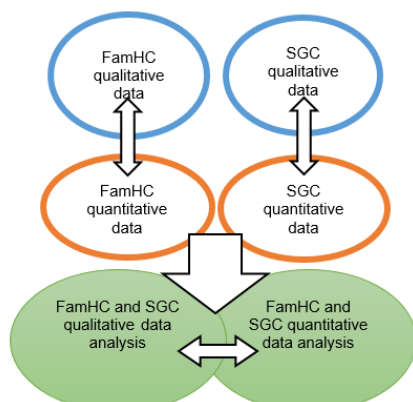


Figure 5. Mixed method analysis process, the triangulation between and within FamHC and SGC.

Ethical considerations

The Ethics Review Board in Linköping approved the studies (record no. 2013/228-31, 2015/367-31, 2016/292-32, 2017/164-32, 2018/572-32 and 2020-04124, 2021-05103, 2021-06585-02). The study has many ethical approvals, due to new amendments, for every clinic we included in the studies. There are many principles to think about in research concerning ethical considerations and values. These include: Non-maleficence – not to kill or harm human life, to respect human rights; Autonomy – to respect the individual's will, and ensure that all concerned may influence decisions; Justice – to distribute equally, as needed, by effort or merit; Beneficence – not to inflict harm, to contribute to well-being. All these principles were upheld throughout the process, from designing the studies to data collection and storage of data (Shamoo & Resnik, 2009).

In all studies, the first task was to send an information letter about the study and consent form to the former ICU patient, with a request for names and addresses of family members he/she wished to take part in the study. Written informed consent was obtained from all participants and the research was carried out in line with the Declaration of Helsinki. Information was provided about the study being voluntary, and that those involved could end their participation at any time without further explanation or without effects on any future care (The World Medical Association, 2013).

After obtaining the signed consent form from the participants, in study I, the former ICU patient was contacted by telephone, and he/she, together

with the family members, decided where they would like to have the interview. During these calls, there was small talk about how the ICU stay had affected the family, and about the study and the voluntary nature of participating.

The follow-up interviews gave the participants more opportunities for small talk with me /the interviewer, as the interviews were scheduled by telephone. The telephone call was also private so the participant could reveal anxiety and stress, and whether they needed to talk to a counsellor.

The data were saved and stored, in a safe locked storage without no identification and accessible only by me. All data were coded with a number. There was no personal identification (Regulation (EU) 2016/679).

All participants were given my phone number and work email address. This was in case they had any questions and/or if there were any issues and the participants needed further information.

During planning of the studies, consideration was given to the inconvenience the participation in the studies might cause. Participating in interviews and writing scores in a questionnaire about experiences of the ICU might bring up feelings of anxiety, fear, lack of hope and helplessness. A close contact with a counsellor and physicians was established in case a family member was in need of further support. The participants were given the opportunity to speak to a counsellor who could write a referral for further assistance if necessary. If issues concerning physical problems around ICU care occurred and could not be addressed, an appointment was made for the patient to talk with a physician working at the ICU. This was done to reveal anxiety and to avoid leaving issues that might occur unresolved. It was important to have the patients and their family's trust. No participant wanted any further contact with health professionals after the studies.

In study II all adult former ICU patients who met with the inclusion criteria were contacted and asked to participate. There were no exclusions concerning communication or if they spoke and read Swedish or not. No interpreter was used at any time and those who had limited ability to communicate in Swedish probably declined to participate in the study. Asking the administrative staff who provided personal data, to review the patient's medical

record to establish their Swedish language ability was not considered possible. Having the possibility to get information about how to communicate with the informant as well as translate the surveys, would be the most ethical choice.

The purpose of the intervention was discussed with the patients and their family during my clinical time as well as during my time at the ICU follow-up clinic. Patients and family members wished to have more follow-up after the ICU, both individually and familywise.

RESULTS

The main results of these four studies will be presented. The results contribute to a general and detailed picture of family functioning of families experiencing critical illness and ICU both during “normal care” and in an extreme case such as the COVID-19 pandemic. The results are shown both individually and for family units.

Family functioning of families experiencing intensive care and the specific impact of the COVID-19 pandemic (I).

Aim to identify, describe and conceptualise the family functioning of families where a formerly critically ill family member had stayed at the ICU, during the COVID–19 pandemic.

The results showed that the families had existential issues, described as value considerateness, anxiety and insecurity in life and insight into the unpredictability of life. The patient and the family were anxious about becoming critically ill with the COVID-19 virus. They were grateful to be alive and valued the concern the family and health professionals had shown during the critical illness. They were afraid of becoming critically ill again and tried to live in the moment with the family. The possibility of talking about their experience made them less anxious. Even if the news and media talked about the high mortality and extreme circumstances during the pandemic in the ICU and made them worried. Since this media information made them “one of those” and everyone had an opinion of the pandemic, it was easy to talk about their experiences, and everyone was interested in listening, which gave confirmation.

Family functioning and family hardiness in families of intensive care patients (II).

Aim to explore family functioning and family hardiness in families of intensive care patients.

The results showed that families, including the former ICU patient, from various families experiencing intensive care scored their family hardiness as high, and family functioning as low, which was seen as good. Just two out of 60 families scored high/low and those families had registered their family relations as friends not living in the same household. The results indicate that the former ICU patients rated their family functioning higher and hardiness lower compared to their family members, but these results were not significant. The fact that the patient and the family members in the same family scored differently might be a sign of possible friction within the family.

Components of family function affected when families participated in Family Health Conversations (III).

Aim to identify which components of family function are affected when families participate in Family Health Conversations.

The results showed the intervention FamHC improved the families' understanding of each other concerning, their anxiety and their unique experience of the same situation, even though they did not recall it in the same way. The patient lost memories but remembered hallucinations, and the family members felt anxiety standing at the bedside during the ICU care not knowing if the patient would survive. Having these conversations and being able to listen to the other family members' experience made the family more concerned for each other. The intervention made the family members take time to talk to each other, and the conversations brought them closer. Showing each other their feelings and weaknesses, made them more supportive. They struggled together as a family to manage the problems and the new situations that appeared when having a critically ill family member needing rehabilitation. The family members now had time to reflect on what could have happened, the ICU patient might have died. The conversation made the family members reflect on how they managed their experiences in diverse ways. The family gained an insight into how they had gone through various processes of working through what had happened during the ICU stay, and understood that it would take a long time for them to process the situation. The intervention made it possible to listen to each other's experiences and these insights needed to be processed, both individually and as a family.

Compare and contrast the responses from two different types of follow-up interventions for families of critically ill patients (IV).

Aim to compare and contrast the responses from two different types of follow-up interventions for families of critically ill persons, focusing on individual hopes, health-related quality of life, family functioning and ability to cope with challenges.

In the follow-up after the FamHC the family talked about how they had a better understanding of each other after the intervention, shown in increased family function, GFS (table 5). The way they talked to each other within the family and with others changed, and the social function in SF36 increased (table 5). The family was feeling better and had experienced support and concern for each other, as was shown in the questionnaire on mental health SF36 (table 5).

The follow-up after the intervention in the SGC was empowered by exchanging experiences of ICU care. Listening to others made it easier to cope with their own families' everyday life, increased the coherence and meaningfulness as was shown in the FSOC-S questionnaire (table 5). The family members had more energy and vitality after speaking and listening to others with similar experience as they scored in the questionnaire RAND-36 under vitality (table 5). The family members talked about how they had been able to look forward and prioritise their own life more. The family functioning had decreased in the quantitative results. There was no one in the follow-up interviews that talked about worse family function, but in some families the former ICU patient was still in care, GFS (table 5). Their hope for the future was reduced as was shown in the HHI questionnaire answers. Their scoring in the questionnaire RAND -36 showed that their sense of ability to function physically and socially was reduced (table 5).

Comparison of the two interventions showed that all participants had been influenced individually and or as a family unit. The results showed differences in the outcome, increased interactional aspects and individual hope with the families in the FamHC, while the SGC intervention increased family members' sense of family coherence and individual vitality (table 5). Both interventions showed that family members, as well as the former ICU

patient in the family, could find follow-up based on family systems nursing useful.

Table 5. Comparison within and between the two intervention groups from baseline to 3 months.

Questionnaires and dimensions	FamH				SGC			FamHC vs SGC
		Mean (SD)	Mean (SD) -patient	p-Value		Mean (SD)	p-Value	p-Value
GFS	Baseline 3-months	1.7(0.6) 1.5(0.5)	1.9(0.8) 1.6(0.6)	.042*/ .144**	Baseline 3-months	1.7(0.6) 2.8(0.5)	.000	.001***
FSOC-S	Baseline 3-months	39.6(8.7) 38.8(11.7)	41.2(3.6) 43.9(3)	.298*/ .709**	Baseline 3-months	41.1(2.2) 46.9(1.8)	.001	.066***
Comprehens ability	Baseline 3-months	16.3(5.1) 15.3(4.5)	16.9(6.1) 17.6(5)	.330*/ .895**	Baseline 3-months	17.7(4.7) 18.7(4.2)	.033	.217***
Manage ability	Baseline 3-months	11.7(2.2) 10.9(1.9)	12(2.1) 12.1(1.9)	.183*/ .576**	Baseline 3-months	10.9(1.4) 10.7(1.9)	.895	.821***
Meaning fullness	Baseline 3-months	13.2(5.6) 12.6(6.6)	14.3(6.9) 17.5(6.1)	.739*/ .703**	Baseline 3-months	13.4(5.3) 14.1(2.5)	.001	.066***
HFI	Baseline 3-months	40.7(4.2) 41.5(5.5)	41.1(4.4) 42.6(5.7)	.076/ .071*	Baseline 3-months	38.5(6.4) 34.1(2.6)	.002	.016***
SF36/RAND								
PF physical function	Baseline 3-months	67.9(32.7) 73.2(25.2)	88.2(12.2) 78.6(26.4)	.703*/ .258**	Baseline 3-months	75.5(22.3) 53.9(17.2)	.006	.599***
RF role function	Baseline 3-months	45.6(44.4) 55.4(46.2)	61.1(48.6) 64.3(47.6)	.605*/ 1.00**	Baseline 3-months	76.3(36.8) 75.5(22.4)	.888	.375***
BP body pain	Baseline 3-months	59.2(27.6) 64.5(29.6)	65.1(25.3) 61.6(28.7)	.835*/ .398**	Baseline 3-months	75.1(21.2) 76.3(36.8)	.419	.073***
GH general health	Baseline 3-months	61.9(20.9) 66.9(21.7)	64.7(21.4) 75.1(21.2)	.357*/ .504**	Baseline 3-months	66.7(19.8) 69.6(21.3)	.141	.779***
VT vitality	Baseline 3-months	57.1(24.4) 65.7(22.2)	56.7(28.6) 66.4(22.7)	.160*/ .180**	Baseline 3-months	53.6(21.5) 66.7(19.8)	.012	.505***
SF social function	Baseline 3-months	61.8(30.8) 81.2(27.2)	68.1(36) 80.4(33)	.049*/ .466**	Baseline 3-months	69.4(29.8) 53.6(21.5)	.001	.110***
RE role functioning	Baseline 3-months	64.7(39.9) 76.2(33.1)	77.8(33.3) 85.7(26.2)	.533*/ .766**	Baseline 3-months	70.4(39.4) 69.4(29.8)	.882	.337***
MH mental health	Baseline 3-months	75.3(15.2) 85.1(11.1)	72.9(16.8) 81.7(13.8)	.040*/ .185**	Baseline 3-months	70.7(20.1) 70.4(39.4)	.963	.584***

*p-value for comparison within group, mean over time; 3 months – baseline

**p-value for comparison within group, mean over time; 3 months – baseline without patient in the FamHC intervention.

***p-value for comparison between groups, mean over time, with 10 logarithm value between the two groups; 3 months – baseline, without patient in the FamHC intervention.

In summary, the results from the four studies show that families experiencing the ICU during the COVID-19 pandemic described their family functioning with warmth. They felt anxious and afraid, had many thoughts about death, being alone and about the future. They all talked about how they saw the family as the light at the end of the tunnel. They wanted to do

everything for each other to be able to ease the challenges, be together, support, and comfort each other.

The same result of having healthy family functioning and family hardiness was shown in families two months after they had experienced the ICU. The family members wanted to reach out and help each other in every way possible. The scores were somewhat lower for family hardiness, and higher for family functioning in the family members who were ICU patients. This might be due to their own challenges after the ICU around not remembering anything and hallucinating.

Having a follow-up clinic with the FamHC intervention, where all the family are given the opportunity to take part and discuss their feelings about the critical illness, could be beneficial. Having a series of conversations with a specialised nurse with knowledge of ICU care, who can communicate and give the family tools to reflect, listen and find out solutions will strengthen family functioning. This strength may increase the family's ability to manage daily living and also ease the family's experience following intensive care. Families experiencing the FamHC intervention found the conversations helpful, since they made them talk and deeply listen to each other properly. The FamHC made the family take time for those important issues, in a tight schedule of everyday life. They wanted the intervention to be permanent as they found that thinking about the conversations made them reflect and support each other more. Reflecting on the different ways they had experienced the critical illness and how they needed each other to be able to go on in life as they processed the different issues in their own time and way.

In the IV study, the FamHC and SGC were compared and contrasted. Both interventions could be useful to strengthen the individuals and the family as a unit, even if the results show differences in the outcomes. The results could be explained by whether the family or individual family members were targeted in the intervention. Family functioning and hopefulness increased after the FamHC, as reflected in the scores and in the follow-up interviews. The family members felt family functioning and hope were better after the intervention, influencing the family to talk more about their feelings and how to manage demanding situations together. They revealed feelings of more hopeful conversations, supporting and helping each other. The family members in the FamHC intervention also showed increased

mental health and an improved ability to function socially. Family functioning and hopefulness decreased in the SGC, and the family members talked about how the intervention had given an individual perspective, but it had also made them feel despair about their own future as a family. Instead the intervention had given/supported an individual perspective, they had gained more vitality, comprehensibility, and meaningfulness after attending the SGC. The patients in the SGC had received care for more days than the average ICU patient, which might have been a sign of being more critically ill. The family members were satisfied with the intervention in the follow-up interviews after attending the SGC intervention, not being alone with their feelings.

DISCUSSION

Results discussion

The overall aim of this thesis was to explore and conceptualise the family functioning of families with a family member treated in the intensive care unit. There was also an intention to describe and evaluate how an intervention affects the family and individual family members in families where a family member received intensive care.

The results show that families had existential issues, anxiety and insecurity in life and insight into the unpredictability of life. Family functioning and family hardiness were described as healthy. Components of family functioning are affected when families participate in the FamHC intervention. Improved awareness of family functioning, and better understanding of each other helped them to become closer. This led to better co-operation within the family, implementation of the “working it through” process, and a greater sense of well-being. By comparing and contrasting the two different interventions based theoretically on family systems nursing, I wanted to determine if they could be compared and if the interventions increased wellbeing for the family. The results showed increased interactional aspects and individual hope in the families in the FamHC, while the SGC intervention increased family members’ sense of family coherence and individual vitality.

The self-reported scores in study II showed healthy family functioning and hardiness in most families. This was somewhat unexpected but has been shown in similar situations of crisis with parents having infants with heart syndrome (Mussatto et al., 2021). The family embraced their love for one another as a family unit, communicating and connecting to each other, which facilitated adaptation to changes (Epstein et al., 1978). In study IV, the result from family functioning, mean 1.7 ± 0.6 SD, was the same before the two interventions and two months after the ICU care. The result differed three months after the interventions. The conversations with the whole family, the FamHC, increased their family functioning mean 1.5 ± 0.5 SD, and the conversations with just family members from various families without the former ICU patient, the SGC, decreased their family functioning mean 2.8 ± 0.5 SD. The families within the FamHC attended the intervention together and felt better and recovered from the ICU earlier

than the patients in the SGC that had longer ICU time care frame, and also had the possibility to communicate 24/7. Some of the patients in the SGC still were cared for in hospital and the family had limited possibilities of communicating with each other. As the theory suggests, communication within the family is crucial (Epstein et al., 1978; McGoldrick et al., 2013). This is something that could also be shown in study III, which increased awareness of family functioning and showed that talking to each other within the family made the family come closer.

Health care professionals need to ask the family about the patient's mental and physical history to be able to give the right/patient safe care. Information given by the health care professionals was something family and patients had good experience of in the qualitative studies I, III and IV. In study I, where the pandemic made it difficult for the family members to attend the ICU, they all were impressed and satisfied with the health care professionals taking the time to phone the nearest family member and inform them about the patients' condition. But also, they were satisfied with being able to phone the ICU 24/7 just to ask how the patient was, to be able to calm their nerves and be able to go to sleep. This was something that was revealed during the follow-up interviews in studies III and IV also. All three studies had family members with experiences of being well informed by health professionals during the ICU care. Giving them time with a counselor and/or a chaplain early in the care might give them even more comfort and support if the nurse does not have the time or does not have the experience (Egerod & Kaldan, 2021). During the COVID-19 pandemic it was reported throughout the media, and everyone was discussing the situation of the virus, social distancing, how to avoid getting infected and so on. Being "one of those affected", being critically ill with the virus, or having a family member critically ill with COVID-19 made them the experts, and many persons not even close to the family wanted to listen to "the real story". This meant the family members had many people to talk to. Family functioning is affected in a good way if individuals in the family have the opportunity to process their feelings, even with persons outside the inner family (McGoldrick et al., 2013). It is important for family members to have the possibility to discuss their feelings with others, and to experience that they are not alone in their anxiety and fear of the unknown.

The results show that the experience shook the family to their foundation. They were anxious and afraid and had existential issues. This is something to address both during and after the ICU stay. Existential issues can be hard

to talk about, even for nurses. Nevertheless, implementation strategies such as education, and learning opportunities such as mentoring supported by organisational structures could improve nurses' unique position to provide care to the family unit. Addressing these feelings is therapeutic (Ortega et al., 2020), and as we know, all individuals have unique needs for support (Ågren et al., 2019; Rengel et al., 2019).

Family systems nursing during and after the ICU stay has been shown to increase the family hardiness and to help patients, family members and health professionals to give individual support. Patients are given more support and individual care by the family members by revealing important information through conversations with the nurse during the ICU care (Stenman et al., 2022). An article from 2008 talks about the importance of implementing family system nursing in critical care, pointing out that the nurses need education to be able to communicate with and listen to the family. They are acknowledging the importance of recovery for the patients with family system nursing as a win - win situation for the patient, family, and health professionals. But ICU care combined with other factors such as multiple nursing responsibilities and nursing shortages may not allow the critical care nurse to appropriately assess, engage with, and involve the family system (Leon & Knapp, 2008).

All assistance the nurse can have in comforting and supporting the patient and their family should be used. A study from the pandemic has shown that face-time with the family for the patient in the ICU, and other communication strategies specific to phone and video can improve the experience for the family (Kennedy et al., 2021). Health care professionals, like nurses, did not have the time to phone the family and talk to them as much as they wanted and were used to doing, during a period that involved a large flow of patients in need of specialized care. They were busy caring for the patients. The counsellor took care of a larger part of the concerns of the family members during the ICU stay of the family. Egerod and Kaldan discuss the contemporary role of hospital chaplains and identifies them as part of the ICU team (Egerod & Kaldan, 2021). The possibility to have the family on the ward could give the nurses a better ability to talk to them about difficult issues. The counsellor and or the chaplain could function as a mentor, discussing occurring issues or acting as a back-up.

The participants also acknowledged that they had always been a strong unit and were willing to listen and care for each other within the family. The

individual development of family functioning only takes place in the context of significant emotional relationships (McGoldrick et al., 2013). The nurse needs insight into the families' will to comfort and help each other during difficulties which emphasizes the importance of a relationship between the nurse and family, to acting on a commitment to be with and for the family (Eggenberger & Nelms, 2007). This hard situation of being critically ill and cared for at the ICU brought up anxiety, loneliness, and uncertainty about the future for both the patient and the family members. The love for the family made it easier; it was easier to tell each other how they felt, and this made it easier to look ahead and consider the future with optimism, having the spirit to work hard. Communication within the family is crucial for family functioning (Zhang, 2018).

Social media reported that the family were not able to visit the hospital, due to social distance restrictions, and how this must have felt, during the pandemic. Studies have found that having the family present at the ICU reduces delirium for the patient and even makes the patient more secure (Rosa et al., 2017), and the care period at the ICU can thus be shorter (Goldfarb et al., 2017). Having all family members come visit around the clock during the COVID-19 pandemic was not possible, and not desirable. But maybe we can learn for the future and require the visitors to show a negative test for the virus, limit the number of family members visiting, and make them use good hygiene and suitable protection such as facemasks (Munshi et al., 2021). An early article talked about how daily structured phone calls to update the nearest family member had been found to lower family stress (Medland & Ferrans, 1998). This was something that was used during the pandemic; the physician had daily phone calls with the nearest family member.

The individual possibility of attending either a FamHC or SGC is also important for recovery and maintaining family functioning. Even if the family is a unit, it is also defined by individuals having different needs for support during and after ICU care (Amass et al., 2022; de Ridder et al., 2021b; Rydwik et al., 2021). The quantitative analysis in studies II and IV showed that family functioning was mostly healthy two months after the ICU care, as well as family hardiness in study II. The results differed after three months in study IV in the quantitative analysis. Family members in the SGC intervention had decreased family functioning and hope, and their ability to function physically and socially was worse. This can only be speculated about but might have been due to the patients' previous mental and

physical health and the fact that the patients in the SGC were more ill and in need of more rehabilitation and support, which required the family members' help (Geense et al., 2021).

The answers in the studies did not differ from before and during the pandemic. The participants talked about how they were happy to be alive and how grateful they were to have a family to belong to. They felt sorry for the patients who did not have any family or at least not that they knew. They wanted health professionals to acknowledge who these patients were and give them more support.

Something that was different was that during the pandemic the family and family members being ICU cared had persons to talk to about what had happened and how they had experienced the critical illness and ICU care. Everyone had an opinion of the care and disease. This is something that patients and family before the pandemic thought could be hard. The participants in studies I, III and IV all said the follow-up after the ICU was important to recall the true facts of what had happened during the ICU for the patient, since, due to hallucinations and nightmares, they did not know which of their memories were real. The differences in how much support and follow-up were needed for patients are shown in the results of former long-term ICU patients (Alexandersen et al., 2021). Family members' different needs for support are important to assess by the health professionals during and after the ICU. This could come up if the nurses used family systems nursing during the ICU care (Kirshbaum-Moriah et al., 2018). The fact that family systems nursing is important for patient safety during the ICU care is documented (Bell, 2013; Björk et al., 2019; Rosa et al., 2017). Family systems nursing: how the family and the nurse experience, perceive, and manage the nursing relationship between them could be used during the whole ICU care as well as in the follow-up. The family system nursing is the way nurses listen and use questions to ease the family members' burden and help them acknowledge their inner strength (Benzein et al., 2008).

How and when the best follow-up for the individual patient and family members as well as the family as a unit is given is still to be evaluated in research. But the question of whether it is important to give follow-up with the opportunity for patients and their family members to vent their thoughts and be listened to has been investigated (Ågren et al., 2019; Azoulay et al., 2022; Connolly et al., 2021; Kirshbaum-Moriah et al., 2018; Rydwik et al., 2021). And tools have been developed to identify and assess stressful memories of the patients' ICU stay (Samuelson, 2022) that could

help find out if the patient is in need of more support. Even if communication and narrative listening are an important fact to take in consideration.

The family's social support during and after the ICU stay has been shown to be of importance (Kleinpell et al., 2019; Wong et al., 2019). Nurses may be able to involve the family in the care, in care decisions and help the former ICU patient if they are aware of signs of poor communication between the patient and the family (Söderström et al., 2009).

Family members and the critically ill ICU patient, as individuals, are affected by the critical illness and ICU care (Rydwik et al., 2021) but in different ways and with different timeframes (Ågren et al., 2019; Rengel et al., 2019). How the mental and physical life was before the ICU is of course crucial to the way the individuals are affected (de Ridder et al., 2021; Geense et al., 2020). The fact that family members as a unit affect each other mentally when something is happening within the unit, develops the family unit and protects it from major disruption (Epstein et al., 1978; McGoldrick et al., 2013). The willingness of family members to communicate and help each other affects the rehabilitation, both mental and physical, of the former ICU patient as well as the mental health of the family members.

Methodological discussion

Different research methods have been used to strengthen the results. Qualitative, quantitative, and mixed method research has been used to address different perspectives. Generalisation in relation to knowledge claims merits careful attention by both qualitative and quantitative research. To cover such issues as planned replication, sampling strategies, systematic reviews, reflexivity and higher-order conceptualisation, thick description, and mixed methods research was used (Lincoln & Guba, 1985; Polit & Beck, 2010).

The concept of the family was described in the information letter of the study, the patient was requested to/could include those family members providing the most support during their critical illness. Family members were not only those living in the same household and/or relatives. The characteristics of the ICU-treated patients and their family varied. This was described in detail, in text, tables and figures in the manuscript and increasing the scope of all studies.

Adult former ICU patients were asked to participate if they had received care for 24h or more in study I, ≥ 72 h in studies III and IV in the FamHC or ≥ 96 h in study II and in study IV for the SGC, two months after ICU care. The interval was constructed this way as literature shows that the prevalence of psychological symptoms, both for the patient and their family, is highest during and near to ICU admittance (van Beusekom et al., 2015). The participants were collected from different ICUs, which might increase the breadth of the participants' characteristics. The results could be applied to a similar group of people in a similar context (Lincoln & Guba, 1985).

How many participants were missed in the data collection via questionnaires can only be speculated on. There was some difficulty in getting former patients and their families to participate, which is why several invitations were sent out.

The interviews were conducted both individually and family-wise, face-to-face, online and by telephone. Online interviews are similar to face-to-face interviews (Kallio et al., 2016). All interviews were audio-recorded and transcribed verbatim, so interviews could be both listened to, to hear pauses, crying, and laughter, and read. This made the analysis more rigorous (Lincoln & Guba, 1985).

The participants all decided where, how and at what time the interview was conducted. This made the participants more comfortable with the environment during the interview situation.

The quotations in the manuscript, illustrate the themes, and give the reader the ability to understand the interpretation and findings (Lincoln & Guba, 1985). Even if quotations are not a choice in GT (Glaser, 1978), I choose to illustrate the core category and categories. They are located at an abstract level, whereas the few quotations presented are located at a descriptive level.

Qualitative study methods show their strengths and limitations with the concept of trustworthiness, which comprises credibility, confirmability, dependability, and transferability (Lincoln & Guba, 1985; Polit & Beck, 2016). GT is not an ordinary qualitative method and uses the concepts of fit, work, relevance and modifiability for judging quality (Glaser & Strauss, 1967; Glaser, 1978).

Quantitative studies work with the same issues in terms of validity and reliability, to be able to follow the audit trail, discuss the planning, collecting and analysis of the data within a research team and with professional statisticians. Text, tables, and figures were used in this manuscript to illustrate and clarify the process (Altman, 1991; Polit & Beck, 2016).

Fit, work, relevance and modifiability (study I)

The sample size in the studies followed the rules of the chosen method and design. In study I, a study with GT, sample size was decided upon when saturation was reached, with nothing new emerging from the data, giving new codes or categories. Then some more interviews were conducted to ensure saturation, one of them being an extreme case in order to reject or confirm the theoretical construct (Glaser & Strauss, 1967).

I conducted all the interviews in study I, and I also transcribed them verbatim. GT research should be cautious with recording to avoid getting stuck on a descriptive level, instead of achieving a conceptual level that focuses on a mutual concern and reoccurring patterns (Glaser, 1978, 1998). This aspect demands strength in the analysis process in order to discover patterns.

I show the relevance, which is determined by how the generated theory captures the main concern being studied and to what extent the theory focuses on real problems for the people who provided the data. The audit trail is shown by presenting the procedures in the research and the processes how the concepts were identified. The ICU patient selected the family members that should participate. This gave comfort and created a more relaxed atmosphere (Veltelen et al., 2018).

An extreme case was an ICU patient with different knowledge and experiences. The ICU patient had good knowledge of how the care in an ICU works and the time since the patient had received ICU care was longer than any of the other participants in the study. This participant was included as one of the interviews as a way to strengthen or reject the theoretical construction. The theoretical construction was strengthened by the extreme case and improved the quality of the study (Glaser & Strauss, 1967; Glaser, 1978, 1998, 2002, 2005).

A limitation is that no families of foreign origin were included and those included here were not typical pre-pandemic ICU patients. Due to the COVID-19 pandemic the ICU patients differed in terms of other underlying diseases or risk factors, and country of birth (SIR, 2022). Former patients without any family were also missing. Another limitation was that no information about previous and/or underlying disease was collected, which might have given a different outcome. The diagnoses for being admitted to the ICU were not recorded either, and maybe there could have been differences if the patients were receiving care for a critical illness, complications or severe trauma like a motorcycle accident or cardiac arrest.

Trustworthiness, credibility, confirmability, dependability, and transferability (studies III, IV)

In the qualitative method, narrative research, there is no rule for the sample size, but a normal sample size is 6-10 participants (Lieblich et al., 1998).

For the data to be considered a secondary analysis the data needs to be rich and informative. The data collection was performed properly regarding technical and ethical issues, in accordance with the research question and not going beyond the primary aim. A five-step holistic analysis was used to learn about variations in the data structure and content and thereby to understand the family and family members' revolutionary life experiences (Lieblich et al., 1998). Secondary analysis was applied to improve and to provide an opportunity for existing qualitative research data to demonstrate new, broader, or deeper perspectives on existing data (Heaton, 2004).

A limitation of a secondary analysis could be that the analysts could be put in a situation of not being present in the actual context, not performing the interviews, and not being able to ask follow-up questions (Easton et al., 2000; Jack, 2008). But here the interviews were conducted by other persons in the research team with similar research questions.

The interviews in studies III and IV varied, as family follow-up interviews for the FamHC, and SGC interviews were collected as individual interviews. Professional researchers in the research team, well aware of ICU care and the research method, performed the interviews. A professional administrator with good knowledge of transcribing interviews transcribed the verbatim transcripts.

The different forms of follow-up interviews in the two interventions may be a limitation (Jack, 2008). A family's ability to function could be hard to determine just by interviewing one family member, even if family members sometimes express their experiences more openly in individual settings (Åstedt-Kurki et al., 2001). A strength might have been to conduct repeated family interviews, as was done in study III, allowing families to explore certain issues in greater depth and to finish uncompleted reflections (Åstedt-Kurki et al., 2001).

In study IV, using a mixed method design of both quantitative and qualitative methods might have strengthened the results. The results from one method were clarified against the results from the other, and the range and breadth were extended using the most appropriate method for the multiple components (Greene et al., 1989; Tashakkori & Teddlie, 2010, 2021).

Another limitation was that the different interventions also differed in time; the FamHC had three sessions during a year and the SGC often had just one session. But the characteristics of the two groups may provide a way of understanding the differences in the outcomes (Jack, 2008).

Reliability and validity (studies II, IV)

Validity refers to the believability, reliability and repeatability of the results in quantitative studies II and IV. Power analysis was carried out and followed a quantitative method (Altman, 1991). And I have explained why the included participants were larger than the power analysis.

The statistical methods, what questionnaires to use, and the analysis were discussed and evaluated within the research team together with a statistician. The p-value in these studies (II, IV) was set at 0.05 (5% risk), a commonly used limit (Altman, 1991). The statistical conclusion is validated by the statistical methods used. Finally to see if conclusions regarding correlations and variances are found in studies II and IV. Cronbach's alpha was used to support the validity (Altman, 1991).

To find out if an intervention could strengthen the support to families experiencing ICU care, the family functioning of families needed to be evaluated. The idea was to carry out a cluster analysis to find out what families might have a higher or lower score in family functioning and/or family hardship. Cluster validation is difficult to achieve within family classifications

of homogeneous groups (Dunn et al., 2017); therefore, we have used statistical tests of significance on variables. The results showed in this study that performing a cluster analysis was not possible since just two out of 60 families had higher/lower scores.

Only 15 % of the former ICU patients agreed to participate in study II, and no reminders were sent. This could be a limitation, but ethical approval was given to not sending a reminder. The low response rates may have affected the results, for example leading to an inaccurately positive picture due to the exclusion of those who were most frail (Wenemark et al., 2010).

The results are strengthened by the sample size and the different clinics used to include participants (Altman, 1991).

It is a strength that valid and reliable instruments were utilised, which includes a psychometric aspect (Keszei et al., 2010). The questionnaires are calculated in the same way as in similar studies. The most appropriate analysis method and the calculations were discussed within the research team. The questionnaires were all given in the same order at all times to all participants in the same way. It was intended that all participants would score the questionnaires in the same order, which strengthened the results.

The cross-sectional design is limited in finding causal conclusions, and family functioning as well as family hardiness were only measured once; this could be a limitation (Altman, 1991). Maybe the results would be different if the data was collected for a long time. One study showed that an intervention with FamHC improved family function and increased perceived health-related quality of life in terms of social functioning and mental health over time and strengthened family well-being regarding stress in the short-term (Ågren et al., 2019).

Validity in the questionnaires was shown in how the instruments measured and what they were intended to measure in relation to the studied population, aim, and dimensions of the instrument (Polit & Beck, 2006, 2010).

Validity in the mixed method study IV was improved by investigating the convergence, corroboration, and correspondence of the results from the different methods (Greene et al., 1989; Tashakkori & Teddlie, 2010, 2021). The sample size was similar in both interventions FamHC and SGC in study IV. The patients were removed from the final analysis to enable the data to be compared between interventions. The former ICU patients were the

ones who choose which family members would participate in the interventions. The results are strengthened by variation within the sample such as gender, age, time of care in the ICU and so on, sample size and the different clinics used to include participants. Data collection took place at the same time for the qualitative and quantitative data. For intra-family correlations data was adjusted (Altman, 1991). The data was collected over time and the difference between three months and baseline was calculated and then analysed using the linear mixed-effects model to adjust for the covariance structure of the data (Field, 2018).

The quantitative and qualitative results from the FamHC intervention were integrated using mixed methods and are shown according to the purpose of interjections between methods. By looking for contradictions and/or new perspectives. I recast the results of qualitative narrative analysis with quantitative results, The SGC results were analysed in the same way. Then the total results from the two interventions were cross-validated. Rich and diverse descriptive information from two types of data source can promote an understanding of proximal similarities and hence allow transferability (Polit & Beck, 2010; Tashakkori & Teddlie, 2021). The validity of the triangulation has been clearly defined by me, with figures, tables, and text, within the manuscript (Fetters & Molina-Azorin, 2017).

Clinical implications

The ICU health care professionals need to be more aware of existential questions and these issues need to be more highlighted both for the patient and family, and the health professionals need more education and practice to develop their knowledge and ability to support families in answering these questions.

Knowledge of family functioning can be used to include the family in decisions concerning the patient. These interventions should be part of the daily care of the patient, and the family of former ICU cared family members can be offered follow-up.

Using family systems nursing during the ICU care may highlight the families' potential difficulties and opportunities to develop strategies to manage the situation, and the health professionals could help them with these issues.

Implementing follow-up interventions gives an opportunity for family members, collectively and/or individually, to reflect on their family, and develop trust which help when communicating within the family about their experience of critical illness.

The pandemic showed the importance of implementing family systems nursing in ICU care for the patient, the family and also the health professionals to ensure patient safety, support the family members and to make the right choices during care.

Future research

More research is needed to find out how to improve and evaluate family systems nursing in the ICU, both during care and as a follow-up. Prospective longitudinal family intervention studies are proposed, with regular clinical nursing to evaluate the effect of nursing directed at the family. Potential outcome variables that can be considered for evaluation are family function, health-related quality of life both at the patient and family level, as well as evaluating health economic factors.

More evaluation is required of how education in family system nursing can develop the nurse's ability to improve communication, information and include the family in the ICU care of the patient. Potential outcome variables that can be considered for evaluation are nurses' security in decision making, safety, improvements in communication and health economic factors.

Studies on how to implement family systems nursing in ICU care are important for the patient, the family and also the health professionals to ensure patient safety and to make the right choices during care.

To study different culture aspects of family functioning in ICU cared patients, born in a different country than Sweden, to see if family functioning differs.

CONCLUSIONS

The family experiencing the ICU find it important to talk about existential issues, their anxiety and insecurity in life. To talk with persons who understand their feelings and who have had similar experiences, helps the patients and their family. These conversations help the family and individuals to consider and gain insight into the unpredictability and thereby better cope with changes in life.

Healthy family functioning showed low scores and family hardiness showed high scores two months after ICU care, which means that there is a willingness to care and to try to understand and support each other within the family.

Families participating in the FamHC experienced improved awareness of family functioning. Their understanding of each other helped them to become closer.

Even if the family is a unit, family members have diverse needs and wishes for support. Some ICU patients need more rehabilitation after the ICU and the family might need support and follow-up.

Family focused nursing during the care could give the health care professionals an opportunity to suggest various support for the family and/or individual family members, and could give the patient, family member and/or family alternatives for follow-up.

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