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Long-Term Impact of Acute, Critical Illness and Admission to an Intensive Care Unit

Perspectives of Patients and Partners

PhD dissertation

Anne Sophie Ågård

Health
Aarhus University
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APPENDICES

Af copyright-hensyn er afhandlingens artikler fjernet fra denne version.

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LIST OF PAPERS

The thesis is based on the following original papers, which will be referred to by their Roman numerals:

I. Ågård AS, Egerod I, Tønnesen E, Lomborg K. Struggling for independence: a grounded theory study on recovery of ICU survivors 12 months post ICU discharge. Intensive and Critical Care Nursing, 2012, 28, 2, 105-113

II. Ågård AS, Egerod I, Tønnesen E, Lomborg K. From Spouse to Caregiver and Back Again: A Grounded Theory Study of Post-ICU Spousal Caregiving.
Submitted manuscript

III. Ågård AS, Lomborg K, Tønnesen E, Egerod I. Rehabilitation activities, out-patient visits, and employment in patients and partners the first year after ICU.
Intensive and Critical Care Nursing, in press.

ABBREVIATIONS

GP	General practitioner
GT	Grounded theory
HRQOL	Health-related quality of life
ICU	Intensive care unit
LOS	Length of stay
NICU	Neurointensive care unit
PTSD	Post-traumatic stress disorder

FIGURES

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INTRODUCTION

In Denmark, 33,000 patients are admitted to an intensive care unit (ICU) annually (1). The purpose of intensive care is to provide continuous and sufficient observation, diagnostics, treatment, and care for patients suffering from potentially reversible failure of one or more organs in order to quickly and effectively maintain, stabilize, or reestablish normal organ function (2). Potential reasons for admission include trauma, cardiac arrest, pneumonia, septicemia, or other medical or surgical conditions. The immediate goal of the ICU is to prevent organ dysfunction and decrease short-term mortality, and traditionally, less attention has been paid to more long-term outcomes (3).

Because the population is aging, the number of patients admitted to ICUs is increasing, and improved medical technology helps even more patients to survive critical illness (4). Consequently, millions of people globally are discharged from the ICU to continue treatment, care, and rehabilitation in general hospital wards, rehabilitation facilities, and at home (5). In the past decade, the long-term physical, psychological, and social outcomes of critical illness and ICU admission have been given increasing attention internationally and are now highlighted as important professional issues (6-11).

Critical illness and admission to an ICU radically affect not only the patients but also their relatives during hospitalization and after discharge (12,13). Little is known, however, about the long-term trajectories of ICU survivors and the concrete challenges facing the patients and their spouses after discharge from an ICU.

In this project, we studied the first 12 months following ICU discharge from the perspectives of the patients and their spouses as individuals and as couples. Studies I and II describe and explain concerns and coping in ICU survivors and their spouses respectively during the first 12 months after ICU discharge. The couples' main concerns and their ways of resolving this during the first 12 months following ICU discharge are described in Study III. Study IV accounts for the trajectories of a group of ICU patients and their partners and identifies their healthcare consumption, work disruption, and rehabilitation during the first year after ICU discharge.

BACKGROUND

This section begins with a review of the literature on patients’ post-ICU outcome followed by a review of the spouses' post-ICU situation. A brief description of the different types of relatives follows, and the chapter ends with a brief summary of the current literature on patients’ and relatives’ post-ICU situation.

The ICU Survivors

During the past decade research has provided insight into important aspects of patients’ situation after ICU discharge. The majority of studies, including three from Denmark (14-16), have used a quantitative design focusing on outcomes related primarily to mortality, depression, anxiety, post-traumatic stress disorder, (PTSD), or quality of life, whereas qualitative studies have focused primarily on patients’ experiences in or memories of the ICU.

Studies have investigated the recovery of other groups of patients not admitted to an ICU, e.g. patients recovering from cancer, stroke, and heart disease. The relatives of these patients have also been studied. Even if there are similarities between the recovery of these patients and ICU survivors, the findings from the non-ICU studies are not readily transferable to the recovery of ICU survivors for several reasons. First, the former groups of patients have not been admitted to an ICU. Second, their recovery may be affected by fear of relapse or imminent death. Third, their illness may have been known in advance to be chronic. Thus, the experiences of non-ICU patients and relatives would be expected to differ from the experiences of ICU survivors and their relatives, and therefore the non-ICU studies are not included in this study. The main results from the current literature on the recovery of ICU survivors are presented below.

Patients are admitted to the ICU for a few days or months depending on the nature of their illness and potential complications. Internationally, the mortality rate for patients in the ICU varies between 8% and 33%, in hospital 11% and 64%; 6-month mortality is 22% to 39%, and 1-year-mortality is estimated at 26% to 63% (17). In the ICU, patients are often unconscious or disoriented, and they might be temporarily unable to speak due to intubation, sedation, or critical illness.

Immediately after the ICU, the patients are transferred to a general ward. After a stay there, they are typically discharged to their home or transferred to a rehabilitation facility.

ICU survivors often suffer from disease-specific sequelae as well as general physical and psychosocial problems (18-20) that require considerable effort to regain pre-ICU functional levels (21). Loss of muscle mass and “ICU acquired weakness” have been identified as particularly important physical factors compromising post-ICU recovery (14,20).

All dimensions of ICU survivors’ health-related quality of life (HRQOL) are lower than in the background population in the first year after discharge (7,22,23) or longer (7,22,24,25). Patients are admitted to the ICU for different reasons, and their pre-hospital morbidity varies greatly. A recent study found that pre-existing disease is the most important factor for long-term HRQOL after critical illness (26). A major part of ICU patients suffer from chronic conditions prior to hospital admission (1). However, in many studies of post-ICU outcome, no distinctions are made between ICU survivors with or without pre-existing disease, limiting the ability to adequately interpret the results. HRQOL has also been negatively associated with delusional memories from the ICU (24). This correlation, however, is uncertain (27).

Accessing pre-admission HRQOL is problematic because patients are often unable to provide adequate information upon admission, and retrospective assessment or by proxy is unlikely to be valid (14). Thus, estimating differences between pre- and post-ICU HRQOL is difficult. Also, assessing the clinical relevance of differences in HRQOL can be complicated because the impact of the illness and possible complications on ICU survivors' HRQOL varies between individuals. For example, a vocalist suffering post-intubation hoarseness may experience a major impact on HRQOL, whereas another patient suffering from major physical sequelae who lives a sedentary life doing computer work from his home may report a more favorable outcome (28).

The prevalences of anxiety and depression have been reported to be 7% to 18% and 3% to 30%, respectively, depending on the methods applied, showing the highest scores among women, younger patients, and patients with stressful experiences from the ICU or delusional memories (24,29-32). Emotional outcome is often associated with the ICU stay, but the question of how the critical illness incident in itself influences emotional outcome still remains unclear. Positive emotional effects may also occur, but this has not been reflected in the literature (29).

A substantial portion of ICU survivors experience cognitive impairment affecting memory, attention, and executive function (19). Deficits in these central functional areas may have important consequences for the activities of daily living, health-care management, and social functioning (33,34). In some studies, however, cognitive or physical complications after discharge are insufficiently described, thus confounding estimates of post-discharge problems.

The prevalence of post-traumatic stress disorder (PTSD) is reported to be 5% to 63% (35). For employed ICU survivors, the ability to return to work can be affected for months or indefinitely (36,37).

Qualitative studies have illuminated ICU survivors' experiences and memories from their stay in the ICU. Some patients have no recollection of their time in the ICU, whereas others have vivid memories of factual events, feelings, or hallucinations (38). Several studies have focused on the meaning of ICU memories and experiences later in life and studied how the ICU survivors cope with them (39-46). For some ICU survivors, the memories and experiences from the ICU remain vivid and encroach on their life after discharge. These studies were conducted some weeks and up to several years after ICU discharge.

The socioeconomic context is expected to influence fundamental aspects of post-ICU recovery. In Denmark like many European countries, post-ICU rehabilitation is tax-financed, whereas in other countries, ICU survivors may have to spend their life savings on rehabilitation, or it may be financed in part or fully through private insurance. Also, health care, sickness benefits, and social services vary considerably between countries, probably affecting patients' trajectories, e.g. regarding access to training programs or rehabilitation services. Thus, if the national socioeconomic context of a study is not explicated, for the sake of an international audience, it is difficult to assess how the context influences reported post-ICU outcome, and generalization of outcome results beyond the study country can be problematic.

Close relatives are a source of support and comfort to the patient throughout the illness trajectory (47-50). However, studies concerning patients' experiences or post-ICU outcome often lack background information about relatives or discussions about the potential impact on the results of having close relatives. Little is known about the concrete assistance and support provided by relatives and the impact this may have on patient outcomes and trajectories.

The focus of most of the studies reviewed has been on measuring patient outcomes in pre-defined terms or on describing particular phenomena known to influence important aspects of patients' lives. Less attention has been paid to providing a detailed description of patients' post-ICU trajectories. Important questions about rehabilitation services provided to the ICU survivors, their training efforts, and the general challenges of post-ICU recovery have not been adequately addressed. Also, the everyday concerns and challenges facing ICU survivors and their ways of coping with these challenges in collaboration with close relatives have not been adequately explored.

The Relatives of ICU Survivors

An increasing interest in the consequences of critical illness has yielded a number of studies on relatives' roles, experiences, and post-ICU outcomes, and the long-term consequences of critical illness for the entire family is now a research priority in critical care (6,13,51). Most of the existing studies focus on the time in the ICU using a qualitative design, and not many report on the time following ICU discharge (13). None of these studies are from Denmark. The design of the outcome studies is predominantly quantitative focusing on, e.g., HRQOL, anxiety, depression, or caregiver burden. A few post-ICU studies have used a qualitative design in the study of relatives' experiences and coping strategies. The majority of post-ICU studies on relatives were conducted in the last decade. In the following, the main results from the literature are presented.

When a person is admitted to the ICU, close relatives such as spouses, parents, or children are also affected by the adverse consequences of critical illness and its aftermath, and for some it can be a crucial experience (12). In patients suffering from chronic conditions prior to admission, the relatives may have been involved in their care for years. In cases of sudden illness, the relatives may not have had caregiving experience prior to the patient's hospital admission. Whatever their pre-admission background, the relatives generally follow the patient throughout hospitalization and convalescence as a source of support and comfort (47-49).

Admission of a patient to an ICU is recognized as being a stressful experience for their close relatives (36). In the ICU, relatives may be confronted with major changes in their lives because of their loved one's illness. Yet, relatives can be strong and they strive to cope and adapt to a changed reality (12,52-55). When the patient gradually recovers and is transferred to a general hospital ward, the relatives follow to support the patient. Transfer from the ICU to the general ward is a source of insecurity for the patient as well as the relatives due to lower staffing and less frequent monitoring (56-58).

When the patient is finally transferred from the hospital to a rehabilitation facility or home, the relatives continue to support the patient. Returning home, the patients may need extensive care and assistance. If provided by a close relative, this sometimes amounts to 20 to 30 hours a week and consequently limits the relative's ability to work (59-62). As informal post-ICU caregivers, they may experience considerable lifestyle disruption and strain (62-64). Relatives' HRQOL is generally lower than in the background population (65), and in the first 12 months after ICU discharge, the prevalence of anxiety and depressive symptoms can be higher than in the relatives of patients suffering from Alzheimer's disease or other chronic conditions (61,62). A few studies suggest that the relatives may be even more anxious or depressed than the patient (66,67). If relatives feel burdened, they might attend less to their own health needs (65,68), and they may not mobilize informal support for their own benefit from friends or family or formal support from community-based services (59,69).

As previously described regarding the patients, little is known about the challenges of daily life facing the close relatives following hospital discharge, even if some problems are most likely reflected in the assessment scores, such as quality of life, depression, or anxiety. In particular, questions about the relatives' role and the actual assistance they provide during post-ICU recovery have not been adequately addressed.

Types of close relatives

In the reviewed literature distinction is rarely made between the types of relationships different family members can have to the patient or reflections on how this may influence the results. Several studies include a combination of spouses, children, or parents. The literature has reported important discrepancies in the experiences of caregiving between the different types of relatives (59,70). To illustrate: A man living with his own family and providing informal post-ICU care to his widowed father will have to divide his attention between his parent and his own family and this may cause a stressful situation. He may also have to spend hours on transportation to the ICU survivor's house and, consequently, have little time to attend to detailed caring for his parent. To some caregivers, living away from the care receiver may be stressful, and for others it could be a relief. Compared to a son living far away, a husband living with his recovering wife will probably be able to provide more continuous care and attend to more details. Caregivers' expectations of providing care based on spousal commitment may also be different from providing care because of filial obligation. From the care receivers' point of view, care provided by a cohabiting spouse or by other relatives may also be different. In summary, fundamental aspects of caregiving are expected to differ between relatives with differing relationships to the patient.

In Denmark, the most common forms of long-term partnerships are marriage and cohabitation (71), and thus cohabiting spouses or partners are expected to be the typical post-ICU caregivers. This study includes married and unmarried couples, thus excluding caregiving children, parents, or friends. We use the terms partner, spouse, or caregiver interchangeably and, correspondingly, the terms patient, ICU survivor, and care receiver. The term relatives or close relatives includes both family and significant other people that might not be blood-related, but who are otherwise close to the patient, consistent with the definition of the word "pårørende" used by the Danish National Board of Health (72,73).

Summary

ICU survivors are reported to suffer from a wide range of physical, cognitive, and psychosocial impairments that affect their recovery for months or years. Sizeable differences have been found in studies of post-ICU physical or cognitive complications and in terms of HRQOL, anxiety, depression, or PTSD. This could be due to the heterogeneity of the ICU population in general, differences in inclusion criteria, socioeconomic differences between the study countries, or perhaps differences between survivors with or without close relatives. Patients' everyday concerns and challenges are most likely reflected in the reported outcome scores, but little is known about the mechanisms involved.

Relatives are often deeply affected by the patient's illness. They follow the patient and provide care and assistance throughout hospitalization and at home. Relatives' HRQOL can be impaired, and some experience anxiety or depression. As informal caregivers, they may provide substantial hours of care, which in some cases affects their ability to work. Also, their interactions with friends and family can be affected. Some studies on relatives' experiences or post-ICU outcomes include spouses as well as children or parents of the patient, limiting transferability of the study findings. Similar to studies of patients' outcomes, the socioeconomic context of caregiving in caregiver studies is often inadequately described, leaving the reader with a poor chance of estimating the impact of national health care and social conditions on the study results.

There is a gap in the international body of knowledge concerning the trajectories and challenges of post-ICU recovery as described from the perspective of ICU survivors and their spouses. Little is known about their use of health care services and their long-term affiliation to the work force after ICU-discharge.

Furthermore, the everyday challenges and concerns of patients and their spouses and the couples' ways of coping individually and together during long-term recovery after ICU discharge have not been adequately described. Further insight into these sparsely researched areas could complement current knowledge on post-ICU convalescence and provide health care staff in hospitals and primary health care with a stronger basis for preparing ICU survivors and their families for post-ICU recovery.

AIMS

The aims of the study were:

Study I. To explore the challenges facing ICU survivors with a cohabiting spouse and explain patients' concerns and coping modalities during the first 12 months after ICU discharge (Paper I)

Study II. To explore the challenges facing cohabiting spouses of ICU-survivors and describe and explain their concerns and caregiving strategies during the first 12 months after ICU discharge (Paper II)

Study III. To describe the joint main concern of former ICU patients and their spouses and explain the couples' ways of resolving this during the first 12 months following ICU discharge

Study IV. To describe the influence of critical illness on patients and their partners in relation to rehabilitation, healthcare consumption, and employment during the first year after ICU-discharge (Paper III)

METHODS AND MATERIALS

Design and Settings

To accommodate the limited insight into the trajectories and challenges of long-term post-ICU recovery as described from the perspective of patients and their partners, an explorative, longitudinal design was chosen. Semi-structured interviews with patient and spouse dyads and separate focus groups of patients and spouses recruited from the dyads population were the primary sources of data. Furthermore, we collected data from public registers.

Participants were recruited from five ICUs within three of the organizational regions of Denmark: the Northern Region, the Central Region, and the Region of Southern Denmark, between February and October 2009. The units were four general ICUs (levels 2 and 3) and one neurosurgical ICU (level 2) with 7–13 beds at three university hospitals and one regional hospital. In 2009, the number of patients admitted to the five ICUs was 492 to 926 from the smallest to the largest unit.

Methodology

Grounded Theory

The focus of studies was to describe the trajectory and challenges facing ICU survivors and their spouses as individuals and as a couple and explain their concerns and coping modalities during the first 12 months after ICU discharge. Grounded theory (GT), with its emphasis on social interaction, was chosen as the methodological framework of this study. GT aims to discover the main concern of the people under study, how they resolve this concern, and explain patterns of behavior (74,75).

In the 1960s, the American sociologists Barney Glaser and Anselm Strauss first described GT in their research on dying people (76). Later, this study was used as a basis for a description of the principles of GT in their book: “The Discovery of Grounded Theory” (74). After disagreements on the further development of GT, Glaser and Strauss went their separate ways. They both continued writing about their method based on different overarching analytic principles (77,78).

Glaser continued to elaborate on the methodology and wrote several books on its use (75,79-81,81-83). In this study we chose his “Glaserian” or “classic” GT approach that aims at generating a theoretical abstraction of the empirical world by use of a primarily inductive process of systematic conceptualizations.

It is generally recognized that GT implies a symbolic interactionist perspective (78,84-86). Glaser, however, positions GT as a generic method independent of the epistemological position: “GT can use SI [symbolic interactionist] type data and its perspective, but as a general method it can use any other type of data […] and in any combination, and any other theoretical perspective […]" (87). Symbolic interactionism is based on three premises: 1) Human beings act toward things on the basis of the meanings that the things have for them; 2) The meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows; and 3) These meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters (88).

Choosing GT as the methodological framework of this study, we emphasize the dynamic relation between individuals, social context, communities, and society and the interrelationship between interpretation of the world and action in the world (74,84). This perspective assumes that individuals are active, creative, and reflective, and that social life consists of processes (89). ICU survivors and their spouses act on the basis of the meaning they themselves ascribe to events, things, or phenomena in their daily lives. They act separately and together shaping the meaning they individually and jointly ascribe to any given thing or phenomenon. By interviewing ICU survivors and their spouses we sought to disclose the meaning they ascribed to post-ICU recovery and identify their main concerns. Since their interpretation of their main concerns and their responsive strategies were assumes to be somehow interrelated, we contend to also get an indication of how they act individually and together.

The ontological position of GT has been debated (84,90,91). We refer to a realist position acknowledging the reality of human constructions against which theories can be assessed. The validity of a grounded theory can be assessed throughout the research process from data collection and analysis to theory development (84).

Criteria for Inclusion

Patients of all ages are admitted to the ICU because of deterioration in previous health conditions, acute illness, or complications following elective surgery, and their trajectories in the ICU vary considerably. This heterogeneity of the ICU population represents a challenge in ICU research (28). The criteria for inclusion to the study were as follows:

1) ICU survivors aged 25-70 years
2) Endotracheal intubation for more than 96 hours
3) Living with a spouse
4) No serious pre-existing health conditions
5) Ability to communicate adequately in Danish

Below, the considerations leading to the definition of the criteria are described.

ICU Survivors Aged 25–70 Years

We initially chose to include patients aged 25 to 55 years to explore post-ICU recovery including participants' long-term ability to work. After 1 month of data collection, however, very few patients eligible for inclusion were identified. To be able to collect a sufficient amount of data and reach the study aims within the study period, we changed the age criterion to include patients aged 25 to 70 years. As retirement age in Denmark is currently 65 years, gradually changing to 70 years, and early retirement starts at 60 years, raising the upper age limit would mean including more retired patients, and lowering the lower age limit would include more students. As the majority of the ICU population are elderly, raising the upper age limit allowed the inclusion of a subset of patients that was more similar to the general ICU population.

Endotracheal Intubation for More than 96 Hours

ICU patients are inhomogeneous as a group. Some patients are admitted to the ICU because of severe illness requiring weeks of treatment and care in the ICU before they are well enough to be transferred to a general ward. Other patients have a short stay in the ICU. Not all patients need ventilator treatment and intubation. As the focus of the study was on the long-term impact of critical illness and admission to the ICU, we intended to include participants with sufficient ICU experience, and consequently, we targeted the most severely ill ICU survivors. Patient assessment scores used on the first day of ICU admission and perhaps throughout the ICU stay to gauge the severity of patients' illness, e.g., the APACHE, SAPS, or SOFA scores,[1] are used to predict mortality, and they do not necessarily predict long-term outcome (92). Also, the included ICUs used different assessment instruments. In contrast, duration of intubation has been reported to be a simple indicator predicting post-discharge morbidity across the heterogeneous ICU population (61,93), and patients intubated for more than 96 hours have been identified as the most severely ill (60). Thus we included patients who had been intubated > 96 hours.

Living With a Spouse

As mentioned above, caregivers' experiences of providing care based on spousal commitment may be different from providing care because of filial obligation (59). Also, from the care receivers' point of view, care provided by a cohabiting spouse may be different from the care provided by other relatives. In the OECD countries including Denmark, the most common forms of long-term partnerships are marriage and cohabitation (on average 61%) (71), and thus cohabiting spouses are expected to be the typical post-ICU caregivers. On this basis, we focused on this typical type of patient-caregiver relationships, leaving out partners living away from the patient as well as children, parents, or friends providing care for the patient.

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[1] APACHE score: Acute Physiology and Chronic Health Evaluation Score; SAPS score: Simplified Acute Physiology Score; SOFA score: The Sequential Organ Failure Assessment Score

No Serious Pre-Existing Health Conditions

Pre-existing illness has been shown to have a major impact on post-ICU outcome (26). To distinguish the impact of critical illness and admission to the ICU from the impact of pre-existing health conditions, we excluded patients with conditions that might have severely affected the patient's daily life prior to ICU admission. Thus, we primarily included acutely ill patients. Patients admitted to the ICU because of complications to elective surgery for a recently diagnosed health problem were also included if we estimated that this health problem had not severely affected the patient's daily life prior to admission and in itself would not have been expected to cause admission to the ICU. Because the majority of ICU patients suffer from pre-existing health conditions on admission (1), our participants, in this respect, do not represent a typical sample of the general ICU population.

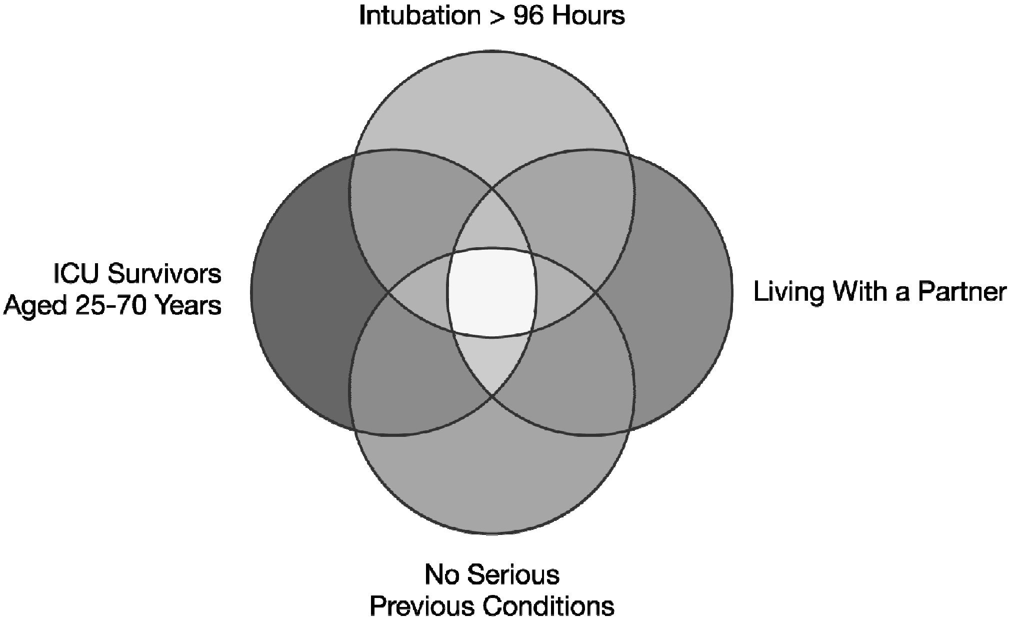
To identify participants without serious conditions prior to admission, we would have preferred using an objective instrument such as the Charlson Comorbidity Index (94). This instrument, however, was designed to identify physical dysfunctions rather than mental illness or severe cognitive dysfunction and, consequently, would not accurately identify all the conditions of interest in our study. Because we were unable to find other instruments suitable for selection, we assessed each potential participant for eligibility on a pragmatic basis using information from hospital charts. The patient was excluded if a description of pre-admission health status was missing in the hospital chart.

In addition to patients with major heart, lung, or neurological disease, we also excluded patients with conditions such as depression, brain damage, schizophrenia, cancer, a recent history of drug/alcohol abuse, or attempted suicide. We accepted conditions such as well-regulated diabetes, glaucoma, minor musculoskeletal problems, and cardiac arrhythmia without symptoms. To ensure consistency, the primary investigator made the assessments of all potential participants based on their hospital charts.

Ability to Communicate Adequately in Danish

ICU patients may be cognitively impaired because of pre-existing conditions, the illness or injury prompting their ICU admission, or complications to their critical illness causing communication problems. To make it possible for participants to tell their stories themselves during the interviews, being able to communicate adequately and in Danish was a criterion for participation. Figure 1 illustrates the inclusion-exclusion procedure.

Figure 1 The Inclusion-Exclusion Procedure



Recruiting Participants

From study onset, the idea was to have nurses in the ICUs prospectively identify potential participants among the patients in their care, and initially ICU staff in three ICUs were informed orally and in writing about the study. After the first month of data collection and initial analysis, however, we realized that this strategy would fail to yield sufficient data. Consequently, we changed the identification strategy and identified patients retrospectively from ICU databases. Moreover, we raised the upper age limit for participation and involved more ICUs thus including, for convenience reasons, ICUs from university as well as regional hospitals.

During a 9-month period participants were consecutively identified and recruited. From the ICU where the primary investigator is employed, patients were recruited during 9 months. From the other ICUs, patients were included from 3-month samples in a staggered pattern that allowed us to enroll enough participants within the time frame of the study. Eight ICUs provided information about potential participants. However, we were able to identify patients fulfilling all criteria for inclusion from only six ICUs. Patients from five ICUs agreed to participate in the study. Tables 1 and 2 provide an overview of the procedure of recruiting participants and characteristics of the collaborating ICUs.

Table 1 Identification and Recruitment of Participants from Eight ICUs

	2009									Identified patients	Participating patients
ICU no	Feb	Mar	Apr	May	June	July	Aug	Sept	Oct		
1	■	■	■	■	■	■	■	■	■	10	6
2	■	■	■							5	2
3	■	■	■							7	1
4		■	■	■						10	8
5			■	■	■					2	0
6			■	■	■					0	0
7			■	■	■					0	0
8							■	■	■	2	1

Table 2 Characteristics of the Eight Collaborating ICUs

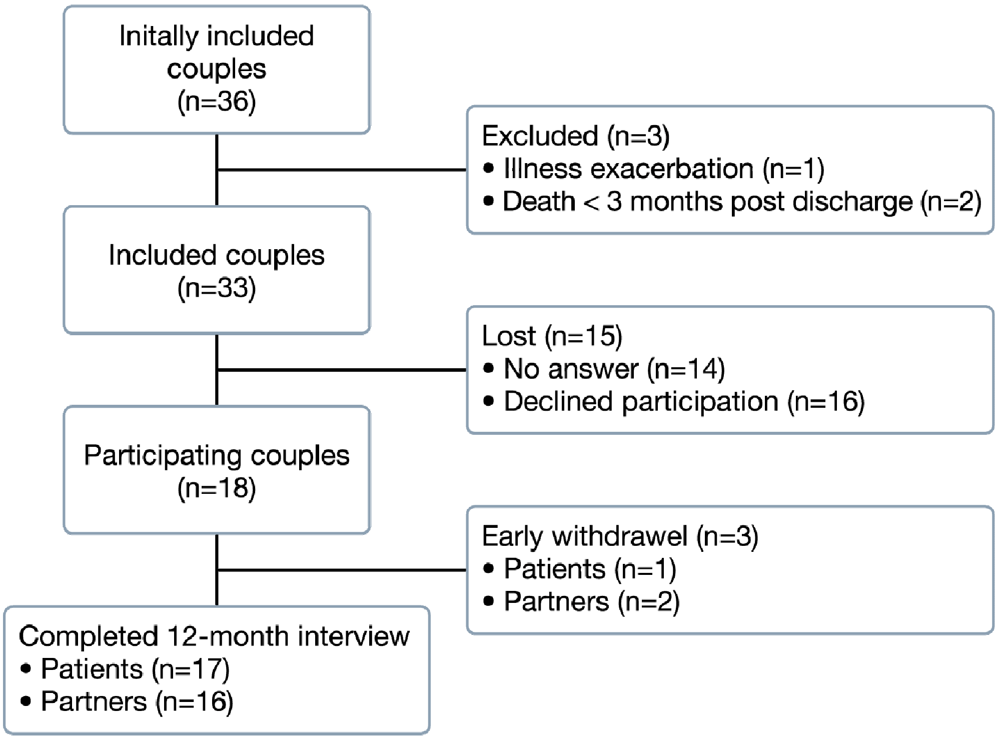
ICU no	Beds	Pt/Year	Type
1	13	746	General
2	12	926	General
3	8	500	General
4	12	532	Neuro
5	8	765	Thoracic
6	10	998	General
7	8	762	General
8	7	492	General

Identification of patient eligibility varied between the collaborating units. Databases at ICUs 1, 6, and 8 identified patients according to age and ventilator duration within a specific timeframe. The database at ICU 4 identified patients according to age and timeframe, and the databases at ICUs 2, 3, 5, and 7 identified patients within a specific timeframe only. Hospital charts provided the information that was lacking in the databases. The number of patients assessed for eligibility in each ICU varied depending on whether the ICU databases could initially identify patients meeting one, two, or three criteria for selection.

Procedure of Enrollment

In Figure 2 the procedure of enrollment is described.

Figure 2 Procedure of Enrollment



A total of 36 potential participants were identified. Two patients had died and one was seriously ill again prior to the initial contact, and these three patients were excluded. The remaining 33 couples were approached by regular mail, inviting them to participate in the study. Of these, one couple refused to participate, because the spouse felt his wife was too ill to participate, and 14 couples never replied in spite of one written reminder. For ethical and legal reasons we were unable to retrieve further information from registers about the non-participants.[2] We found no discernible patterns in differences between participating patients and non-participating patients with regard to type of ICU or hospital, reasons for ICU admission, length of ICU or hospital stay, age, or sex.

Participants

Eighteen patients and 18 spouses participated in the study. The patients were aged 35 to 70 years, and 11 patients were men. The spouses were aged 30 to 72 years. The patients suffered from a wide range of physical and cognitive complications (See Papers I, II, and III). One couple and one spouse withdrew from the study before the 12-month interview without stating why.

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[2] The National Board of Health was consulted on the issue in January 2011 and again in January 2013 (Katrine Winther Hansen)

Data Collection

Table 3 provides an overview of the course of data collection. The numbers represent each dyad and focus group interview.

Table 3 Overview of Data Collection

		Jan	Feb	Mar	April	May	June	July	Aug	Sep	Oct	Nov	Dec
2009	Dyads					1,2, 3	4,5, 6	7,8, 9		10, 11, 12	13	14, 15	16, 17, 18
2010			(3)[a]	1,2, 4,5, 6	7	8,9	10, 11[b]	13	12, 14, 16	15		17, 18	
	Groups			1,2, 3,4									
2011	Register data	X											

[a] The couple left the study before the 12-month interview;
[b] The partner left the study before the 12-month interview.

Theoretical Sampling

Glaser and Strauss suggest that the investigator should not decide in advance which data should be included in the study. Instead decisions about which data to include next should be made as the theoretical understanding of the field under study evolves (74), thereby allowing the emerging theory to be grounded in the issues most salient to the participants (78). This ongoing process of collecting new and still more focused data, *theoretical sampling*, is a corner stone in grounded theory. "Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them in order to develop his theory as it emerges. This process of data collection is controlled by the emerging theory" (75). As a result of our methodological choice to study the first 12 months after ICU discharge for each participant recruited from a limited group of potential participants within the planned timeframe of the study, we did not include participants other than those identified and recruited during the 9-month period (February till October 2009). However, according to Glaser, theoretical sampling focuses on including new *data*, which does not necessarily imply including new *interviewees* (95)[3].

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[3] I had the chance to discuss this particular issue with Dr. Barney Glaser on a Grounded Theory course in Oxford in February 2011, where he confirmed my understanding of this methodological question.

We applied to the principle of theoretical sampling by consecutively conducting new interviews during the entire 19-month period of concurrent data collection and analysis as illustrated in Table 3. Also, asking new questions to existing data allowed us to confirm or reject the evolving theoretical understanding of patterns in the field gradually saturating our theory (75). Also, in the dyad interviews we sampled for both qualitative and quantitative data, thus continuously adding new types of data to our study.

To support theoretical sampling of new interview data, the dyad and group interview guides were adjusted several times to reflect our evolving understanding of the field (74). Each of the 40- to 90-minute interviews was audiotaped and transcribed verbatim.

Dyad Interviews

Dyad interviews with patients and their partner were chosen as the primary data source. The focus of the study was on the couples' ways of coping as individuals and as a couple with their post-ICU challenges in the context of their life together. Separating individuals' perspective from dyad interviews has been questioned (96). However, from a social interactionist perspective, meanings and actions are handled in and modified through the social interaction one has with one’s fellows (97). In joint interviews, the spouses can corroborate or supplement each other's stories. They can probe, correct, challenge, or introduce fresh themes for discussion that can result in richer data (96). In this study, observations of interactions and discussions among the spouses during the interview sessions and the couples’ communication patterns regarding the issues raised were included as data about their coping strategies and joint challenges (98,99). To illustrate, a spouse silently left the dyad interview for a minute to get some medicine and a glass of water for the patient. She didn't articulate this activity but returned quietly to the interview 1 minute later. This type of information about the couples' interactions would be lost in individual interviews with the patient and spouse (100). However, when interviewing dyads, there is a risk that one person dominates the conversation (100) or sensitive issues may not be brought forward. During the interviews, I realized that when one spouse stopped talking, the other spouse often took over. Consequently, I addressed one of the spouses specifically when I wanted information from that person. This strategy usually provided time and space for each spouse to comment on issues important to them.

The two rounds of interviews were planned at 3 and 12 months after ICU discharge. At 3 months, we expected that most patients would have returned home, and both patient and partner would have some experience with everyday life after discharge. The second round of interviews was planned at 12 months after discharge from the ICU and was seen as a relevant time span to explore long-term impact. For practical reasons, the first round of interviews was conducted at 3 to 4 months after ICU discharge and the second round at 12 to 16 months after ICU discharge. The interviews took place in the couples’ home, or, if the patient was in hospital, in a quiet room in the hospital or the rehabilitation facility (five interviews).

In the first interview round, the aim was to gain initial insight into the challenges facing the patient and spouse, their concerns, and ways of coping in the first 3 months after ICU discharge (See Appendix 4). In the second round of interviews, the focus was to some extent on the issues from the 3-month interviews (See Appendix 5). Also, in accordance with GT's focus on social processes and the longitudinal design of the study, I asked questions about process, trajectory, changes over time, turning points, and strategies developed to cope with the challenges facing the couple over time (75). In both interview rounds, I also asked probing questions about important issues reported in the literature concerning patients' lives after ICU discharge, e.g. memories from the ICU, nightmares, or strange dreams.

Information regarding how participants attended public or private training programs, their employment situation, and post-ICU use of community services was not available from registers and was obtained through the dyad interviews (See Appendices 4 and 5).

Focus Group Interviews

To complement the dyad interviews and allow ICU survivors and spouses to discuss general aspects of post-ICU recovery and perhaps sensitive issues or topics of domestic disagreement (54,101), I conducted two focus group interviews with patients only (*n* = 3 and *n* = 7) and two with spouses only (*n* = 2 and *n* = 7). Potentially, focus groups can inspire discussions among participants, encouraging them to share views and perceptions (102). Focus group interviews also have the advantage of getting reactions from a range of participants in a relatively short time, and they can be useful to check hypotheses and provisional conclusions (103).

The group interviews were conducted between the 3- and 12-month interview rounds (See Table 3) in meeting facilities at one of the hospitals, and all the couples were invited to participate. To allow as many patients and partners as possible to attend, each interview was scheduled according to participants' wishes, e.g., regarding date, time of day, and whether patient and spouse preferred to attend the interviews on the same or separate days. In spite of the burdensome situation experienced by some of the couples, 10 of the 18 couples managed to participate in the focus groups, and several of them drove 45 to 90 minutes to get there. The ideal size of a focus group is 4 to 10 persons depending on the nature of the topics. More sensitive issues require smaller groups (102). For practical reasons, only three patients and two spouses (one cancellation) participated in the small focus groups, allowing each participant to elaborate more on the questions raised than in the larger focus groups. We found no pattern in the characteristics of the focus group participants as compared to non-participants. The small focus groups took place 1 to 2 weeks before the larger interviews, allowing time to adjust the interview guides and consider the logistics of the large groups. Table 4 provides an overview of participants in the group interviews.

Table 4 Focus Group Participants

Patient				Spouse		Focus groups			
						1	2	3	4
ID	Age	Sex	Type of admission	Age	Sex	Patients	Spouses	Patients	Spouses
1	35	M	Trauma	33	F				
2	39	F	Neuro	39	M			X	X
3	40	F	Cardiac	42	M			X	X
4	40	F	Gastric	39	M			X	X
5	40	M	Neuro	30	F				
6	45	F	Pulmonary	43	M	X	[a]		
7	50	M	Neuro	55	F	X	X		
8	53	M	Trauma	48	F				
9	55	F	Neuro	58	M				
10	58	F	Pulmonary	73	M			[b]	[b]
11	60	M	Neuro	57	F				
12	63	M	Trauma	58	F			X	X
13	64	M	Trauma	60	F			X	X
14	67	M	Cardiac	62	F				
15	68	M	Cardiac	66	F			X	X
16	68	M	Trauma	60	F			X	X
17	70	M	Medical	66	F	X	X		
18	70	F	Gastric	72	M				

[a] One spouse cancelled

[b] The couple cancelled on the day of the interview

As moderator, I asked the participants to briefly present themselves and explain their background for participating before proceeding to the planned questionnaire route (See Appendices 6 and 7). The atmosphere at the focus group interviews was friendly, and there were moments of both humor and serious reflection.

At the large group interviews (three and four), when first the ICU survivors and later the partners were interviewed on the same day, the partners waited in a different room and switched rooms when it was their turn. A fellow research nurse looked after the waiting groups and joined their conversation. She later reported that conversations in the groups of waiting ICU survivors and partners were lively, and that the participants seemed to have a lot to talk about. On the day of the group interviews, the group of ICU survivors was interviewed first, because I expected that waiting might be tiring for them. Consequently, the partners waited together before their interview, leaving them with the opportunity to discuss issues important to them prior to the interview.

In the large partner group interview, I was aware that discussions had already taken place. Noticing how participants sometimes referred to discussions from the waiting room, I was encouraged to ask questions about their previous conversations. Also, on one occasion I was surprised that the partner group did not bring up a particular issue, leading me to ask about the relevance of this issue. It turned out that they had already discussed it in the waiting room.

To record impressions from the interviews and provide feedback on my role as a group interview moderator, an observer joined the two large group interviews. The observer, a nurse researcher with experience with group interviews, focused on my ability to promote an open and respectful atmosphere, to listen attentively, to ask probing questions while keeping the conversation on track, and my ability to encourage those who might otherwise say little, allowing them the time and space needed to elaborate on their views while perhaps moderating more dominant talkers (102).

Each group interview lasted 70 to 100 minutes. They were audiotaped and transcribed verbatim.

Register Data

"All is data" - a methodological stance often repeated by Glaser (104). The interviews revealed that in the first 12 months after ICU discharge, the lives of patients and partners were disrupted by on-going rehabilitation, outpatient visits, commuting, and employment changes. To provide rich detail to our description of recovery and understand the interaction between patients' everyday lives and different elements of participants' post-ICU trajectories, we combined information from the interviews with quantitative data from registers. From the study onset, the idea was to encourage both patients and partners to note down in a calendar whenever they interacted with health care services, including hospital readmission, doctor's visits, etc. during the first year after ICU discharge. However, after the first interview we realized that patients and partners were not always sufficiently reliable historians. Furthermore, we found it inappropriate to burden them by asking them to keep track of events for our sake, when this information could be obtained in other ways. Instead, data concerning participants' contacts to hospitals, clinics, GPs, and other health care services were provided by The Danish National Board of Health[4] with permission from the participants. To be able to compare the participants' use of health care services before and after ICU admission, data for each participant were obtained for the 12-month period before ICU admission and the 12 months after ICU discharge.

The Researcher's Role

During the interviews, the participants and the primary investigator developed a good rapport through conversation in the friendly environment of the couples' homes. Because of my professional background as a critical care nurse, I easily related to the participants' accounts of their time in the ICU, which facilitated the interviews. At the same time, I was focused on being open-minded, not letting my professional background blur my attention toward the couples' post-ICU challenges of which I had little knowledge. The

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[4] Landspatientregistret and Sygesikringsregistret.

friendly atmosphere provided a good basis for in-depth interviews. On the other hand, I had to remain focused in order to not let the friendly atmosphere disrupt my professional distance as a researcher.

In the interviews, I paid attention to possible conflicts between the spouses that signaled whether or not it was all right to talk about a particular matter, letting the couples themselves decide what they wanted to relate. I sometimes asked probing questions about possible conflicts, being careful not to take on a therapist's role. For the couples, verbalizing difficult issues could stir up marital disagreements. On the other hand, it could also be a relief talking about such issues with an outsider.

Ethical Considerations

The ethical and legal procedures of the study were approved by The National Board of Health (J.nr. 7-604-04-2/158/ EHE) and The Danish Data Protection Agency (J.nr. 2009-41-3022).

As the mortality rate is high among ICU survivors (1,17), we checked hospital registers to make sure the patients were still alive before the participants were approached the first time.

Prior to enrollment, participants were informed in writing about the study including information on ethical and legal aspects and the right to withdraw from the study at any time without explanation. Moreover, they were informed that refusal to participate or later withdrawal from the study would not affect later contacts with hospitals or clinics (See Appendix 1). Participants were asked to return a letter declaring their interest or refusal to participate in the study (See Appendix 2). At the first interview session a few weeks later, I brought the written information and repeated it verbally. After this, patients and partners were asked to sign a letter of consent agreeing to both interviews and the collection of register data (See Appendix 3).

Before each interview, the enrolled ICU survivors were contacted by regular mail asking them if I could contact them to arrange the interview. Participants replied in a stamped, addressed envelope or by email or telephone. If the reply was not returned after 2 weeks, a reminder was sent.

Anonymity in the group interviews could not be maintained. At the start of the group interviews, I pointed out that only participants' first name would be used, and that each should decide how much they would like to relate.

Data Analysis

Staying Theoretically Sensitive

In his writings, Glaser emphasizes how theory should emerge from data and not be forced through schematic analysis (80). However, developing a grounded theory is not a passive process, with theory emerging from data by itself. Rather, it involves an active interplay between data and the researcher throughout the research process. In this process, the researcher is not a neutral instrument of research. GT acknowledges that the researcher is not a tabula rasa, and that personal background, experiences, and context influence the researcher's methodological choices and perspective (74). Also, from a symbolic interactionist perspective, the researcher is co-creator of the study findings. While acknowledging the active role of the researcher in all aspects of the research process, we take a realist epistemological position acknowledging social constructs as real (84).

In the long process of data collection and analysis, several structural dimensions and their mutual influence on the first year of post-ICU recovery were constantly compared: A temporal dimension, an individual dimension, a couple dimension, and a collective dimension. In the *temporal dimension*, by focusing on two points in time I studied the first year of post-ICU recovery. Here, I had to balance between two positions: On the one hand, because of the longitudinal nature of the study, I had to remain open to prevent premature assumptions about participants' main concerns and coping modalities, as their situation and concerns were likely to change during the 12-month study period. On the other hand, I had to identify tentative core categories and decide which issues were more important than were others to explore further in order to be able to gradually focus the study. In the *individual dimension*, the focus was on the main concerns of the former ICU patients and their spouses as individuals. In the *couple dimension*, the couples' perspective was explored. Finally, in the *collective dimension*, the focus was on illuminating more general aspects of recovery as well as issues that the couples might have found sensitive to discuss in the dyad interviews.

In (74,79)the study, my personal background and my experience from many years as a critical care nurse as well as my background as a research nurse in the field of critical care shaped the initial focus of the study as well as subsequent methodological decisions. In designing the study, I made systematic efforts not to let my background blunt my theoretical sensitivity. To remain analytically sensitive and avert premature analytical ideas and conceptions, several strategies were applied. First, in accordance with the GT principle of constant comparison (74,79), I constantly went back in the data to compare new findings with earlier ones. For example, I went back to earlier interviews and recoded information in relation to codes developed later in the process. Also, prior to each second-round interview, I reheard the first interview with the couple recalling their particular situation. Second, I discussed the analytic process and provisional findings with the primary supervisor, who also analyzed some of the interviews. Third, writing memos including notes of impressions from the interviews and later notes in the form of text and figures on ideas about the relationship between, e.g., codes and categories during the entire process of data collection and analysis enabled me to track the emergence of provisional ideas and compare these with later findings (75). Furthermore, when I started writing up the findings, the memos formed a rich bank of impressions and ideas and provided "integrative binding"(95) supporting the final structuring of the GTs.

Dyad Interviews

In accordance with the GT approach, data collection and analysis were performed concurrently (74). GT involves three parallel, simultaneous processes: data collection, coding, and memo writing. By coding, the researcher fractures the data and simultaneously develops two types of codes: substantial and theoretical codes. Substantial codes conceptualize the empirical substance of the area of research, whereas theoretical codes conceptualize how the substantive codes may relate to each other (75). Memos are “the theorizing write-up of ideas about codes and their relationship as they strike the analyst while coding” and are “the bedrock of theory generation” (75).

The analytic process involved open, selective, and theoretical coding in which the analytic perspective gradually evolved from a focus on particulars to a general level conceptualizing social processes in the empirical world (105). During the initial round of interviews, the primary investigator analyzed the interview transcripts line-by-line, developing open codes and gradually drawing a provisional first picture of the main concerns of the study participants. Presumptions and insights from the first interviews were used to guide some of the questions in subsequent interviews, allowing me to continuously refine the focus of the study and gradually identify the participants’ major concerns and their ways of coping individually and together with the challenges faced.

The initial idea designing the study was to generate a GT on the main concerns and coping strategies of the couples. However, during the interviews we realized that even though the ICU survivors and spouses both struggled to overcome the challenges implied by the critical illness event, in some areas their main concerns were fundamentally different during the first 12 months after ICU discharge. To adequately describe in detail the concerns and ways of coping of the patients and their spouses individually and as a couple, we therefore decided to generate three separate accounts.

The developed codes were merged into a number of categories, and by constantly coding, analyzing, and theoretically sampling more data categories and their dimensions and properties were gradually identified. When a higher order category consistently relating to many other categories was identified, this core category became the basis of a latent structural pattern of the substantive theory (79) and the starting point of further selective and theoretical coding. When the subsequent data collection and analysis did not seem to make further contributions to the emerging theory, it was considered theoretically saturated (75).

The dyad interviews were conducted 3 and 12 months after ICU discharge. However, the participants' recovery evolved in a gradual process at a varying pace and with individual perspectives. Our goal was not to identify participants' concerns and strategies at these specific points in time. Rather, we intended to describe the process of recovery during the first 12 months after ICU. The two interviews were intended for completeness, not comparison.

Software package NVivo 8 (106) was used to support the analysis and structuring of analytical considerations throughout the study. All types of codes were generated electronically and applied to the interview transcripts in NVivo. Memos too were recorded in NVivo. Using NVivo also allowed coding of memos and adding links between different types of data to provide an overview of the data and the analytic procedures.

Quantitative Interview Data

Information from the dyad interviews about patients' and spouses' participation in public or private training programs, their employment situation, and post-ICU use of community services was recorded in the NVivo database. To support our analysis, these individual day-to-day trajectories of patients and partners were also processed in Microsoft Excel with different color codes, gradually providing a visual overview. The rehabilitation, contacts to hospitals, clinics, or GPs, and sick leave during the 12-month period of recovery were compared between each participant and their spouse as well as with the other participants. Background information regarding participants’ age, sex, children, etc. was also recorded in NVivo, allowing us to explore whether these demographic characteristics affected the participants’ concerns or strategies and thus should earn their way into the theory, as Glaser puts it (75). To illustrate, when we explored the couples' strategies to cope with the consequences of critical illness and admission to an ICU to their partnership life, data about children in the household were included and enhanced our understanding of the couples' situation. Descriptive statistical accounts of patients' stay in the ICU, general wards etc. were processed in Excel and reported as mean, median and range.

Focus Group Interviews

The purpose of the focus group interviews was to provide more insight into issues of relevance to post-ICU recovery and to also encourage participants to discuss issues that the participants might not want to discuss with their spouse in the dyad interviews. Furthermore, it provided an opportunity to explore the hypotheses and discuss provisional conclusions developed during the first round of dyad interviews with the participants.

As with the dyad interviews, each group interview was initially coded openly line-by-line followed by selective and theoretical coding based on the set of codes developed during the first round of dyad interviews. The analysis of the group interviews also yielded new codes related to topics that had not been discussed in depth during the dyad interviews, e.g., patients’ worries about domestic roles and relatives’ burden and responsibility. Furthermore, I wrote memos during the analysis of the group interviews to record impressions and analytical ideas for further data collection and analysis of the remaining dyad interviews to be conducted. The narratives of the individual participants were coded with the identity of the participant, enabling me to analyze how each participant talked about a particular issue at the 3- and 12-month interviews as well as in the groups.

Register Data

A university data manager initially prepared the raw register data for analysis by electronically converting figure codes to labels, enabling me to read and structure the data. The register data were descriptively analyzed using Microsoft Excel to describe and compare participants’ use of health care services before and after stay in the ICU. Because of the limited number of participants, we did not perform statistical analysis of the register data. Patients’ and spouses' visits to different types of outpatient clinics or admissions to hospital wards were categorized with inspiration from Williams et al. (36).

SUMMARY OF FINDINGS

The thesis is based on four studies. Studies I, II, and III describe the challenges facing ICU survivors and their partners as individuals and as couples and explain their concerns and ways of coping during the first 12 months after ICU discharge. Study IV accounts for the influence of critical illness on patients and their partners in relation to rehabilitation, healthcare consumption, and employment during the first year after ICU-discharge. The findings from the study of the couples' perspectives (study III) have not yet been prepared for journal publication. Therefore, the findings from study III will be described at greater length than the findings from studies I, II, and IV.

Profile of Study Patients

An account of the ICU survivors' characteristics is given in Table 5. The study patients were admitted for a range of diagnoses that included subarachnoid hemorrhage, subdural hemorrhage, meningitis, cardiac arrest, myocardial infarction, complications to cardiac valve surgery, complications to gastric surgery, pneumonia, respiratory failure, traumatic injury to the abdomen, perforated ulcer, and sepsis.

The ICU survivors reported a wide range of physical, cognitive, and psychosocial issues, e.g., weight loss, fatigue, loss of appetite, impaired fine motor skills, or difficulty swallowing. Depending on the diagnosis, some of the patients experienced reduced physical function, e.g., partial paralysis, bone fractures, or impaired eyesight or hearing. Patients with primary brain injuries or cerebral problems secondary to other conditions, e.g., hypoxia or septicemia, reported cognitive symptoms such as reduced memory, concentration, or planning ability. Patients with no history of cerebral damage also reported confusion or lack of initiative and reduced concentration or irritability in the initial period after ICU discharge.

Table 5 Patient Characteristics in the ICU and at 12 Months after ICU Discharge

ID	Age	Gender	LOS ICU (days)	LOS general ward. (days)	LOS rehab. facility (days)	Tr. physical (weeks)	Tr. neuropsych. (weeks)	Tr. private phys. (weeks)	Sick leave F.t. (days)	Sick leave P.t. (days)	Employment pre, (hours/week)	Employment post, (hours/week)
1	35	M	11	12	-	12	-	-	353	0	37	20
2	39	F	10	13	-	12	-	4	203	148	30	30
3	40	F	5	8	-	-	-	-	357	0	12	0
4	40	F	67	8	106	20	13	-	251	0	37	16
5	40	M	10	6	21	-	-	-	Ue	Ue	Ue	Ue
6	45	F	73	47	119	28	-	-	92	107	37	12
7	50	M	22	3	16	8	-	-	346	0	37	0
8	53	M	11	9	-	-	-	-	154	120	37	37
9	55	F	9	2	48	25	20	-	315	0	37	0
10	58	F	10	37	-	8	-	-	90	0	15	15
11	60	M	12	6	57	3	18	8	302	0	37	30
12	63	M	11	42	-	34	-	-	323	0	37	0
13	64	M	51	7	174	25	-	-	Ret	Ret	Ret	Ret
14	67	M	74	7	27	12	-	-	Ret	Ret	Ret	Ret
15	68	M	7	16	-	8	-	28	Ret	Ret	Ret	Ret
16	68	M	21	3	55	8	-	-	Ret	Ret	Ret	Ret
17	70	M	8	63	15	5	-	-	Ret	Ret	Ret	Ret
18	70	F	11	20	-	8	-	-	Ret	Ret	Ret	Ret

LOS = Length of Stay; Tr. = Training; F.t. = Full time (37 hours/week);
P.t. = Part time (<37 hours/week); Ue = Unemployed; Ret = Retired

Study Patients vs. Background Population

Because narrow criteria were used in the section of participants in the study, we compared the demographic profile of the study patients with that of two reference groups of patients admitted to two general ICUs in October 2009. Results are given in Table 6.

Our study group differed considerably from the reference groups particularly in four areas: A) Pre-ICU morbidity in terms of severe afflictions affecting daily life prior to hospital admission was 0% in the study group and 73 to 74% in the reference groups; B) The percentage of long-term intubations in the study group was 100% and in the reference group 12 to 17%; C) Twelve-month mortality in the study group was nil and in the reference groups 63 to 67%; and D) All study participants had a cohabiting partner, which was the case for 41 to 74% in the reference groups.

Table 6 Demographic Profile of Study Patients Compared with Patients from Two General ICUs

Characteristics	Study group (n = 18)	Reference group 1 (n = 49)	Reference group 2 (n = 54)
Age, mean years	55	60	60
Gender, male, n (%)	11 (61)	30 (61)	41 (76)
Alive 12 months after ICU discharge, n (%)	18 (100)	31 (63)	36 (67)
Intubated > 96 hours, n (%).	18 (100)	6 (12)	9 (17)
Severe afflictions affecting daily life prior to admission, n (%)	0 (0)	36 (73)	40 (74)
Cohabiting partner, n (%)	18 (100)	20 (41)	40 (74)

Profile of Study Spouses

The spouses were generally in good health. A few reported physical problems, such as pain and arthritis, and one spouse described social problems and a history of drug abuse. The couples had been together from 4 to 45 years. One couple separated during the first year after discharge from the ICU. In Table 7 selected characteristics of the spouses are summarized.

Table 7 Characteristics of Study Spouses

ID	Age	Sex	Pre-ICU employment ^{a}	Post-ICU employment ^{a}	Sick leave F/T (days)	Sick leave P/T (days)	Children living at home	Distance to ICU (km)	Distance to general ward (km)	Distance to rehab.facility (km)
1	33	F	37	37	7	0	1	155	75	-
2	39	M	37	37	17	7	2	127	2	-
3	42	M	37	37	10	0	1	35	35	-
4	39	M	37	37	42	128	3	14	14	34
5	30	F	UE	UE	UE	UE	-	3	3	26
6	43	M	37	37	7	21	1	3	3	29
7	55	F	20	UE	146	0	-	35	10	30
8	48	F	33	33	34	0	1	30	30	-
9	58	M	37	37	21	0	1	127	127	2
10	73	M	Ret	Ret	Ret	Ret	-	110	72	-
11	57	F	37	37	25	106	-	11	11	106
12	58	F	32	32	35	0	-	63	16	-
13	60	F	37	Ret	7	51	-	59	59	40
14	62	F	37	37	9	0	-	47	15	21
15	66	F	Ret	Ret	Ret	Ret	-	87	38	-
16	60	F	37	37	0	72	-	87	87	93
17	66	F	Ret	Ret	Ret	Ret	-	10	10	10
18	72	M	Ret	Ret	Ret	Ret	-	4	4	-

Ret = retired; UE = unemployed; F/T = full time (37 hours/week);
P/T = part time (<37 hours/week); ^{a} Employment in hours/week

The Danish Socioeconomic Context

The social conditions in different countries vary, and consequently this can be expected to influence many aspects of health care and post-ICU recovery. To understand the context of post-ICU recovery in Denmark, a brief account of selected socioeconomic issues is provided below.

The Danish welfare system provides tax-paid health care that includes hospital services, outpatient clinics, rehabilitation facilities, community-based rehabilitation programs, and general practitioners. Home nursing or care in a nursing home is also provided free of charge. Sickness benefits matching the patients' customary salary are provided for up to 12 months if this is included in their terms of employment. If not, the individual is eligible for benefits from the community but at significantly lower rates. After 12 months, benefits may be reduced depending on the nature of the disability. Also, partners who are temporarily unable to work in relation to the illness event or due to caregiving responsibilities are eligible for benefits for a limited time.[5]

Recovery of ICU Survivors 12 Months after ICU Discharge: Struggling for Independence (Study I, Paper I)

For the ICU survivors, the first 12 months of post-ICU recovery were generally characterized by hope for further recovery. Some of the patients experienced progress or even recovery in most areas, while others still struggled with residual complications. *Struggling for independence* was identified as the main concern of ICU survivors. The struggle involved three modalities: recovering physical strength, regaining functional capacity, and resuming domestic roles.

Recovering Physical Strength

Due to loss of weight and muscular strength during hospitalization, regaining normal physical strength in order to perform everyday activities required a lot of effort. Consequently, re-establishing premorbid physical strength was central to the patients' struggle for independence. Even after substantial training for a year, not all participants had returned to their pre-ICU levels of physical strength and activity. Frequent visits to the hospital, clinics, or GP left little time and energy for other activities, such as interaction with friends or family.

Regaining Functional Capacity

As the patients gradually recovered their physical strength, they simultaneously tried to regain the functional capacity that would allow them to perform everyday activities of pre-ICU life. The ICU survivors, whether with or without brain injuries or cerebral problems secondary to, e.g., hypoxia or septicemia, had to relearn or develop new ways of performing all sorts of activities to compensate for physical or cognitive shortcomings.

If the patients were unable to perform a specific activity, they would try again later or develop alternative strategies. Sometimes the partner assisted them in completing the activity, or the partner took over and completed the activity. As the patients gradually recovered basic functions, their goals shifted toward practicing functions at a more complex level such as planning, organizing, shopping, driving a car, or per-

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[5] Social worker Merete Stoubæk, The Danish Nurses' Association, kindly assisted with interpreting the Danish social laws and statues guiding public assistance during convalescence.

haps returning to work. The ICU survivors were pleased as they gradually regained independence of the health care or social system. One of the patients stated: *"Happiness is doing things yourself"*.

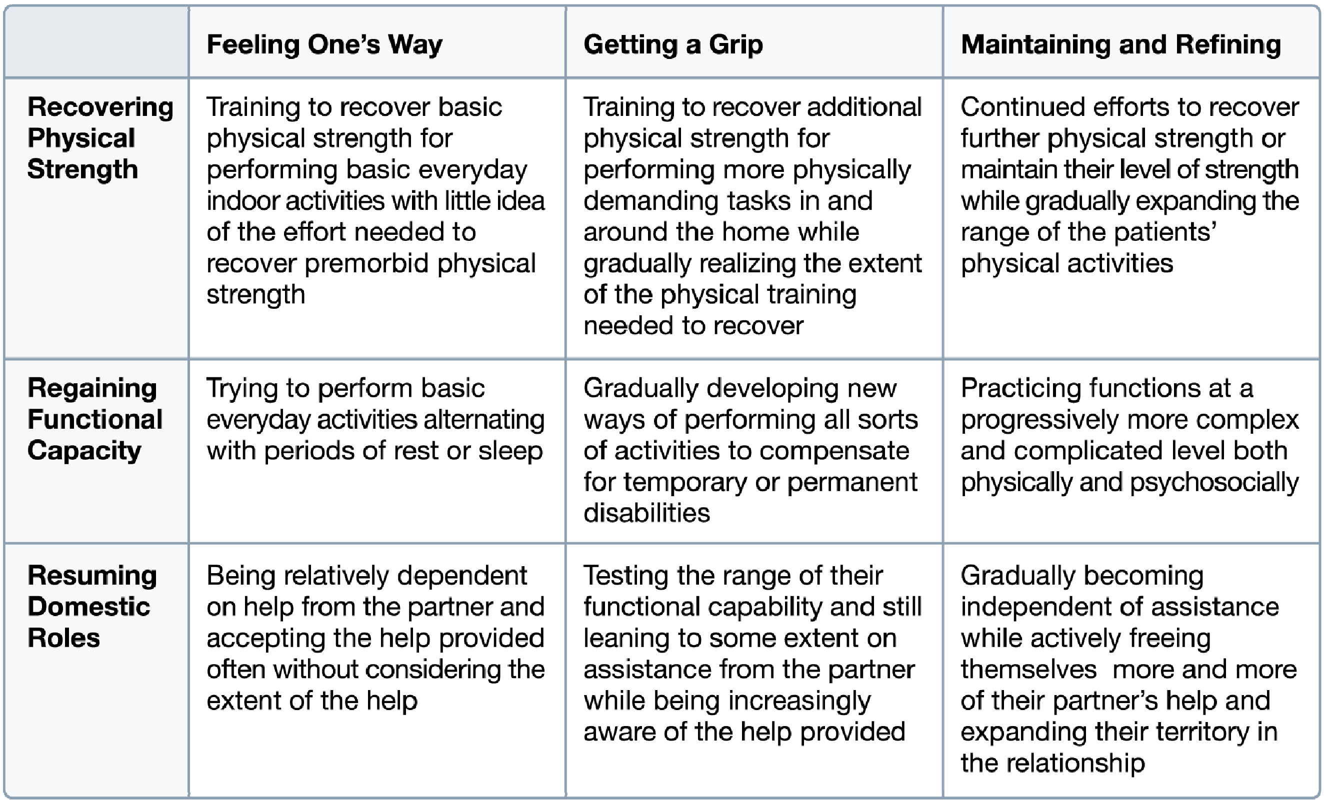
Resuming Domestic Roles

After their illness, the patients were often weak and unable to concern themselves about the extent of the help provided by their spouses. Later, they became increasingly aware of their changed role in the relationship. During recovery, the ICU survivors gradually and actively attempted to reduce their dependence and burden on their partner. As one of the patients stated: *"It sucks knowing that I am a burden."* Generally, the patients appreciated the assistance from their spouses, but when the patients felt capable of performing a certain activity on their own, they were annoyed by their partner's interference. To gradually expand their domestic territory, they had, on the one hand, to lean on assistance from their partner, and on the other hand, they sometimes had to tell the partner to stop helping or advising them.

Three Phases

The first 12 months of post-ICU recovery evolved in three phases, all characterized by training, perseverance, and continued hope for recovery. A summarizing description of the phases is provided in Table 8.

Table 8 The Three Phases in Patients' Coping Modalities during the First Year of Recovery

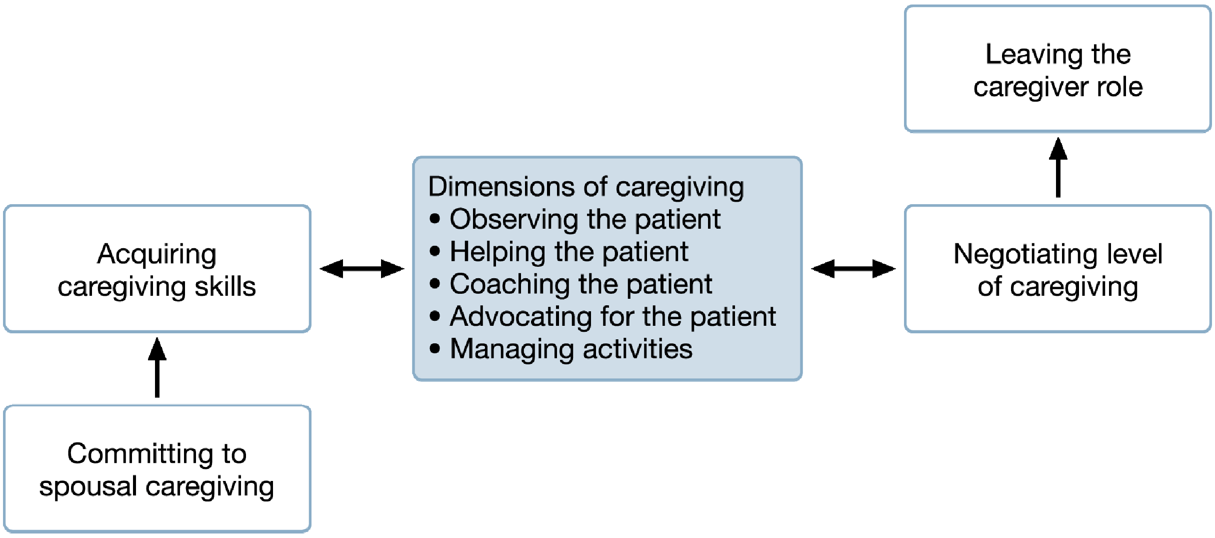


	Feeling One's Way	**Getting a Grip**	**Maintaining and Refining**
Recovering Physical Strength	Training to recover basic physical strength for performing basic everyday indoor activities with little idea of the effort needed to recover premorbid physical strength	Training to recover additional physical strength for performing more physically demanding tasks in and around the home while gradually realizing the extent of the physical training needed to recover	Continued efforts to recover further physical strength or maintain their level of strength while gradually expanding the range of the patients' physical activities
Regaining Functional Capacity	Trying to perform basic everyday activities alternating with periods of rest or sleep	Gradually developing new ways of performing all sorts of activities to compensate for temporary or permanent disabilities	Practicing functions at a progressively more complex and complicated level both physically and psychosocially
Resuming Domestic Roles	Being relatively dependent on help from the partner and accepting the help provided often without considering the extent of the help	Testing the range of their functional capability and still leaning to some extent on assistance from the partner while being increasingly aware of the help provided	Gradually becoming independent of assistance while actively freeing themselves more and more of their partner's help and expanding their territory in the relationship

Spousal Caregiving Post ICU: From Spouse to Caregiver and Back Again (Study II, Paper II)

The main concerns of the ICU patients' spouses were to promote progress in the patient's recovery while simultaneously keeping the couple's practical and social lives together. The spouses resolved their concerns by shifting their role from spouse to caregiver and back again, which was identified as the core category of the study. The spousal role shifts progressed in a dynamic process initially triggered by the critical illness event and later influenced by the patient's gradual recovery. The role shifts involved four elements: committing to caregiving, acquiring caregiving skills, negotiating level of caregiving, and gradually leaving the caregiver role. The spousal caregiving was constituted by five dimensions: observing the patient, assisting the patient, coaching the patient, advocating for the patient, and managing activities (see Figure 3).

Figure 3 From Spouse to Caregiver and Back Again



Four Elements in Spousal Role Shifts

The role shifts involved the four elements described below.

Committing to Caregiving

To become a caregiver, the spouses had initially to commit themselves to the task. Some spouses immediately took on an active role as caregiver, while others were more hesitant or insecure about how to act. The spouses felt responsible for the recovery of the patient as well as the couples' household and daily life together, although their expectations were not always clear.

Acquiring Caregiving Skills

The spouses generally demonstrated resourcefulness in their caregiving capacity. They had no special caregiving experience prior to the patient's illness but gradually developed their caregiving skills related to immediate or future challenges in a learning-by-doing process. They described rewarding feelings when able to provide effective solutions to the multifaceted challenges in the couple's everyday life. However, some spouses struggled to manage and would have appreciated more formal support.

Negotiating Level of Caregiving

Throughout recovery, the spouses assessed the patients' abilities and caregiving needs by means of a feedback mechanism by which they continuously evaluated the patients' ability to manage, their confidence in doing things independently, and their ability to be by themselves. When the patients regained their capacity to perform a given task, the spouses would encourage the patients to take over and gradually withdraw assistance.

Leaving the Caregiver Role

As the patient recovered, the spouses were gradually able to let go of the caregiver role and increasingly resume their previous role as spouse. They missed doing things on their own and longed to be a spouse again. In most cases, the recovery of the patient allowed the spouses to gradually leave the role of caregiver. For the more challenged patients, there might still be a chance of recovery after 12 months, but their spouses anticipated the ongoing need for assistance and gradually became aware of more permanent changes in their spousal role.

Five Dimensions of Spousal Caregiving

Below the five dimensions of spousal caregiving are described.

Observing the Patient

The partners' care and support were based on continuous observations of the patient's health and well-being. In this process, the partners gradually familiarized themselves with changes in the patient's condition. They looked for signs of recovery, stability, or setbacks based on the patient's behavior or verbalization.

Assisting the Patient

Throughout hospitalization and recovery, the spouses provided care and practical assistance to the patient. They resourcefully found ways to provide a stable environment that facilitated the patients' recovery and ability to manage in the home, e.g., by installing a handrail or rearranging the furniture. Besides spouses' other activities as sole housekeepers, they typically provided the patient with a balanced diet, gave medication reminders, assisted with personal care, and provided transportation.

Coaching the Patient

Encouraging continued progress in the patient's situation was a central element in spouses' efforts to gradually leave the caregiver role. The spouses praised the patient's efforts to get well again and patiently pointed out examples of progress to cheer the patient up and inspire to continue training. If the patients lost their resolve, the spouses would try to keep the process of recovery moving forward.

Advocating For the Patient

Advocating for the patient in terms of getting the right treatment, training, or other types of help was a central task for the spouses at all stages of the trajectory. Most of the spouses had the sole responsibility for contact with the health care or social systems during the early phase of recovery. Most of the spouses were frustrated in their efforts to navigate within the healthcare and social systems and struggled to find the right people to help during recovery. Advocating for the patient required resourcefulness and perseverance.

Managing Activities

As some of the ICU survivors had trouble keeping track of time, appointments, and other activities, their spouses would often keep a calendar to provide an overview of daily activities. Taking charge of the couple's social life was another element in the managing role. Even if visits from family and friends were generally encouraging, in the early stages of recovery the partner tried to protect the patient by reminding family and friends to keep visits short or by asking them to send text messages or emails instead of visiting.

The Joint Main Concern of Former ICU Patients and Their Partner: Regaining Partnership Balances (Study III)

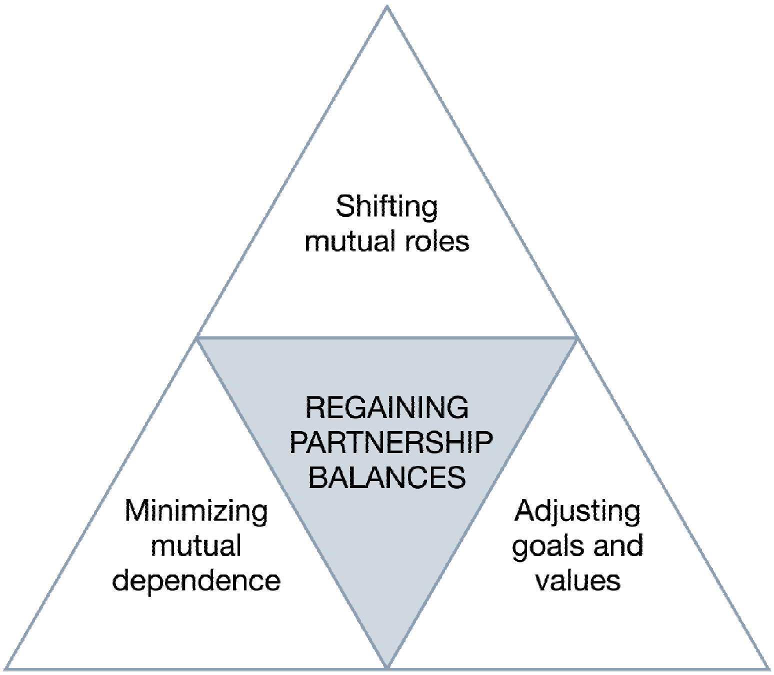
The findings from the study of couples' perspective regarding coping with the consequences of critical illness to their partnership life has not yet been prepared for journal publication. Therefore, the findings from study IV will be described at greater length than the findings from studies I to III.

During the first year of post-ICU recovery, the joint main concern of the couples was to cope with the consequences of critical illness to their partnership life. The couples solved this concern through various strategies to *regain partnership balances*. Three types of couples emerged: *the strugglers, the locked,* and *the adapted,* reflecting different ways of applying the strategies as they coped with the consequences of critical illness to their partnership life. Below the strategies and the ways in which the three types of couples applied the strategies are described.

Three Strategies

The couples' strategies to cope with the consequences of critical illness to their partnership life all encompassed elements of minimizing mutual dependence, adjusting goals and values, and shifting their mutual roles from patient and caregiver to being a couple again. Changes in the couples' mutual dependence due to progress in recovery or the acknowledgement of chronic impairment in the patient's functional level, stimulated them to adjust their goals and values correspondingly, leading perhaps to a shift in their mutual roles in the process of becoming a couple again. The strategies were applied dynamically by the couples in an ongoing process during the first year of post-ICU recovery.

Figure 4 Three Strategies Applied by the Couples to Regain Partnership Balances



The couples' strategies were influenced by the level of clarity regarding the prospects for the patients' recovery. As progress in the patients' physical and psychosocial recovery varied and differed considerably among the participants, we were not able to define specific time-related patterns in the couples' application of the strategies. To illustrate, at the 3-month interviews some of the adapted couples seemed to have reached a steady state in their efforts to regain new partnership balances, while other adapted couples did not describe reaching similar levels until the 12-month interviews. The couples' strategies were also influenced by their affiliation with the labor market, e.g., if the couple were retired, and by children living at home. The three strategies and the couples' ways of applying them are described below.

Minimizing Mutual Dependence

Minimizing mutual dependence evolved in a dynamic reciprocal process aiming at minimizing dependence for both patient and caregiver. The strategies were focused on two areas: the patient's needs for personal assistance and domestic workload. The overall logic of this strategy was that the more functionally independent the patient, the less caregiving assistance was needed from the caregiver. Similarly, if the patient was able to contribute to necessary domestic activities, less household work was needed from the caregiving partner. A dialogue from one of the group interviews with partners summarizes the dynamic nature of minimizing mutual dependence:

> Spouse 1: *"My wife quickly took over the things she could manage. She gradually did more and more. I told her not to overdo it, and that she should leave it to me when I returned home from work, if it was too much."*
>
> Spouse 2: *"We are also trying. Yes, we are not up to full steam yet, but this is how it is. They [patients] want to get back to normal."*
>
> Spouse 3: *"My husband does a lot of the housework that he didn't do before. He empties the dishwasher and hangs clothes to dry. But it is often me who says: 'Now you can also do it today'. But – he knows it already and knows he doesn't have to wait for me to say it – now it's more like he says: 'Now I will do this and this' and 'Now I have done it today'. He does it more on his own without my prodding. And I think that when summer comes he'll do more gardening – he'll mow the lawn, and such. We'll see."*
>
> Spouse 4: *"Well, I have the feeling that it is their [patients'] way of reciprocating. The feeling of being a burden is what they really want to get rid of, and change it to: 'I am actually able to do it'. And the acknowledgment of saying: 'I am no longer ill'. I mean, what are the limits and what is possible. There is no doubt that … that I think it is second nature for us all to realize how big the chores are and how great the progress has been; and how far we have come."*
> (Spouses at group interview)

Adjusting Goals and Values

Being struck by critical illness and experiencing the ups and downs of post-ICU recovery had a major impact on the couples' lives together. During the first year post ICU, the prospects of recovery and the couples' future lives together could be clear, unclear, or still progressing. Some of the patients' impairments were recognized as being chronic, such as impaired eyesight or hearing, whereas the majority of patients were still recovering physical or psychosocial functions 12 months after ICU discharge. For most of the employed patients, their ability to return to work was not clarified. Across the wide range of recovery levels represented in our study, the couples met these challenges by gradually adjusting the goals and values of their lives together.

Shifting Mutual Roles

Initially, when the critical illness occurred, the spouses' roles suddenly reversed from husband and wife to patient and caregiver. This role shift was exemplified by some of the patients humorously referring to the caregiver as my private nurse, the senior doctor, my lawyer, my boss, etc., illustrating some of the functions managed primarily by the caregiver during a period of the first year of recovery. The patient role was involuntary from the onset of illness, whereas their partners took on the caregiver role by choice or obligation. Some partners immediately took on an active or even proactive role as caregivers, while others were more hesitant or insecure about how to act.

Later in the trajectory after ICU discharge, if the recovery of the patient permitted, the couples strove to gradually leave their roles of care receiver and caregiver, assuming instead new roles of husband and wife. Some of the difficulties involved in shifting roles are illustrated by one of the caregivers:

> *"It is a challenge to have to … like … from being a patient or caregiver to becoming … what can I say … a couple again. I mean, it's like … hard to change… I mean, I took on the role of managing this and that, and assisted you when you needed something, and now I have to cook and … I am mostly the caregiver."*
>
> (Partner 3-month interview)

Three types of couples

Three types of couples emerged: *the strugglers, the locked,* and *the adapted,* reflecting different ways of applying the strategies mention above as they coped with the consequences of critical illness for their partnership lives.

The Strugglers

For the strugglers the prospects of patient recovery were clarified or still progressing. The strugglers persistently negotiated to regain satisfactory relationship balances. The patient was still recovering functions, and the couple maintained a constant focus on minimizing their mutual dependency by increasing the patient's contribution to household and family activities. As this fundamental element of the couples' mutual dependency was still evolving, they kept adjusting their goals and values of everyday life, determined to continuously challenge the limitations to their lives together, as illustrated below:

> *"I mean, this is about how far we are in the course and how far we are in our lives. It's clear that people that are 65 or who are on their way to retirement – they have a different view on things. For them it is probably more about getting the best out of what is left. But us, who are younger, we have further to go and this is not just the home stretch. We still have a ways to go and lots of things can happen".*
>
> (Caregiver 4)

In this process, the couples struggled to gradually leave their patient and caregiver roles and develop new ways of being husband and wife. The couples showed resourcefulness as to identifying and overcoming their difficulties by actively seeking help from the hospital and community services as well as from family and friends. Most of the couples with children living at home were among the strugglers. Moreover, they represented the younger participants, and they were all employed prior to the illness that caused their admittance to the ICU.

The Locked

For the locked couples, there was insecurity regarding the prospects for the patients' recovery and implications for their future lives together. They described loosely organized efforts to minimize mutual dependence and seemed to have little idea about which goals to strive for in order to regain partnership balances. These couples seemed stuck in unclear partnership roles with uncertain perceptions about which direction to take their lives together and what roles to strive for. Consequently, they seemed locked with regard to regaining partnership balances. The spouses had difficulty explicating personal needs, and they expressed resignation as to attaining relevant information or getting help as exemplified below:

> Patient: *"There are many loose ends. Just as many as there were at the beginning, I think. Not more, perhaps, but just as many."*
>
> Caregiver: *"It is frustrating because you discover that something is stuck, and then you realize that there are other possibilities to try, and then we get stuck there too. And what to do next?*

> *Then we lean back and say: ‘Well yes, but we’ll make it work as it is’. We more or less give up and let it work as it is.”*
>
> (Patient 3 and caregiver 3 at 12 months).

The locked couples did not themselves seek help from family or friends. However, they appreciated emotional or practical support offered by close family members. The locked couples had children living at home and were employed prior to the critical illness event.

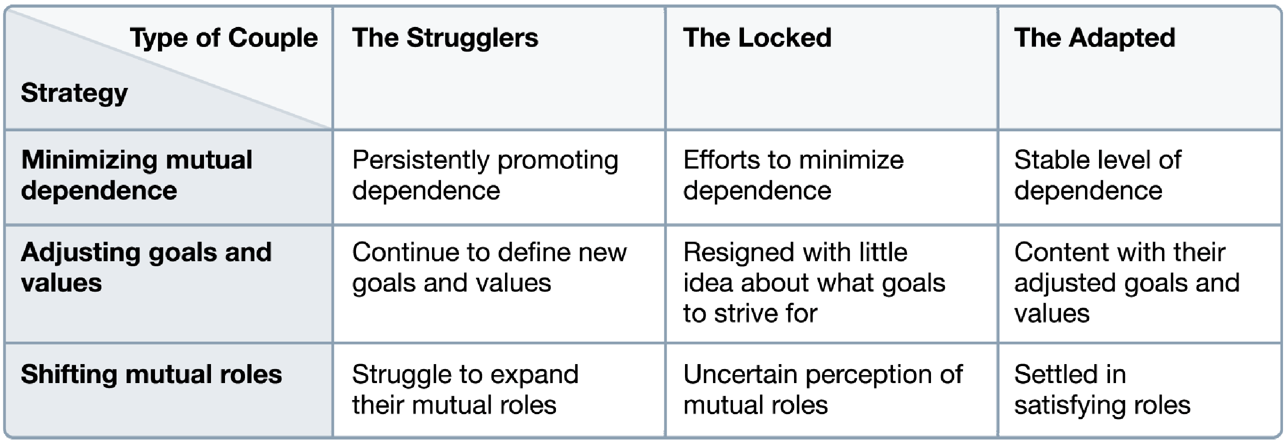
The Adapted

The adapted couples had a clear idea of the prospects for the patient’s recovery, which were largely clarified. They seemed to have reached a steady state in their efforts to regain new partnership balances following critical illness. The recovery of the patient was still progressing slightly or had reached a stable level. To minimizing mutual dependence, the couples’ focus was still on facilitating minor improvements of the patient’s functional level. The couples described efforts to adjust values and set new goals to accommodate the changes to their lives together imposed by the critical illness event:

> *“I promised my husband [patient] that I would also take early retirement when he came home from rehabilitation. We actually qualify for public help for personal care, but we have declined. We feel that … we know that many think otherwise, and I have gotten many reprimands, but we feel that this way our daily life is more our own style. I mean, we aren’t on a schedule, which we would have to be if we got outside help. Then the helper comes at this and this time. We would rather decide for ourselves.”*
>
> (Caregiver 13)

Their accounts of daily life showed resolve and a high degree of activity towards identifying and overcoming the challenges they were facing. The adjusted couples seemed settled in redefined partnership roles. Due to permanent disability, some of the couples were settled in permanent roles as care receiver and caregiver. Other couples seemed to have been able to leave the care receiver-caregiver roles and return to redefined roles as husband and wife. They appeared capable of attaining the information and support needed. The adjusted couples sought and appreciated practical and emotional support provided by family and friends. They also found support in hospital or community services. Most of the adapted couples were retired prior to the critical illness event. Table 9 summarizes how the three types of couples applied the strategies.

Table 9 The Strategies Applied by the Three Types of Couples Coping with the Consequences of Critical Illness to Their Partnership Life



Type of Couple / **Strategy**	**The Strugglers**	**The Locked**	**The Adapted**
Minimizing mutual dependence	Persistently promoting dependence	Efforts to minimize dependence	Stable level of dependence
Adjusting goals and values	Continue to define new goals and values	Resigned with little idea about what goals to strive for	Content with their adjusted goals and values
Shifting mutual roles	Struggle to expand their mutual roles	Uncertain perception of mutual roles	Settled in satisfying roles

Trajectories of ICU Survivors and their Spouses 12 Months after ICU (Study IV, Paper III)

Patient Trajectory

A summary of the patients' trajectories including rehabilitation is provided in Table 10. For further information, see table 5. Most patients needed comprehensive physical training after ICU discharge. Following a stay in the general ward, 10 patients were transferred to a rehabilitation facility for intensive physical training and/or neuro-rehabilitation for a median of 52 days (range 15–174). Three of these patients attended further community-based neuropsychological training focusing on physical, cognitive, emotional, social, and work-related functioning for 13 to 20 weeks. Fifteen patients participated in community-based physical training a few hours 2 to 3 times a week for a median of 12 weeks (range 3–34 weeks). Three of the 11 employed patients had returned to the level of their pre-ICU employment after 12 months.

Table 10 Summarizing Description of the Patients' Trajectories

Patient Trajectory	
ICU, median (range) days	11 (5–74)
Ward stay after ICU, median (range) days	10 (2–63)
Post-discharge rehabilitation, median (range) days	51 (15–174)
Public physical training, median (range) weeks	12 (3–34)
Resumed pre-ICU employment rate, *n* (of 11 employed)	3

Spouse Trajectory

The majority of spouses were women aged 30 to 73 years. Seven couples had children living at home. Five spouses were retired or unemployed (see Table 7 page 33). Most of the spouses were in good health. The spouses reported considerable sick leaves from the beginning of their partners' ICU admission to 12 months after discharge. Table 11 provides an overview of spouses' sick leaves.

Table 11 Mean Sick Leave of Employed Partners

Sick Leave for employed partners n = 13	Full time	Part time
During ICU stay, mean days	11	9
During ward stay, mean days	5	2
During post-discharge rehabilitation, mean days	3	13
At home, mean days	9	6
Total, mean days	28	30

During hospitalization and patients' stay in a rehabilitation facility, we found that transportation was a major issue for the spouses. Their mean commute from home to ICU was 56 km (3–155), from home to general ward 34 km (2–127), and from home to rehabilitation facility 22 km (2–106). Furthermore, when the patients returned home, the spouses often drove or accompanied them to various clinics as a measure of support. Commutes were longer if spouses used public transportation.

Healthcare Consumption

As presented in Table 12, the number of the patients' hospital admissions and visits to outpatient clinics and GPs increased during the 12 months following ICU discharge. Particularly ophthalmology, ear/nose/throat, and otology clinics were frequented. Six patients and one spouse received counseling post-ICU by a psychologist, psychiatrist, or their GP.

Table 12 Summary of Patients' and Spouses' Hospital Readmissions and Visits to Outpatient Clinics and GPs 12 Months Before ICU and 12 Months after ICU discharge

	Hospital Readmissions	Outpatient Clinics	General Practitioner [b]
Patients before stay in ICU	8	35	203
Patients after ICU discharge	29	113	302
Spouses before stay in ICU	9[a]	31	160
Spouses after ICU discharge	5[a]	36	180

[a] All hospital admissions were related to one particular spouse, who also represented 20% of the visits to out-patient clinics.

[b] Number of visits (GP: Visits or consultations by telephone)

DISCUSSION

The aim of the study was to explore and describe post-ICU recovery as seen from the perspective of ICU survivors and their spouses. We choose a grounded theory design to generate a theoretical account of the trajectories of the participating patients and spouses as individuals and couples and describe their main concerns and ways of resolving them during the first 12 months after ICU discharge. A grounded theory is "An integration of categories and their properties, and the internal relations between these which explains the meaning, correlation and relevance of the basic social process or event under study" (74). In this study we generated three substantive grounded theories on the individual perspectives of the patients, the spouses, and the couples. Also, we described the trajectories of patients and spouses during the first year of post-ICU recovery. Together the findings complement the current literature on post-ICU recovery and contribute to the existing body of knowledge offering new insight into the details of everyday concerns and patterns of coping in a group of Danish ICU survivors and their closest relatives. The concerns and behavior of the ICU survivor and their spouses as well as participants' use of health-care services and employment are discussed in papers I-III (see Appendix section). In the following, I will discuss first some central clinical issues that emerged through our study of post-ICU recovery. Second, I will address some methodological issues that arose from the study. Furthermore, selected issues regarding the couples' concerns, which are not presented in a paper, will be discussed.

Post-ICU Recovery in a Domestic Partnership

The relational context of our study was patients and spouses living in a domestic partnership. Domestic partnerships differ from more casual relationships and have been characterized by knowledge, caring, interdependence, mutuality, trust, and commitment (107). In the current study, we recognized these six characteristics as the backdrop of participants' patterns of behavior: From the interviews we got the impression that the patients and spouses shared their histories, preferences, feelings, and desires (knowledge); their lives were intertwined and they influenced each other (interdependence); the partners recognized the overlap between their lives and thought of themselves as "us" rather than "me", "her", or "him" (mutuality); they expected their spouse to care for them and treat them fairly and decently (trust); and finally, the participants were committed to spend time and effort to maintain the partnership (commitment).

In our studies of post-ICU recovery, the interdependence of patient and spouse was particularly evident: From the patients' initial focus on recovering physical strength and regaining functional capacity, in their struggle for personal independence gradually they were able to pay more attention to resuming their domestic role by increasing their independence and consequently, relieving the burden on their spouse

(Study I). In the spouses' dynamic process of shifting their role from spouse to caregiver and back again the aspect of interdependence was also clear: When the former ICU patient had to depend on assistance from the spouse, it challenged their interdependence prompting the spouse to take on the caregiver role while staying focused on gradually resuming the role as spouse (Study II). As couples, the participants strove to cope with the consequences of critical illness fot their relationship. This process involved a fundamental reciprocal strategy to minimize their mutual dependence in order to be able to move on and regain partnership balances (Study III).

Other international studies have described couples' interdependence and strategies to cope with the consequences of post-ICU recovery (65,93,108). Couples' coping with health problems and their efforts to gradually move toward regaining a more even balance in their interdependence has also been described in non-ICU contexts (109-112). Together, these studies underline that in a couple, the life and well-being of one spouse is inseparably intertwined with the life and well-being of the other. Consequently, as Nolan has suggested, to meet the couple’s needs it is essential to plan the provision of health care services and rehabilitation in conjuction with the caregivers as well as with the persons being cared for (113).

Marriage has been shown to improve physical and mental health as well as health-promoting behavior (114). In a study of heart failure marriage was even identified as an independent predictor of survival (115). It is being debated whether this is because healthier people or people with certain personality traits marry or whether marriage actually improves health (116). As married and cohabiting couples have almost the same status in Denmark, we did not record participants' formal marital status. Instead, the duration of their partnership was recorded. We have no knowledge of whether the participants' committment to their partner differed within or between the married and cohabiting couples or with partnership duration. In our study (Study II) the spouses, whether married or not, all provided a wide range of individualized care to the patient. Based on these findings, we believe living with a caregiving spouse fundamentally influences the health and well-being of recovering ICU survivors.

Other studies have described similar types of caregiving in a mixed group of spouses and other family caregivers (117) suggesting that marriage in itself is not the determining element and pointing instead to other factors such as the commitment of the caregiver or the abily to acquite the necessary skills. From an earlier focus on primarily instrumental and emotional support provided by caregivers, research has moved on to also investigate the processes and acquisition of skills involved in informal caregiving (113,118,119). Our description of post-ICU spousal caregiving (Study II), which is summarized in the model "From Spouse to Caregiver and Back Again" (Figure 3 page 36), incorporates the various dimensions of post-ICU caregiving as well as the processes involved. To our knowledge, neither the specific dimensions of spousal caregiving nor the processes involved have been described before in the field of post-ICU recovery. Identification of the processes of post-ICU spousal caregiving and possible critical points in this endeavor could perhaps facilitate focused interventions to support spousal caregivers. Based on our findings, all four elements in spousal role shifts, i.e. committing to caregiving; developing caregiving skills; negotiating level of caregiving; and leaving the caregiver role could be critical points in the caregiving process in which spouses might need coaching to provide the best care for the patient and themselves. Further investigation is needed to identify possible interventions to support spousal caregiving in the hospital and after discharge.

Post-ICU Recovery

Recovery has been defined as "the progress or process of integration of physically changed functions and transition from illness to health and from feeling ill to feeling well" (120). In the current study, the patients gradually moved from feeling their way to getting a grip and, from there, moved on to maintaining and refining progress reflecting post-ICU recovery as a process (Study I).

In the first 12 months of post-ICU recovery the patients struggled for independence (Study I). Independence has been defined as "The freedom to organize your own life, make your own decisions, etc. without needing help from other people" (121). In the early phases of recovery, the patients' focus was primarily on overcoming everyday physical and functional challenges, probably like many other patients with or without ICU experience. Similar findings have been reported elsewhere (37,122). Later, as the patients recovered, they gradually directed more attention to their domestic roles and the help provided by their spouses. So, from an initial focus on personal independence, the patients seemed to gradually acknowledge their interdependence as a spouse emphasizing the reciprocal nature of recovery in a domestic relationship.

The training efforts required in post-ICU recovery were extensive (Study IV). After extensive training, some of the patients still felt their physical condition was not back to pre-ICU levels after 12 months. Physical impairment caused by critical illness and hospital bed rest is well described (6,19,21,123). However, to our knowledge, apart from a Swedish study (124), the level and types of post-ICU rehabilitation provided and the barriers and facilitators with regard to rehabilitation have not been described before, making difficult a general assessment of post-ICU outcome. More research is needed to determine the optimum level, content, and format of rehabilitation programs for patients following critical illness after hospital discharge (125-127).

The Danish welfare system provides extensive financial and healthcare-related security for ICU survivors and their spouses, and the study participants did not report worries about financing their future life including rehabilitation programs. This is in contrast to reports from other countries of financial worries related to illness and recovery (128-132), highlighting the importance of considering the overall socioeconomic context when evaluating post-ICU outcomes. We were not able to identify other studies specifying the socioeconomic context of post-ICU rehabilitation or ICU survivors' training efforts in other countries, so we have no knowledge of how financial circumstances may impact these central elements of recovery in other socioeconomic settings.

Depression, anxiety, and PTSD are common among ICU survivors and caregivers (131,133). Studies from the United Kingdom and the United States report the prevalence of anxiety and depression in ICU survivors to be from 7% to 18% and from 3% to 30%, respectively, depending on the methods applied (29). In the present study, compared to their focus on physical rehabilitation, the patients seemed to focus less on traumatic experiences or psychological complications due to the ICU stay or from the illness event causing their hospital admission. Unlike the present study, the majority of studies on post-ICU outcome are based on questionnaires, which may account for some of the discrepancies between the present study and the current literature. Participants may more readily disclose negative feelings or health problems in a questionnaire than in a face-to-face interview (100). To assess whether our understanding of participants' situation was due to misinterpretations or my lacking abilities as an interviewer, I asked probing questions during the interviews related to traumatic experiences or memories, burdens, feelings of anxiety or depression, etc. This data collection strategy yielded information about a wide range of challenges facing the participants, but gave no indications that the patients were anxious or depressed. However, based on the above-mentioned evidence of post-ICU distress, it must be acknowledged when assessing our finding that we did not perform screenings using validated instruments such as The Impact of Event Scale (IES) and/or The Hospital and Anxiety and Depression Scale (HADS), which are often used in critical care. These instruments could systematically establish whether the study patients or spouses presented symptoms of depression, anxiety, or other psychiatric conditions.

Younger patients report higher levels of post-ICU depression, anxiety, and PTSD (29). Other studies have found that female ICU survivors report more emotional distress post-ICU (29,31,134). The participants in the present study were primarily older, male ICU survivors suggesting they could be among the less anxious or depressed. More recently, studies have explored how personality traits influence recovery and found that optimism was a predictor for less anxiety and depression (134,135). We did not evaluate the personality trait of the study patients, but a generally optimistic personality could have influenced some of the particpants' approach to the recovery process or their willingness to join our study yielding perhaps a study group with less distress than the general ICU population.

Neuropsychological impairment is known to cause significantly higher depression levels in patients 6 months after hospital discharge (136), The majority of the study patients and their spouses reported significant progress in the patient’s physical condition during the 12-month study period, inspiring hope for further recovery. This may have positively influenced the overall well-being of the patients. However, several of the study patients suffered from various degrees of cognitive impairment. The serious impact of brain damage on the patient and family is well known (34), and in the present study particularly cognitive impairments expected to be chronic were a source of worry for both patients and spouses.

Recovery Beyond 12 Months After ICU Discharge

The temporal constraints of the study only allowed us to focus on the first 12 months of post-ICU recovery. There are, however, indications that patients may experience more emotional effects of critical illness after physical recovery is achieved than before (24). Oeyen and colleagues reported a tendency toward the appearance of more emotional problems among ICU survivors if the follow-up period exceeds 12 months (20). This could be related to the initial hopefulness about recovery and the eventual realization of loss of function or potential, with the resulting development of emotional problems (29). These mechanisms influence the spouses and the couples' partnership too.

At 12 months after ICU discharge, there was still hope for further recovery for most of the participants in the present study, and as suggested in Studies I, II, and III, the recovery and everyday life of patients and spouses might not yet have reached a stable level. Extending the follow-up period beyond the first year of recovery could provide further insight into the mechanisms involved in post-ICU recovery, spousal caregiving, and the couples' lives together. For patients, extending the study period beyond 12 months could allow the identification of further phases in patients' long-term recovery. For spouses, studying post-ICU caregiving after 12 months could shed light on spouses' concerns and strategies when the prospects for the patient's recovery and the couple's future life were fully clarified. Also, studying couples' life beyond the first year of post-ICU recovery could yield important information on couples' coping and the characteristics of the domestic partnerships in a longer perspective as couples cope with recovery or permanent disabilities.

Spouses' Responsibility

Our description of the important role of spouses in post-ICU recovery (Studies I and II) supports earlier reports of their role in the ICU and afterwards (37,43,47,54,65,93,108,137-139). The study highlights spouses' vital and sometimes taxing responsibility during post-ICU recovery.

Other studies have investigated the role of spouses in a variety of clinical areas such as Parkinson's disease (110,111), cancer (140), traumatic brain injury (141), heart conditions (109), chronic illness (142,143), and trauma (64). These studies all support the notion that spouses or other close relatives play an important role for individuals suffering from acute or chronic illness, and informal caregiving has been described as the backbone of care provision (144).

In Denmark and internationally, an increasing number of patients survive critical illness and are discharged from the ICU to continue treatment, care, and rehabilitation in general hospital wards, rehabilitation facilities, and at home (4,5). As shown in our study, some of these patients need substantial informal caregiving that require considerable time and efforts from their caregiving spouse (Studies I- IV). In Danish secondary health-care many surgical procedures formerly requiring inpatient care are now carried out on a day surgery basis, shifting responsibility of care to patients and their relatives (145). For other types of surgery, fast-track programs reducing hospitalization have been developed that also place responsibility on informal caregivers (146,147). This trend in contemporary health care in Denmark appears to gradually shift more responsibility from hospital staff to informal caregivers, and the question is whether relatives - and patients - are adequately prepared for this.

In 2006, The Danish Cancer Society published a report showing that many relatives of cancer patients feel neglected by the healthcare system (148). Similar dissatisfaction rates were found in a repeat study in 2013 (149), suggesting that the approach of the professional healthcare system may not adequately meet caregivers' needs. Together, the findings from our study and the Danish studies mentioned above highlight a need for further investigations into informal caregiving in various clinical areas asking questions such as: What is the nature of caregiving in this specific area? What type and level of skills are needed to provide proficient informal care? How can spouses be prepared for their caregiving roles? What are the possible facilitators and moderators of successful informal caregiving? Can spouses or other close relatives refuse to take on the responsibility of informal caregiving? And how should society support informal caregiving?

In Denmark, the level of formal societal support, including the distribution of responsibility among patients, relatives, and professionals in relation to rehabilitation, is currently under debate (73,145,147,150-152). Similar issues have been raised in other countries (144,153,154). Recent initiatives by central players in Danish healthcare with the aim of discussing the role of patients, spouses, and professionals in contemporary and future healthcare in Denmark (73,151,155,156) with an explicit focus on relatives' role seem to be a promising enterprise. The findings from our study and the studies mentioned above can contribute to informing healthcare professionals and policy makers of the vital role of relatives in rehabilitation in Denmark and provide a basis for further discussions about relatives' future role and responsibilities in healthcare in Denmark.

Family Resources

In our study, when one of the patients returned home from hospital, his spouse was not prepared to take on the responsibilities related to post-ICU recovery and left home for a while (Study II). This suggests that spousal caregiving may not be a matter of course. The couple's situation highlights committing to caregiving as the first, necessary step of spouses' endeavor to care for their ill partner.

Recent Danish studies have explored relatives' caregiving role after day surgery (145), after fast-track surgery (147), and in various rehabilitation settings (150). As in our study, these studies from the field of elective surgery found that relatives provide extensive care after hospital discharge but do not always feel sufficiently prepared or skilled to provide care for the patient, which sometimes causes frustration and distress (145,147,150). The studies also describe how relatives may not have been explicitly requested to take the caregiver role. Instead, taking a role as "the extended arm of health professionals" seemed to be an implicit expectation passed on by health care professionals (147) and accepted by relatives perhaps without anticipating the full extent of this responsibility. In our study, the responsibilities of caregiving entailed a heavy burden on some of the caregivers (Studies II, III, and IV), and not all the spouses felt confident as caregivers, particularly with regard to advocating for the patient and finding their way in the healthcare and social systems on behalf of the patient. Some spouses would have appreciated more professional assistance and guidance.

Spouses' ability to commit to caregiving may rely on several factors such as their self-confidence or ability to visualize clear goals for the future. Also, self-efficacy, defined as the conviction that one can succesfully execute the behavior required to produce the outcomes (157) could influence spouses' ability to take on the caregiver role and sucessfully cope with the caregiving process described in out study which involves acquiring caregiving skills; negotiating level of caregiving; and leaving the caregiver role. Thus, assessing caregiver resources, e.g., in terms of self-efficacy, and identifying means of supporting and empowering caregivers' efforts seem to be important areas for future investigations. Further insight into the processes and content of caregiving could lay the ground for identifying targeted interventions to assist spouses and families in their efforts to support the recovering patient.

Our study (Study III) describes the couples' various coping behavior striving to regain partnership balances. Of these couples, particularly the couples showing a locked pattern of behavior stand out as showing a need for support. They seemed to have uncertain perceptions about which direction to take their lives together and what roles to strive for. Providing families with the knowledge and skills required to manage an illness at home is at the very core of nursing practice (117,158). To support patient-caregiver dyads and thereby the larger family system during post-ICU recovery, particularly identification of couples who are locked in their coping efforts seems important. Research to identify the couples most in need of support as well as investigations into the best timing and organization of family support is required.

Methodological Considerations

Selection of Study Participants

Given the heterogeneity of the general ICU population (28), our criteria for inclusion were narrow, allowing us to focus on a specific subset of ICU patients to develop detailed insight into central aspects of their post-ICU recovery. We believe this is a strength of the study. The selection strategy, however, also implies some limitations to the study. As illustrated in Table 6, the study patients are not representative of the general ICU population. The patients did not have severe chronic conditions prior to admission, as many ICU patients do (1). Furthermore, the patients were selected from among the most critically ill ICU patients, defined by the duration of mechanical ventilation. Also, in Denmark and Europe, approximately 1/3 of the population is single or widowed (71,159) and so not all ICU patients have a cohabiting partner. In summary, the findings from our study may not be transferable to ICU survivors with chronic conditions prior to ICU admission, to patients with short-term admissions to the ICU, or to patients without a cohabiting spouse.

Other studies have chosen different subsets of ICU survivors based on patient diagnosis, e.g., trauma patients (23,160,161), survivors of acute respiratory distress syndrome (ARDS) (108,162), or medical ICU patients (136). The diagnosis upon ICU admission, however, does not necessarily indicate patient outcome or level or type of post-ICU complications. To illustrate, in the present study a patient admitted to the ICU after minor gastric surgery later developed multiple organ failure causing severe hypoxic brain damage. Another patient admitted after cardiac arrest suffered minor brain damage but struggled with major physical impairments after a long stay in the ICU. A third patient with primary minor injuries to the head later suffered from physical weakness related to long-term bed rest. In the present study, patients with varying diagnoses upon ICU admission were included. Across this range of variation, we found concurrent patterns in the participants' main concerns. This suggests that when studying post-ICU recovery and caregiving as described from the perspective of patients and spouses instead of diagnosis selection criteria such as length of hospital or ICU admission, comorbidity, or living with a cohabiting spouse may be more relevant. In particular, living with a cohabiting spouse seems to be an important factor. Whatever subset of ICU survivors is chosen, given the important role of the spouses described in our study (Study II), in future research on post-ICU outcome and recovery living with an informal caregiver will, perhaps, be an important predictor of post-ICU outcome across a wide span of diagnoses.

Non-spousal informal caregivers also provide care after hospital discharge (59), and the experiences of caregiving and receiving care provided by relatives other than spouses most likely differ from the caregiving experieces described in our study. To illustrate: An adult son caring for his widowed mother would have to divide his attention between his mother and his own family, which might live far away. This could be expected to cause other types of challenges and concerns for the caregiver, and consequently, the findings from our study are not transferrable to non-spousal caregivers living away from their ill relative.

Non-participants

In our study 18 out of 33 approached couples participated. Similar participation rates have been found in quantitative post-ICU studies (134,135). We found no patterns in the discrepancies between participants and non-participants regarding reason for admission, length of stay in hospital or ICU, type of hospital, age, or sex that would explain why some couples decided to participate and others did not. For ethical and legal reasons, we could not approach the non-participants for elaboration on their reasons for not participating[6]. Hence, we can only speculate whether the non-participating patients had more or fewer post-ICU complications; suffered from conditions that were not described in their hospital charts; were less content with the hospital stay; had more or fewer social problems; were reluctant to participate in research; had other physical or social problems; or whether their decision not to participate or return the letter of consent was based on coincidence. Also, we had no indication regarding whether the decision to participate in our study was made by the patient and spouse together or by one of the partners. Considering the patients' situation and spouses' efforts to manage family activities (Studies I, and II) around the time our study invitation was sent 10 weeks after ICU discharge, their decision to accept the invitation or not may have more often been made by the spouses than by the patients. Thus, the decision to participate or not may reflect both spousal and patient characteristics.

Dyad Interviews

The focus of our study was on the couples' ways of coping as individuals and as a couple with post-ICU challenges in the context of their life together. Assuming that important information regarding the interactions between the spouses would be lost in individual interviews, dyad interviews complemented by separate group interviews with patients and spouses were chosen as the primary source of data collection. It has been argued that in joint interviews with couples, the presence of a spouse may enhance or limit the richness of interview data (96). Dyad interviews allow participants to "co-construct" their version of the research topic (163), which is consistent with our view that couples consist of two mutually influencing partners, and that interviewing them together provides insight into the collective meanings attributed to concerns and coping during post-ICU recovery.

However, the viability of separating individuals' perspective from dyad interviews has been questioned (96,164). We believe combining dyad and group interviews allowed exploration of the most salient post-ICU challenges facing the participants individually and as a couple. Still, it cannot be ruled out that, compared to group interviews with spouses and partners, patients or spouses would have elaborated more on sensitive issues in individual interviews and described in more detail the strategies applied and patterns of coping involved in post-ICU recovery. To provide further insight into issues that may not have been elaborated on in this study, in future research dyad interviews with patients and spouses could be made to further elaborate our theories.

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[6] The National Board of Health was consulted on the issue

Trustworthiness

The Interview Studies (Studies I, II, and III)

In the original introduction to GT methodology, Glaser and Strauss suggested that theories based on a flexible research design should be evaluated on their credibility, plausibility, and trustworthiness, including the actual strategies used for collecting, coding, analyzing, and presenting data when generating theory, and on the way in which people read the theory (74). Later, others too have highlighted how, in social research, the focus of evaluation should be shifted from inspecting the end product to checking the quality of all aspects of the research process (165-167). This urges the researcher to explicitly describe the methodological choices made during the research process to make it as transparent as possible (168). In the Methods section, each step of the research process is addressed, thereby providing insight into our methodological considerations and procedures and allowing the reader to evaluate the trustworthiness of our study.

Glaser & Strauss also described four criteria for the evaluation of a grounded theory: fit, work, relevance, and modifiability (75), and they both continued to advocate these criteria in each of the 'GT schools'. From a realist position, *fit* means that the conceptual codes and categories of the theory have to emerge from data and not from pre-conceived or pre-existent categories, and that the categories must correspond to phenomena in the area under study (84). In the present study, we carefully adhered to the analytic strategies of the methodology and applied the following strategies to ensure fit and provide transparency regarding all aspects of the research process:

- When planning the study, we discussed whether my experience as a critical care and research nurse or my knowledge of the existing post-ICU literature would negatively influence the study. It could direct the focus of my attention in unintended ways and impede my sensitivity toward concerns addressed by the participants. GT methodology acknowledges that the pre-understanding and experience of the researcher fundamentally influences the entire research process. On the other hand, Glaser warns not to let prior understandings restrict the researcher's sensitivity toward new discoveries emerging from the field during the study (75). As described below, we made several efforts to address this possible problem. Still, it cannot be ruled out that my pre-understanding influenced the interaction with patients and spouses as well as my interpretation of their accounts of their concerns and strategies in unintended ways. We believe, however, that my insights from clinical practice and the literature were generally a strength of the study. It enabled me to make good rapport with the participants, facilitating the conversations and the depth of the interviews. Furthermore, my previous insights enabled me to identify when participants' accounts deviated from the literature, allowing me to ask further questions and look for new data to explain apparent discrepancies.

- We have explained the decisions and procedures regarding patient enrollment and inclusion.
- We have sought to describe in detail the procedures and considerations of concurrent data collection and analysis through constant comparison.
- To ensure fit, after the first few interviews, we changed the initial strategy for data collection and analysis. Designing the study, we initially intended to generate a GT on the main concerns and coping strategies of the couples. However, data suggested a different approach directing us to initially focus on the concerns and strategies of the patient and spouse individually and later to turn to the concerns and strategies of the couples, developing during the process three separate theories.
- By continuously writing memos we have been able to track the emergence of conceptual ideas helping us to stay analytically sensitive and averting premature conceptions throughout the long process of data collection and analysis. In summary, we believe these strategies ensure the fit of our theories to describe and explain the main concerns of this selected group of ICU survivors and their spouses during the first 12 months.

Work refers to the theory's ability to explain, predict, and interpret what is happening in the field under study (75). Do the concepts and the way they are related sufficiently account for how the main concern of participants is continually resolved? (95). We are confident that our theories provide a coherent description of the main concerns and coping modalities of the participants. By focusing on the issues most salient to the participants and illustrating aspects of their concerns and ways of resolving them through quotations from the interviews, we are confident that ICU staffs and perhaps other professionals working in the field of rehabilitation may find the three theories *relevant* and useful in their clinical work. By outlining the challenges facing the couples and their concerns and strategies used to cope during post-ICU recovery, the theories may also be relevant to ICU survivors and their partners who wish to to see their situation from a more general perspective. Finally, *modifiability* refers to the future modification of the theories by comparing new relevant data with existing data, ensuring the theories' continuing relevance and value to the area from which they emerged. Knowledge is not definitive (169), and as the context of post-ICU recovery changes, so does post-ICU recovery, and consequently the theories must be modified to adequately reflect what is happening in the field.

The Register Study (Study IV)

In our study of the concrete elements of participants' post-ICU trajectories and their use of health care services and loss of work, validity was sought by combining all available information from the interviews with data from registers and hospital charts. The register data provided consistent information on participants' use of health care services that might otherwise have been subject to recall bias due to retrospective inaccuracy in the interviews. The interviews yielded information on the extent to which participants actually attended the training programs offered, and furthermore, they provided insight into non-public health care activities, e.g. private training initiatives. Combining data from different sources strengthened the overall trustworthiness of our description of participants' trajectories.

CONCLUSIONS

Our findings contribute to the existing body of knowledge about recovery after critical illness and admission to the ICU as seen from the perspective of survivors and their spouses. The study describes the main concerns of patients and spouses as individuals and as couples and their ways of resolving them during the first 12 months after ICU discharge. Also, the study offers insight into post-ICU rehabilitation, healthcare consumption, and employment of patients and spouses in a Danish setting. With reference to the aims of the study, the following major conclusions can be drawn:

- In their struggle for independence, the main concerns of the ICU survivors were to recover physical strength, regain functional capacity, and resume domestic roles. Their first year of recovery evolved in three phases from initially feeling their way, to getting a grip, and later maintaining and refining progress and recovery. The first year was characterized by training, perseverance, and continued hope of recovery (Study I).
- To promote progress in the patient's recovery while simultaneously keeping the couples' practical and social lives together the spouses progressively shifted their role from spouse to caregiver and back again. Spousal role shifts progressed in a dynamic process involving four elements: committing to caregiving; acquiring caregiving skills; negotiating level of caregiving; and gradually leaving the caregiver role (Study II).
- Five dimensions constituted spousal caregiving after ICU discharge: observing the patient, assisting the patient, coaching the patient, advocating for the patient, and managing activities. The partners played an active and vital role throughout post-ICU recovery by providing wide-ranging support to the patient (Study II).
- The shared main concern of the former ICU patients and spouses was to cope with the consequences of critical illness to their domestic partnership. In their efforts to regain partnership balances the couples sought to minimize mutual dependence, adjust goals and values, and gradually shift their roles from care receiver and caregiver to those of husband and wife again (Study III).
- The study identified three types of couples: the strugglers, the locked, and the adapted reflecting different post-ICU coping approaches (Study III).
- In the first 12 months after ICU discharge, most of the ICU survivors had comprehensive physical or neuropsychological rehabilitation needs requiring extensive training efforts. Even after attending months of extensive training in hospital or rehabilitation facilities as well as in community-based programs, 12 months after ICU discharge most of the patients did not feel fully recovered and were unable to return to work at pre-ICU employment levels (Study IV).

- The patients’ use of health care services was markedly increased in the first 12 months after ICU admission (Study IV).
- The spouses often required comprehensive sick leave related to the critical illness of their husband or wife (Study IV).
- In a domestic partnership, the life and well-being of one spouse is inseparable from the life and well-being of the other, and during post-ICU recovery, the concerns and coping efforts of the patient and spouse as individuals and as a couple are intertwined.
- For some spousal caregivers, the responsibilities of post-ICU caregiving entailed a heavy burden and not all the spouses felt confident as caregivers.
- For patients and their spouses, recovery after critical illness and admission to an ICU entailed a dynamic, reciprocal process requiring substantial efforts from both parties as individuals and as a couple.

PERSPECTIVES

We are confident that the findings from our study reflect the major concerns of the participating ICU survivors and their spouses and thus are relevant to healthcare professionals in the field of intensive care. The findings do not apply to all ICU survivors but add new insight into the everyday concerns and coping strategies applied by ICU survivors and their spouses during the first 12 months of post-ICU recovery in a Danish setting. Internationally, the need to increase awareness of the problems involved in post-ICU recovery has been highlighted (51). We hope the study will contribute to raising the general awareness of the implications of critical illness and post-ICU recovery and the coping mechanisms involved as they pertain to ICU survivors as well as to their spouses and families.

For ICU survivors, the study highlights their focus on regaining physical strength and functional capacity and provides insight into the extensive training effort required to recover. The physical impairments caused by critical illness and hospital bed rest are well known (18-20), and the participants' accounts of some of the everyday consequences of physical impairment further underline this as an important professional issue in the ICU, in general wards, and after hospital discharge. Rehabilitation following critical illness predominantly takes place after the patient leaves the ICU. However, providing early mobilization of patients during a long or short stay in the ICU is becoming an emerging standard of care (170) that is considered both feasible and safe (171) and early mobilization should be a priority in the ICU. Promoting early mobilization requires close collaboration between ICU staff and rehabilitation professionals such as physiotherapists and occupational therapists, who all have important professional contributions to make to the resourceful implementation of early mobilization strategies and the continued rehabilitation throughout the patients' hospital stay (51).

Acknowledging that in a couple, the life and well-being of one spouse is inseparable from the life and well-being of the other, spouses should be included throughout hospital admission and in post-discharge interactions with healthcare or social services. Including spouses has several important implications. First, it will be helpful to the patient. Second, including spouses could provide an opportunity to assess their caregiving resources and support them in their efforts to care for their ill partner. Third, as the caregiving spouses often take sole responsibility for a household with children or other family members, supporting spouses could be supportive for the entire family.

Support for patients and their spouses could be provided on several levels. First, to include spouses during the patient's hospital stay, visitation policies in the ICU and general wards must be liberal, promoting flexible visitation that allows the relatives to visit and support the patient at liberty (137). Second, oral and written information from the ICU as well as from the general ward could prepare spouses for some of the challenges they may face during the patient's recovery (172,173). This information could be composed in collaboration with relatives, healthcare professionals from the ICU and general wards, a social worker, etc. (174,175) Also, tailored internet-based information could be provided that allowed patients and spouses to seek information whenever convenient. Third, as hospital-based post-ICU follow-up services may not always focus on both patients and relatives (176), we recommend reconsidering the purpose of this service to explicitly include support of relatives. Fourth, support groups in which patients and spouses can meet with peers during post-ICU recovery have been shown to be beneficial to both parties (177). Finally, based on spouses' accounts of frustrations in trying to navigate the healthcare and social systems on the patient's behalf we suggest establishing lifeline services for patients and spouses that enable them to receive individualized support when needed throughout the trajectory of recovery.

The study identified post-ICU spousal caregiving as a process involving several potentially critical points which could all be the focus of interventions to assist spouses in their caregiving efforts. Caregiver resources may be assessed using validated instruments evaluating, e.g., spouses' self-efficacy or coping style. In continuation hereof, particularly identifying couples with a locked pattern of coping should be a priority. We encourage healthcare and rehabilitation professionals in hospitals and community-based services to consider the best content, timing, and organization of supportive measures that aim at assisting spouses or other informal caregivers in their support of recovering patients and themselves as caregivers in the best possible way.

The patients and spouses in our study were all active players in post-ICU recovery. When planning future ICU care and follow-up services, we recommend the inclusion of ICU survivors and their relatives to inspire healthcare providers in their efforts to develop future primary and secondary healthcare, particularly with the aim of acknowledging the vital role of spouses throughout the process of critical illness, ICU admission, and recovery.

FUTURE RESEARCH

The findings from the present study point to other areas for future research:

- Considering the vital and sometimes taxing support provided by spouses during post-ICU recovery, more research is needed to identify and test relevant foci, timing, and organization of supportive initiatives to assist the caregivers as they assist the patient
- To identify the couples most in need of support, we suggest further investigation into couples' situation during recovery
- Given the fact that a major part of ICU patients have comorbidity prior to hospital admission, the recovery of patients with previous health problems is an important area for future qualitative research
- Extending the qualitative study of ICU survivors' recovery beyond 12 months could provide further insight into the mechanisms involved in the process of recovery
- One-third of the European population lives alone, and studying the patterns of recovery and ways of getting the assistance needed after critical illness in this group of single individuals is another area for future research
- To provide further insight into sensitive issues that may not have been elaborated on in this study, separate interviews with patients and spouses could be made to further elaborate our theories.
- Not all post-ICU caregivers are partners. Studies into how non-spousal caregivers manage their caregiving responsibilities, and how it affects their lives, could provide healthcare professionals with a more solid basis for providing support to different subgroups of caregivers
- To assess the impact of the rehabilitation services provided, post-ICU research could be carried out in a collaboration between ICU researchers and rehabilitation professionals that could provide additional professional angles to the study of post-ICU outcome and inspire further co-operation between different groups of professionals involved in the recovery of ICU survivors
- In the current literature, the impact of the socioeconomic context on recovery in different national settings has not been adequately addressed, and we encourage other ICU researchers to compare post-ICU outcomes in different, specified socioeconomic settings to shed further light on contextual factors influencing recovery
- Studying the extent and impact of cognitive impairment in separate groups of ICU survivors with and without primary brain damage could further illuminate an important factor effecting post-ICU recovery

- Finally, qualitative research into possible differences in the concerns and coping modalities of male and female ICU survivors and partners could provide new insight into possible gender-related mechanisms involved in post-ICU recovery
- The fact that post-ICU caregivers may experience burden, anxiety, depression, or distress seems well established. In future research, we suggest further exploration of contextual and personal factors influencing caregivers' experiences.

ENGLISH SUMMARY

The focus of the study was to describe post-ICU recovery as seen from the perspective of ICU survivors and their spouses in a Danish setting. The aims were to describe the trajectories of the participating patients and spouses and generate theoretical accounts of their main concerns and ways of resolving them as individuals and couples during the first 12 months after ICU discharge.

Critical illness and admission to an ICU radically affect not only the patients but also their relatives during hospitalization and after discharge. Little is known, however, about the long-term trajectories of ICU survivors and the concrete challenges facing the patients and their partners after ICU discharge, particularly as seen from their own perspectives.

In this longitudinal grounded theory study, data were collected from dyad and focus group interviews with 18 previously healthy ICU survivors and their partners and from public registers.

The ICU survivors struggled for independence, and their main concerns were to recover physical strength, regain functional capacity, and resume domestic roles. Recovery evolved in three phases from initially feeling their way, to getting a grip, and later maintaining and refining progress and recovery. The first year was characterized by training, perseverance, and continued hope of recovery. Most of the ICU survivors had comprehensive physical or neuropsychological rehabilitation needs requiring months of training in hospital, rehabilitation facilities, and in community-based programs. Also, they had frequent outpatient hospital visits.

The spouses played an active and vital role throughout recovery. To promote progress in the patient's recovery while simultaneously keeping the couples' practical and social lives together, the spouses progressively shifted their role from spouse to caregiver and back again in a dynamic process involving committing to caregiving, acquiring caregiving skills, negotiating level of caregiving, and leaving the caregiver role. Spouses' wide-ranging support to the patient was constituted by five dimensions: observing, assisting, coaching, advocating, and managing. The spouses often required comprehensive sick leave related to problems that arose because of the patients' critical illness and hospital admission.

As a couple, patients and caregivers sought to regain partnership balances. The study identified three types of couples: the strugglers, the locked, and the adapted, reflecting different post-ICU coping approaches. The study shows that during post-ICU recovery, the life and well-being of one spouse is inseparable from the life and well-being of the other, which emphasizes the need to include and support spouses in all phases of the critical illness trajectory.

Recovery after critical illness and admission to an ICU entailed a dynamic, reciprocal process requiring substantial efforts from both parties as individuals and as a couple.

The findings contribute to the existing body of knowledge about recovery after discharge from an ICU by offering insight into the concerns, coping strategies, and trajectories of a group of Danish ICU survivors and their spouses. To counter physical impairment caused by immobilization, we recommend a strong interdisciplinary focus on early mobilization in the ICU. Also, we encourage healthcare and rehabilitation professionals in hospitals and community-based services to consider the best content, timing, and organization of supportive measures aimed at assisting spouses in their support of recovering patients.

To broaden the overall insight into the recovery of the heterogeneous population of ICU patients, we suggest that further studies be done of other subgroups of ICU survivors and relatives from diverse societal contexts and beyond 12 months after ICU discharge.

DANSK RESUMÉ

Formålet med undersøgelsen var at beskrive, hvilke udfordringer patienter og partnere møder i det første år efter akut, kritisk sygdom og indlæggelse i intensivafdeling (ITA), og hvordan de hver for sig og sammen håndterer disse udfordringer. Ydermere beskriver undersøgelsen, hvordan det første år forløber for patienter og partnere.

Kritisk sygdom og indlæggelse i ITA kan være en skelsættende begivenhed for patienten, og tiden efter udskrivelsen kan være præget af nedsat helbredsrelateret livskvalitet og nedtrykthed. Også patientens nærmeste påvirkes af sygdomsforløbet og dets konsekvenser. Den eksisterende forskning belyser dog ikke i tilstrækkeligt omfang patienters og partneres egne perspektiver på, hvilke konkrete udfordringer de står overfor efter udskrivelsen. Ligeledes har vi endnu kun sparsom viden om det langsigtede forløb efter udskrivelse fra ITA.

Studiets design var kvalitativt, eksplorativt og longitudinelt med grounded theory som metodologisk ramme. Undersøgelsen var baseret på interviews med 18 tidligere raske intensivpatienter og deres partner henholdsvis 3 og 12 måneder efter udskrivelsen samt på fokusgruppeinterviews og data fra registre.

For intensivpatienterne var det første år efter udskrivelsen præget af træning, vedholdenhed og håb om fortsat bedring. De kæmpede for personlig uafhængighed og var særligt optaget af at genvinde fysisk styrke, praktiske funktioner og at genindtage deres vante rolle i hjemmet. Undersøgelsen viste, at de tidligere patienter efter udskrivelsen deltog i omfattende genoptræning på hospitalet, på rehabiliteringscentre og i kommunalt regi. Trods en omfattende træningsindsats havde patienterne efter et år ikke fuldt ud overvundet de fysiske eller neuropsykologiske følger af deres sygdom og indlæggelse. Efter udskrivelsen var patienternes brug af sundhedsydelser forøget væsentligt sammenlignet med året før indlæggelsen.

Partnerne spillede en afgørende rolle og ydede vidtrækkende støtte til patienterne gennem hele forløbet. Ved dynamisk at ændre deres rolle fra at være partner til at blive uformel omsorgsgiver og siden partner igen, forsøgte de at fremme bedring for patienten og samtidig at holde sammen på parrets praktiske og sociale liv. Partnernes rolleskift foregik i et fremadskridende mønster, hvor de indledningsvis engagerede sig i at hjælpe den syge og i forlængelse heraf løbende stræbte efter at erhverve de nødvendige kundskaber og færdigheder med henblik på at kunne løfte opgaven. I takt med at patienten fik det bedre, forhandlede partnerne med den syge om behovet for hjælp, hvorved de gradvist kunne lægge rollen som uformel omsorgsgiver bag sig og vende tilbage til i højere grad at være partner. Partnernes omfattende hjælp til den syge indbefattede at observere, hjælpe, coache, være patientens talsmand og hjælpe den syge med at styre aktiviteter og planer i hverdagen. De pårørende viste sig at have et betragteligt behov for at være sygemeldt i forbindelse med patientens sygdom og indlæggelse.

Som par forsøgte patient og partner i fællesskab at genvinde balancen i deres parforhold ved at minimere deres gensidige afhængighed, justere mål og værdier og gradvist at vende tilbage til at være ligeværdige ægtefæller. Undersøgelsen fandt tre forskellige måder, hvorpå tiden efter kritisk sygdom blev håndteret og i forlængelse heraf tre par-typer: fighterne, de fastlåste og de tilpassede. Resultaterne peger på, hvordan velbefindendet for henholdsvis den syge og omsorgsgiveren i et parforhold er uløseligt forbundet. På den baggrund bør partnere inddrages i alle faser af forløbet omkring kritisk sygdom og indlæggelse i intensivafdeling.

Undersøgelsens beskrivelse af forløbet efter udskrivelse samt af de udfordringer, en gruppe danske patienter og deres partnere møder og håndterer undervejs som enkeltpersoner og som par, bidrager til den eksisterende forskning med ny indsigt i, hvad der har betydning for parterne i rekonvalescensperioden, og hvilke mekanismer der spiller ind i det langsigtede forløb efter kritisk sygdom og indlæggelse i ITA. Studiets resultater peger på betydningen af et målrettet, tværfagligt fokus på tidlig mobilisering i ITA med henblik på at modvirke fysisk svækkelse i forbindelse med immobilisering og efterfølgende behov for genoptræning. På baggrund af de pårørendes store betydning i forløbet er det afgørende, at de inddrages under hele indlæggelsesforløbet såvel som i det efterfølgende genoptræningsforløb. I tilrettelæggelsen af fremtidens sundhedsvæsen bør det overvejes, hvilke behov uformelle omsorgsgivere har samt hvordan, hvor og hvornår man bedst kan støtte dem i at hjælpe patienten.

Da intensivpatienter er en heterogen gruppe, er der behov for videre forskning i, hvordan forskellige velafgrænsede grupper af intensivpatienter og deres pårørende klarer sig efter udskrivelsen, herunder forskning ud over det første år og i forskellige samfundsmæssige kontekster.

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APPENDICES

1. Participant information sheet
2. Declaration of interest letter
3. Informed consent form
4. Interview guide dyad interviews 3 months
5. Interview guide dyad interviews 12 months
6. Interview guide group of patients
7. Interview guide group of partners

Århus Universitetshospital
Skejby
Anæstesiologisk-Intensiv Afdeling I

INFORMATION OM PROJEKT:
Langsigtet betydning af akut, kritisk sygdom og indlæggelse i intensivafdeling. Patienters og pårørendes perspektiv

Kære patient og pårørende

Dette brev er en anmodning om I vil deltage i en videnskabelig undersøgelse af, hvordan det første år efter udskrivelse fra intensivafdeling forløber.
Vi, der arbejder med intensiv behandling og pleje, ved efterhånden ganske meget om, hvordan selve indlæggelsen i intensivafdeling kan forløbe for både patienten og for den pårørende, der står ved siden af. Til gengæld ved vi ikke nok om, hvordan det går efter udskrivelsen. Jo bedre viden vi har på dette område, des bedre kan både hospitalspersonalet og kommunerne hjælpe og støtte både patienten og de pårørende efter udskrivelsen.
Undersøgelsen gennemføres i et samarbejde mellem Institut for Folkesundhed, Afdeling for Sygeplejevidenskab, Aarhus Universitet og Aarhus Universitetshospital. Økonomisk er undersøgelsen støttet af Dansk Sygeplejeråd, Aase og Ejnar Danielsens Fond, Sygekassernes Helsefond og Novo Nordisk Fonden
Vi håber I vil deltage, men før I beslutter Jer, beder vi Jer læse denne skriftlige information. I er også velkommen til at kontakte undertegnede, som leder undersøgelsen.

Venlig hilsen

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Hvad indebærer det at deltage?

Vi vil bede Jer om at svare ja eller nej til at deltage i undersøgelsen ved at udfylde vedlagte *forhåndstilkendegivelse* og returnere den i den frankerede svarkuvert. Hvis I svarer ja til at deltage, vil vi kontakte Jer snarest med henblik på at lave en aftale om at komme hjem til Jer og interviewe Jer i alt to gange inden for det første år efter udskrivelsen fra intensivafdeling. Hvert interview varer cirka en time. Derudover vil I senere blive spurgt, om I har lyst til at deltage i et interview med en gruppe patienter eller en gruppe pårørende.
Hvis ikke I ønsker at deltage, får det ingen betydning for eventuel senere kontakt til sygehuset.

Jeres rettigheder og beskyttelse

Det er frivilligt at deltage, og I kan på ethvert tidspunkt udtræde af undersøgelsen uden begrundelse, og uden at dette vil påvirke nuværende eller fremtidige kontakt til sygehus.
Projektet er forelagt Den Regionale Videnskabsetiske Komité og er anmeldt til Datatilsynet, som har fastsat vilkår for projektet til beskyttelse af deltagernes privatliv. I er sikret anonymitet ved offentliggørelse af undersøgelsens resultater.

Maj 2009

Århus Universitetshospital
Skejby
Anæstesiologisk-Intensiv Afdeling I

TIL PATIENT OG PÅRØRENDE

Forhåndstilkendegivelse

Vi har tidligere fået både skriftlig og mundtlig information om projektet *"Langsigtet betydning af akut, kritisk sygdom og indlæggelse i intensivafdeling. Patienters og pårørendes perspektiv".* På den baggrund tilkendegiver vi herved, at:

____ Vi ønsker *ikke* at deltage i et afsluttende interview

____ Vi vil begge gerne deltage i et afsluttende interview om, hvordan det første år efter udskrivelse fra intensivafdeling er forløbet.

Vi kan kontaktes på følgende måde:

Patientens navn:	
Den pårørendes navn:	
Adresse:	
På telefon Ja ____ Nej ____	Telefonnummer (gerne flere):
Pr. brev: Ja ____ Nej ____	
På email: Ja ____ Nej ____	Email adresse:

______________ ____

Dato Underskrift

Forhåndstilkendegivelsen returneres i den frankerede svarkuvert. Hvis vi ikke har modtaget svar fra jer inden 14 dage, vil vi kontakte jer igen.

ERKLÆRING OM SAMTYKKE

- i forbindelse med undersøgelsen:

Langsigtet betydning af akut, kritisk sygdom og indlæggelse i intensivafdeling. Patienters og pårørendes perspektiv

Vi har fået både mundtlig og skriftlig information om projektet og erklærer herved, at vi gerne vil deltage i undersøgelsen.

Vi er indforstået med:

- At interviewet optages på båndoptager
- At vi ikke vil kunne genkendes ved senere offentliggørelse af undersøgelsens resultater
- At regler fastsat af Datatilsynet og Sundhedsstyrelsen sikrer, at vores cpr-numre kun kan anvendes til at indhente oplysninger om forhold, der ligger inden for undersøgelsens emne.
- At vi til enhver tid kan trække vores samtykke tilbage og udgå af undersøgelsen, uden at det får betydning for nuværende eller fremtidige kontakt til sygehus

Cpr-nummer ____

Dato ______________ Underskrift _______________________________________

Cpr-nummer ____

Dato ______________ Underskrift _______________________________________

INTERVIEWGUIDE (3 mdr.)

Forskningsspørgsmål	**Interviewspørgsmål**
Hvordan klarer den tidligere intensivpatient og dennes nærmeste pårørende sig i det første år efter patientens udskrivelse	Kan I huske, hvordan det var, da X kom hjem?
	Var I forberedt på, hvordan det ville være efter udskrivelsen?
	Hvordan klarede I hjemkomsten helt konkret? Tog den pårørende fri fra arbejde?
	Er der noget, der er kommet bag på jer?
	Har I et forslag til noget, der kunne være grebet anderledes an?
	Er der noget, der særligt har haft betydning for jeres situation efter udskrivelsen?
Hvilke særlige udfordringer møder patient og pårørende hver for sig og sammen i relation til rekonvalescens af patienten?	Hvad har været det bedste ved at komme hjem?
	Hvad har været det værste ved at komme hjem
	Hvordan synes I det går nu?
Hvordan former kontakt med sundhedsvæsen, andre instanser og eget netværk sig for patienten og den nærmeste pårørende det første år efter udskrivelsen til hjemmet?	Er der noget, I haft brug for hjælp til efter udskrivelsen?
	Hvem er det, der har hjulpet jer?
	Har I haft kontakt med sygehuset efter udskrivelsen?
	Har I været hos jeres egen læge?
	Har I haft kontakt med kommunen?
	Hvordan ser det ud med hensyn til arbejde?
	Hvordan går det med kontakten til venner og familie?
”Tillægsspørgsmål”	Hvad betyder tiden i intensivafdeling for jer?
	Er der små eller store problemer, som I mener stammer fra tiden i intensivafdeling?

INTERVIEWGUIDE (12 mdr.)

Forskningsspørgsmål	**Interviewspørgsmål**
Hvordan klarer den tidligere intensivpatient og dennes nærmeste pårørende sig i det første år efter patientens udskri velse	
	Hvordan synes I det går nu, sammenlignet med da vi talte sammen for 9 måneder siden?
	For 9 mdr. siden talte vi om, hvad der havde været det værste og det bedste efter udskrivelsen. Hvad vil I sige i dag har været *det værste*?
	Hvad vil I sige i dag har været *det bedste*?
	Er jeres liv forandret i dag sammenlignet med før indlæggelsen? Hvordan?
	Nu har denne undersøgelse jo fokus på tiden i intensivafdeling, og jeg har tænkt, at det må være svært at skille det, at man bliver ramt af sygdom, fra alt det, der kommer bagefter. Kan man det?
	Til pt: Er du begyndt at arbejde igen?
	Til pår.: Hvordan er det gået med hensyn til dit arbejde?
Hvilke særlige udfordringer møder patient og pårørende hver for sig og sammen i relation til rekonvalescens af patienten?	
Mål, midler, strategier	Da patienten blev syg, var det jo en helt ny situation for Jer. Hvordan finder man ud af, hvordan man skal gøre, når man aldrig har prøvet det før?
	Når I i dag ser tilbage på hele forløbet fra sygdommen opstod og så til nu, er der så noget, der har haft særlig stor betydning for jer i forløbet?
	Det har jo været et langt forløb. Har der været nogle særlige vendepunkter undervejs?
	En af deltagerne i undersøgelsen har tidligere sagt, at man jo bare gerne vil have hverdagen tilbage. Hvad mener I om det udsagn?
At være par	Jeg forestiller mig, at der må være sket en del forandringer for jer som par i forbindelse med alt dette her. Har jeg ret i det?
Overordnet	Set i bakspejlet er der så noget, I gerne ville have vidst eller have haft hjælp til?
	Hvis I nu, et år efter ulykken og indlæggelsen, skulle give et godt råd til andre i samme situation, hvad skulle det så være?
Intensiv	Hvad betyder tiden i intensivafdeling for jer i dag?
	Har I lyst til at komme tilbage til intensivafdeling?
	Er der små eller store problemer, som I mener stammer fra tiden i intensivafdeling?
Erindringer	Er det siden sidst dukket erindringer op fra indlæggelsen i intensivafdeling? Måske drømme eller mareridt?
	Synes du (pt), at du i dag har et nogenlunde billede af, hvad det var der skete i forbindelse med din sygdom og under indlæggelsen i den tid, du ikke kan huske?
	Hvor stammer din viden om forløbet fra?

Forskningsspørgsmål	**Interviewspørgsmål**
	Hvilken betydning har det for dig i dag, at du ingen erindringer har fra den tid?
Hvordan former kontakt med sundhedsvæsen, andre instanser og eget netværk sig for patienten og den nærmeste pårørende det første år efter udskrivelsen til hjemmet?	
	Hvordan går det med kontakten til venner og familie? Sammenlignet med tiden før indlæggelsen, har I så mere eller mindre kontakt med dem nu?
	Hvilken rolle har Jeres egen læge spillet i hele forløbet?
	Har I haft kontakt med hospitalet siden sidst?
	Har I haft kontakt med nogen i kommunen siden sidst?
Andet	Kan I huske, hvad det var der gjorde, at I i sin tid sagde ja til at deltage i denne undersøgelse?
	Hvis jeg inden for de næste par måneder kommer i tanke om noget, jeg gerne vil spørge Jer om, må jeg så have lov til at ringe til Jer?

INTERVIEWGUIDE FOKUS GRUPPER *PATIENTER*

Velkommen!

1. Jeg vil gerne starte med at sige tak fordi I ville være med her i aften. Nogle af jer er endda kørt langt for at komme her til. For nogle af jer er det måske første gang, I er her på hospitalet. Andre af jer har været her før og kender det måske endda alt for godt.

2. I har alle det til fælles, at I har været ramt af akut, kritisk sygdom og indlagt i intensivafdeling inden for det seneste års tid, og der er selvsagt gået meget forud for, at I hver især sidder her i dag. Under rundbordssamtalen kan I fortælle så lidt eller så meget om jeres egen situation, som I har lyst til.

3. I aften skal fokus særligt være på tiden efter udskrivelsen fra intensivafdeling – altså der, hvor det første akutte forløb er ovre.

4. I sådan en rundbordssamtale som denne her er der ingen rigtige eller forkerte svar. Vi vil gerne høre alle de forskellige meninger, der kan være, og målet er ikke at blive enige om en bestemt måde at se tingene på. Vi håber derfor I vil følge op på det der bliver sagt undervejs og give jeres mening til kende, så vi får så nuanceret et billede af tiden efter intensiv set fra jeres side som muligt.

5. Når snakken nu kommer i gang, er det vigtigt, at vi kun snakker en ad gangen, og det kan man jo let komme til at glemme. Så måske vil jeg minde om det undervejs.

6. Samtalen her er anonym i den forstand, at I kun bliver præsenteret for hinanden ved fornavn, og at ingen senere vil kunne genkende jer eller henføre det, I har sagt, til jer.

7. Vi starter med en kort præsentationsrunde, hvor I hver især har cirka 1 minut til at fortælle, hvad I hedder, og hvad der er baggrunden for, at I er her i aften.

INTERVIEWGUIDE FOKUS GRUPPER *PATIENTER*

Led i interviewforløbet		**Interviewspørgsmål**
Introducerende spørgsmål:	**1**	Vores undersøgelse drejer sig blandt andet om, hvilken betydning indlæggelse i intensivafdeling har på længere sigt. Mange husker intet fra intensiv, og flere har givet udtryk for, at den tid ikke betyder noget for dem. Omvendt er der andre, der har et stort ønske om at få så meget som muligt og så mange detaljer som muligt at vide om den tid, de ikke husker. Hvorfor tror I der er så stor forskel på, hvor meget man gerne vil vide?
Overgangsspørgsmål	**2**	Når man bliver udskrevet fra sygehuset efter at have været så syg, så kan man måske være lidt nervøs for, hvordan man skal klare det, når man kommer hjem. Var I bekymrede, dengang I skulle til at hjem?
	3	Jeg har et par gange hørt en tidligere patient sige til sin mand eller kone: *"Det er næsten dig det har været værst for"*. Har I også haft det på den måde?
	4	Jeg forestiller mig, at når man er kommet hjem, så kan man nogle gange spekulere lidt over, hvordan det hele skal gå. Jeg hørte engang en der sagde *"…men det fortæller jeg ikke til min mand, for han er bekymret nok i forvejen"* Er det noget I kan genkende?
Hovedspørgsmål	**5**	Når man kommer hjem, kan man jo have brug for hjælp fra sin mand eller kone til mange forskellige ting. Er det svært at finde en balance mellem at få den hjælp, man har brug for, og ikke at blive pylret unødigt om?

INTERVIEWGUIDE FOKUS GRUPPER *PATIENTER*

Led i interviewforløbet		**Interviewspørgsmål**
	6	Når man pludseligt bliver syg, som I hver for sig har været, så ser det ud til, at forholdet mellem mand og kone i perioder kan ændre sig til at være et forhold mellem ”den syge” og ”hjælperen”. Jeg har fx hørt nogle omtale deres mand eller kone som ”hjemmesygeplejersken”, ”chefen”, ”overlægen”, ”min advokat” og så videre. Hvordan kan man finde tilbage fra at være ”den syge” og ”hjælperen” til bare at være mand og kone igen?
	7	En af deltagerne i undersøgelsen sagde engang: *”Jeg vil jo bare gerne have hverdagen tilbage”*. Er det også sådan, I ser på det?
Afsluttende spørgsmål	**8**	Vi skal snart til at runde af, og jeg vil derfor stille jer et sidste spørgsmål Hvis I skulle give et godt råd videre til andre tidligere patient, der netop var blevet udskrevet fra intensivafdeling, hvad skulle det så være?
	9	Jeg synes vi har fået mange forskellige synspunkter frem. Er der noget vigtigt, vi ikke har nået at snakke om?
		Så vil jeg gerne sige tak for jeres bidrag til rundbordssamtalen her. **Tak fordi I kom og kom godt hjem**!

INTERVIEWGUIDE FOKUS GRUPPER *PÅRØRENDE*

Velkommen!

1. Jeg vil gerne starte med at sige tak fordi I ville være med her i aften. Nogle af jer er endda kørt langt for at komme her til. For nogle af jer er det måske første gang, I er her på hospitalet. Andre af jer har været her før og kender det måske endda alt for godt.

2. I har alle det til fælles, at I er pårørende til en mand eller kvinde, der har været ramt af akut, kritisk sygdom og indlagt i intensivafdeling inden for de seneste 6-18 måneder, og der er selvsagt gået meget forud for, at I hver især sidder her i dag. Under rundbordssamtalen kan I fortælle så lidt eller så meget om jeres egen situation, som I har lyst til.

3. I aften skal fokus særligt være på tiden efter udskrivelsen fra intensivafdeling – altså der, hvor det første akutte forløb er ovre.

4. I sådan en rundbordssamtale som denne her er der ingen rigtige eller forkerte svar. Vi vil gerne høre alle de forskellige meninger, der kan være, og målet er ikke at blive enige om en bestemt måde at se tingene på. Vi håber derfor I vil følge op på det der bliver sagt undervejs og give jeres mening til kende, så vi får så nuanceret et billede af tiden efter intensiv set fra de pårørendes side som muligt.

5. Når snakken nu kommer i gang, er det vigtigt, at vi kun snakker en ad gangen, og det kan man jo let komme til at glemme. Så måske vil jeg minde om det ind imellem undervejs.

6. Samtalen her er anonym i den forstand, at I kun bliver præsenteret ved fornavn, og at ingen senere vil kunne genkende jer eller henføre det, I har sagt, til jer.

7. Vi starter med en kort præsentationsrunde, hvor I hver især har cirka 1 minut til at fortælle, hvad I hedder, og hvad der er baggrunden for, at I er her i aften.

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Led i interviewforløbet		**Interviewspørgsmål**
Introducerende spørgsmål	**1**	Når ens mand eller kone bliver udskrevet fra sygehuset efter at have været så syg, så kan man måske være lidt nervøs for, hvordan man skal klare det, når han eller hun kommer hjem. Var I bekymrede, dengang jeres mand eller kone skulle udskrives?
Overgangsspørgsmål	**2**	Jeg forestiller mig, at man nogle gange kan være lidt bekymret for, hvordan ens mand eller kone skal klare det eller for, hvordan det hele skal gå. Jeg hørte engang en der sagde *"…men det fortæller jeg ikke til min mand, for han har nok at spekulere på i forvejen".* Er det noget I kan genkende?
	3	I vores undersøgelse ser det ud til, at når den syge har fået det bedre og kommer hjem og skal til at komme til kræfter og finde sig til rette med en forandret hverdag, så kan man som pårørende måske allerede føle sig lidt slidt ovenpå det første, akutte forløb. Kan I genkende det billede?
Hovedspørgsmål	**4**	I mine interviews kan jeg høre, at pårørende i mange situationer trækker et ret stort læs i hverdagen, og jeg forestiller mig, at det ind imellem kan opleves som lidt af en byrde. Har jeg ret i det?
	5	I mine interviews har jeg et par gange hørt en tidligere patient sige til sin mand eller kone: *"Det har næsten været værst for dig"*. Hvad mener I om sådan et udsagn?

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	6	Siden jeres mand eller kone blev syg, har I nok hver især skullet påtage jer nogle nye og anderledes opgaver i forhold til ham eller hende. Jeg har for eksempel tidligere hørt pårørende omtale sig selv fx som ”hjemmesygeplejerske”, ”chef” eller ”advokat”. I har nok også undervejs haft sådan en slags nye ”stillingsbetegnelser”. Hvordan kan man finde tilbage fra at være ”den syge” og ”hjælperen til bare at være mand og kone igen?
	7	I undersøgelsen ser det ud til, at man som pårørende løbende afpasser sin hjælp og støtte til den syge, afhængig af hvordan det går. Nogle har beskrevet det som *”en balancegang”* og sagt, at man heller ikke må *”pylre”*. Hvordan finder man ud af at afpasse sin hjælp til den syge?
	8	En af deltagerne i undersøgelsen sagde engang: *”Jeg vil jo bare gerne have hverdagen tilbage”*. Er det også sådan, I ser på det?
Afsluttende spørgsmål	**9**	Vi skal snart til at runde af, og jeg vil derfor stille jer et sidste spørgsmål. Hvis I skulle give et godt råd videre til andre pårørende, hvis mand eller kone netop var blevet udskrevet fra intensivafdeling, hvad skulle det så være?
	10	Jeg synes vi har fået mange forskellige synspunkter frem. Er der noget vigtigt, vi ikke har nået at snakke om?
		Så vil jeg gerne sige tak for jeres bidrag til rundbordssamtalen her. **Tak fordi I kom og kom godt hjem!**

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