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Family Members of Patients with Burns

Experiences of a Distressful Episode

JOSEFIN BÄCKSTRÖM



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Abstract

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A severe burn is a trauma associated with long lasting consequences, not only for the survivor but also for the family. Although it is recognized that family members are central in providing social support for the patients, previous research has not focused extensively on this group. The aims of this thesis were to increase knowledge about psychological symptoms and health-related quality of life (HRQoL) in family members of patients with burns, as well as to explore their experiences of burn care and rehabilitation. The research questions were approached using quantitative and qualitative methods.

The results showed that most family members demonstrate normal to mild levels of psychological symptoms, while one third demonstrate moderate to severe symptoms during care. The symptoms decreased over time and could be predicted to a certain degree by early symptoms.

Further, family members' report of HRQoL is similar to that of the general population. An improvement is seen over time and HRQoL could be predicted in part by earlier life events and psychological symptoms.

Family members' experiences were explored in an interview study. Qualitative content analysis revealed that the time in hospital is stressful, although there were experiences of a positive character. Family members might benefit from being cared for in a more individualized way. The communication between health care providers and the family members could be improved.

Finally, a qualitative content analysis revealed that family members' experiences and views concerning support is highly individual. There were experiences of sufficient support as well as lack of professional support. Treatment of family members should be modified according to personal circumstances, and it is important to actively include family members in the care process, both before and after discharge.

In summary, being a family member of a burn survivor is a distressful experience, not only during care but in many cases also after discharge. The treatment of family members within burn care should be individualized. Some persons are more vulnerable than others and it might be possible to identify those in need of support while care is still ongoing.

Keywords: Critical care, Burns, Experiences, Health-related quality of life, Family members, Nursing, Support, Psychological symptoms

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*What do I do when my love is away?
Does it worry you to be alone?
How do I feel by the end of the day?
Are you sad because you're on your own?
No, I get by with a little help from my friends.*

*From "With a Little Help from My Friends"
written by John Lennon & Paul McCartney (1967).*

List of Papers

This thesis is based on the following Papers, which are referred to in the text by their Roman numerals.

- I Bäckström J, Ekselius L, Gerdin B, Willebrand M. (2013) Prediction of psychological symptoms in family members of patients with burns 1 year after injury. *Journal of Advanced Nursing*, 69:384-93.
- II Bäckström J, Öster C, Gerdin B, Ekselius L, Willebrand, M. (2013) Health-related quality of life in family members of patients with burns. *Journal of Burn Care & Research*. [Epub ahead of print].
- III Bäckström J, Willebrand M, Sjöberg F, Haglund K. (2013) Family members of patients with severe burns: Experiences during care and rehabilitation. *Manuscript*.
- IV Bäckström J, Haglund K, Sjöberg F, Willebrand M. (2013) Family members' experiences of support during care and rehabilitation of patients with severe burns. *Manuscript*.

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Abbreviations

| | |
|---------|---|
| ANOVA | Analysis of Variance |
| CTQ | Coping with Trauma Questionnaire |
| EQ-5D | EuroQol Five Dimensions |
| HADS | Hospital Anxiety and Depression Scale |
| HRQoL | Health-Related Quality of Life |
| ICU | Intensive Care Unit |
| IES-R | Impact of Event Scale-Revised |
| LOS | Length of Stay |
| LTE-Q | List of Threatening Experiences-Questionnaire |
| PTSD | Posttraumatic Stress Disorder |
| QoL | Quality of Life |
| SD | Standard Deviation |
| SSQ-6 | Social Support Questionnaire-Short Form |
| TBSA | Total Body Surface Area |
| TBSA-FT | Total Body Surface Area-Full Thickness |
| VAS | Visual Analogue Scale |
| WHO | World Health Organization |

Introduction

Burn injuries

A severe burn is traumatic and has been described as one of the most distressing events a person can experience. The survivor of a severe burn might have to deal with disabilities and disfigurements, as well as psychological, social and economic consequences, that may affect not only the patient but also family members [96; 106]. A burn is per definition an injury of the skin or other tissue that is commonly caused by thermal energy such as fire and scalding; however, electricity, radiation, friction and chemicals also cause burn injuries [135]. The severity and consequences of a burn depend mainly on the depth and distribution of the injury, although premorbid diseases and the injuring agent also contribute to the outcome [73; 132].

Epidemiology of burns

In an international perspective, burn injuries are a major cause of death and disability in both adults and children [50; 84; 97; 135], and result in about 195 000 deaths every year [135]. The incidence, aetiology and gender distribution vary greatly by country, however, burns are more frequent in low- and middle-income nations [35; 50]. Burn injuries are more common in low socioeconomic groups and the consequences may include increased poverty after recovery [96]. In Sweden, the incidence of burns is low compared to other countries. During 2011 the incidence of burn injuries was 11/100 000, and just over 1000 individuals were admitted to hospitals due to injuries caused by fire [85]. In contrast, in Spanish Catalonia the incidence was reported to be 31/100 000 [7], in parts of Great Britain it was 29/100 000 [104], and in Bangladesh the incidence of non fatal burns in children was reported to be 288/100 000 [76].

Rehabilitation

For the burn survivor, hospitalization in the burn-specific intensive care unit might last from a few days up to several months. The rehabilitation process following a severe burn is often long and challenging, and the first year is believed to be the most demanding when it comes to dealing with stressors such as pain, memories related to the accident and general burdens [93;

137]. Long lasting physical effects following a severe burn may include itching, pain, and hypertrophic scarring associated with disability. Extensive rehabilitation is therefore essential [44; 45]. In addition, psychological distress is also often prevalent after a burn [48], and symptoms of anxiety, depression, PTSD and substance related disorders are common [37; 40; 89; 129]. The presence of psychological symptoms early in the rehabilitation process, coping style, and the experience of life threat during the accident are predictive of psychological symptoms after burn [140]. Improvements in functional health are mainly seen during the first year post burn, while skin-related problems decrease at a slower pace up to several years after the injury [141; 142; 148].

To optimize psychosocial adjustment after a burn, a team consisting of a number of different professions, including nurses, physicians, physio- and occupational therapists, social workers and psychologists, is essential [2; 21; 52]. The teamwork can be complex [2; 19], and rehabilitation of a burned patient is often challenging for the staff. This process can, however, also be rewarding, since rehabilitation with positive results will provide the patient with a more meaningful existence [113]. Despite the strains and potential long-term consequences of a severe burn, research has shown that many patients are satisfied with the care they receive, in particular the care given by the nursing staff [138; 139].

Nursing in burn care

Nursing in burn care is complex and includes wound care along with nutritional and metabolic support. A main task for the nurse in burn care is assessment and management of the patient's pain and anxiety. The nurse is also involved in the rehabilitation procedure when preparing the patient for discharge. In addition, nursing responsibilities include family education, which needs to be adjusted to the specific family structure [8]. Nurses have been described as comprising a central profession in the care of the burn survivor, and as potential burn team leaders due to their pivotal position in the care of the patient [21]. The complex recovery process associated with severe burns has resulted in nursing in burn care being described as a combination of intensive care nursing and psychiatric nursing. Changes in the patients' wellbeing are often first observed by nurses, who therefore are well positioned to initiate interventions, including provision of social support to the patient and family members [2]. Nurses in general intensive care are often positive toward involving family members in the care [120], believing them to be an essential part of the care [42]. In home care not related specifically to burns, family members have been described by nurses both as a resource and a burden [9].

Social support

The concept of social support has been linked to positive health outcomes in general [128] and can be measured and defined in different ways. Four commonly used definitions of the different functions of social support are emotional, informational, tangible and belonging [127]. The link between social support and health relies mainly on two models, the buffering model and the direct effects model. In the buffering model social support is related to wellbeing for individuals undergoing stress, and the support protects the person from the negative influence of traumatic events. The direct effects model suggests that social support has positive effects on a person regardless of the presence of stressful incidents [29]. When relating social support to physical health, it is important to distinguish between perceived and received support [128]. Women tend to seek more emotional social support than men and are also more likely to vent health stressors concerning themselves and others [122]. The importance of social support for psychological wellbeing, and in the recovery process of patients with severe burns, has been shown in previous studies [32; 91; 98; 116]. Burn survivors find support from family members to be very important during recovery, and psychosocial needs may be given more priority than physiological needs [70; 116].

Family members in intensive care

The situation of family members of patients treated in intensive care units has been of interest to researchers since the late 1970s, and it has been acknowledged that this group may need specific support [31; 64; 82]. Family members play an important role when a person is admitted to intensive care [110]. Within burn care, family members have been described as a part of the psychosocial care of the patient [13], and it has been proposed that this group should also be included in the care after discharge [13; 133].

Experiences and needs of family members

The experiences of family members of burn survivors have not been extensively studied in the past. However, there are studies suggesting that family members are concerned about pain and about what impact the burn might have on the injured person's appearance [53; 99; 124]. Also, worries concerning possible consequences of a physical as well as a psychological character for the injured person, together with logistical uncertainties and the family members' own needs, have been reported [1; 16; 105; 124]. The situation after discharge might be of concern and it has been suggested that family members should be made aware of the psychological aspects of the reha-

bilitation process [74]. Family members can be experiencing guilt in relation to the accident [15; 24] and new roles might have to be assumed [115].

It has been established in general intensive care that it is stressful for family members to witness their relative being admitted to hospital [64]. It is difficult to endure the uncertainty associated with the hospitalized person's condition [39; 43; 146], and being forced to undergo changes in the relationship, roles and responsibilities may be demanding [25].

In burn care, it has been demonstrated that family members appreciate social support provided by family and friends [124]. Proximity to the patient, receiving support in meeting personal needs and in understanding the patient's condition, and assistance with financial concerns can also be of importance [1; 124]. In general intensive care, it has been suggested that needs of family members can generally be described as cognitive, emotional, social and practical [131]. It is important to be in close contact with the injured person and to be supportive regarding the person's integrity [39; 43; 72; 80; 121; 146]. Family members may put their own wellbeing aside in favour of the patient [131; 146]. Maintaining hope even in critical situations has been emphasized as one of the most important needs [39; 43; 80; 131], and receiving information is often rated high by family members [95]. The time after discharge has previously been described as a time of adaptation and change that can be difficult for family members [121].

Psychological symptoms in family members

Within burn care, few previous studies have focused on psychological symptoms in family members. One study that did so demonstrated that relatives experienced high levels of distress during the acute phase of hospitalization and up to six months post burn, and that intrusive and avoidant symptoms were predictive of long-term stress [24]. The other study showed that close relatives of patients with burns had symptoms of anxiety and depression, as well as suppressed immune function, following the incident [114].

In general ICU settings, several studies have demonstrated that family members experience a burden, including a range of psychological symptoms [79]. Family members could display high levels of stress when someone in the family was admitted to intensive care [5; 6; 28; 62; 90]. Being of a young age, female, having a lower level of education, being the spouse of the patient, having high levels of trait anxiety or having experienced a lack of advance directives concerning end-of-life decisions are examples of factors associated with higher levels of stress [28; 78; 125] or higher levels of anxiety and depression [34; 90; 101]. In studies of relatives of patients in general ICUs, symptoms of depression have been reported to occur in up to 97 % [90], and symptoms of anxiety in up to 85% [144]. Psychological symptoms tend to peak during acute care and decrease after discharge or at the second assessment [5; 27; 90; 125].

Health, Quality of life and Health-related quality of life

Ideas concerning health have been of importance for people since the beginning of human civilization. The concept has been defined in a number of ways over the years and it is often described in a primarily biological or sociological perspective. As early as during roman antiquity there were theories of a polarity between *hygiea* (health) and *nosos* (disease) [63]. In the 1970s Boorse [14] presented the Bio-Statistical Theory (BST) in which health is defined as statistical normality of function. Other more holistic approaches to the concept are the biopsychosocial model supported by Engel [41] and health as ability, as emphasized by Nordenfelt [87]. A well-known definition of health is the one presented by the WHO in 1948, where the concept is described as multidimensional, comprising complete physical, mental and social well-being and not only the absence of disease or infirmity [103]. The WHO definition has been criticised for being unrealistic and utopic.

An increased interest in individuals' preferences in relation to health care and the subjective experience of the impact of illness has contributed to the establishment of the concepts Quality of Life (QoL) and Health-Related Quality of Life (HRQoL). There are several definitions of both [49]. Quality of Life aims to describe a person's overall wellbeing, and the idea of QoL was originally viewed as a complement to the primary definitions of health [123]. The concept is multifactorial and is formed by the individual's physical and psychological health state, social relationships, level of independence and environmental factors [109; 136]. The concept HRQoL was developed to comprise aspects of QoL that could be considered to be affected by health. One definition of HRQoL, emphasized by Fitzpatrick [49], is that the concept can be described as the level of well-being and satisfaction associated with a person's life and how it is affected by disease, accidents and treatments.

Assessment of Health-related quality of life

Over the years several ways of assessing HRQoL have been developed with the aim of addressing the individual's subjective experience of consequences of health and illness [49]. There are mainly two different groups of instruments: 1) Generic instruments, for example the EQ-5D [46], designed to be applicable for use regardless of underlying disease and able to be used to compare outcomes across different populations and interventions, and 2) disease-specific measures created to be relevant for specific groups of individuals, often defined by a disease. Specific instruments are sometimes more sensitive to particular changes that might be of importance to the specific group of individuals or patients [30; 92]. There are several different opinions concerning what dimensions should be encompassed in an instrument aim-

ing to describe HRQoL. Primary dimensions have been suggested to include physical, psychological and social functioning, as well as overall life satisfaction and perceptions of health status. Additional dimensions include personal productivity, sexual functioning and spirituality [86].

Health-related quality of life in family members

Few studies focusing on HRQoL in family members of critically ill adult patients have been carried out. Two previous studies, performed in general intensive care settings, demonstrated that family members experience an impaired HRQoL after the patient's discharge [6; 69]. Thus far HRQoL has not been studied in family members of patients with burns.

Scientific methods

In this thesis, the situation of family members is explored by using quantitative as well as qualitative research methods. Quantitative methods are based on numerical data, analysed by using statistical methods, while qualitative methods use non-numerical data such as interviews and case studies and non numerical methods for data analysis [83]. Although both quantitative and qualitative paradigms strive to increase and create knowledge, it has been argued over the years that they rely on fundamentally different ontological and epistemological approaches, which would make combining them next to impossible [88]. Despite the previous polarization, it has been pointed out that in reality, the paradigms share more similarities than differences. For example, both perspectives use observations to tackle the research question in a systematic way, and verifying data is central in both paradigms. The main differences that have been highlighted are the goal of generalization and the possibility of investigating causal relationships within quantitative research, while qualitative research focuses on improving in-depth understanding of selected phenomena [61; 88]. Many researchers have adopted a pragmatic approach, choosing the method that fits the particular research question. Combining quantitative and qualitative methods, sometimes referred to as mixed methods [61], is growing in popularity and in many cases it could be an appropriate approach by which to broaden the aspects of a particular research question [83]. In this thesis, the overall aim, which is to broaden the understanding of the family members' experiences, is approached by both qualitative and quantitative methods.

Background and aims of the study

This research is part of a longitudinal interdisciplinary project where the focus has been on psychological outcome and rehabilitation of persons surviving a severe burn. This project was formulated on the basis of a hypothesis suggesting that the patient's recovery and adjustment after severe injury is determined by several interacting factors, including social support. It is known that social support is vital for these individuals. A key component within the concept of social support is the interaction between family members. For these reasons it is important to study the effects of a severe burn on family members, as well as their experiences of care and rehabilitation, and support. Figure 1 illustrates the working hypothesis that formed the research questions for this thesis. It suggests that several factors may influence the ways in which relatives are affected when a family member or close friend undergoes a trauma such as a severe burn, and that family members are also in a process of adaptation.

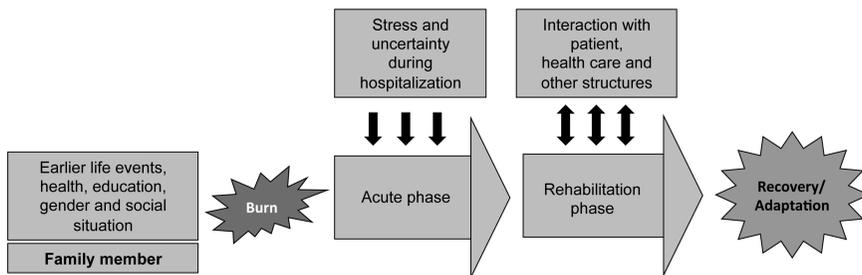


Figure 1. An illustration of the hypothesis regarding this process for family members.

The general purpose of this thesis was to increase and deepen the understanding of the situation for family members of patients with burns during the time in hospital and rehabilitation. The specific aims were:

- To describe the psychological symptoms of anxiety and depression in family members of patients with burns and to find predictors of those symptoms. (Paper I)
- To describe HRQoL and to find predictors of HRQoL in family members of patients with burns. (Paper II)
- To explore family members' experiences during burn care and during the rehabilitation phase after hospital discharge. (Paper III)
- To explore family members' experiences and views on support during care and during the rehabilitation phase after hospital discharge. (Paper IV)

Methodology

Design and setting

Papers I and II are part of a prospective, longitudinal study where physical and psychological health in persons surviving a major burn trauma have been studied previously. Family members of this group of patients were included in a parallel prospective and longitudinal study. These studies were performed at the Uppsala Burn Center, which at the time of the study had a catchment area of approximately three million inhabitants. Papers III and IV were performed at the Uppsala Burn Center, Uppsala University Hospital and The Burn Center at Linköping University Hospital. The inclusion area included the whole of Sweden with around 9.5 million inhabitants. Criteria for admission to the centres are based on the recommendations of the American Burn Association [3]. Papers III and IV are based on a qualitative research design.

Participants

In Papers I and II, consecutive adult patients, who were admitted for burn treatment between 2000 and 2007 and had agreed to participate in a prospective, longitudinal study, were asked if they had a family member that the research team could contact regarding a parallel study. Inclusion criteria for the family members were (1) minimum age of 18 years at the time of the incident, and (2) proficiency in the Swedish language. One participant was included at 17 years of age as the parent, who was the patient, gave consent. Out of 93 patients, 17 were missed due to administrative reasons and 49 responded that they had a family member who could be contacted. Initially, forty-eight family members agreed to participate. Two were excluded and two did not respond; thus 44 individuals participated in the study.

In Papers III and IV, a relevance sampling strategy was applied [67]. Inclusion criteria were as follows: (1) family members of patients with burns who were present during hospitalization and rehabilitation, (2) burn incidents at least one year before inclusion, (3) burns covering 10 % or more of the total body surface area (TBSA) and a length of stay (LOS) of seven days or more, (4) a minimum age at the time of the incident of 18 years, and (5) proficiency in the Swedish language. Patients with self-inflicted injuries

were excluded. Twenty-four adult patients, admitted to the burn centres between 2009 and 2010, were contacted and asked whether they had a family member whom they would allow the research team to contact, and 13 of these adult patients gave their consent. Of the 13 contacted family members, 11 originally agreed to participate in the study, and 10 of these family members completed the study. Data collection took place between September 2011 and June 2012.

Procedure

In Papers I and II, the first assessment took place toward the end of the initial hospital stay, and thereafter questionnaires were sent to participants at 3, 6 and 12 months after injury. In Papers III and IV, the interviews took place at locations chosen by the participants, which in most cases was the participant's home; however, a few interviews were performed in cafés.

Assessments and measures in Papers I and II

Injury characteristics of the patients

Total Body Surface Area burned (TBSA burned), Total Body Surface Area with Full-Thickness burns (TBSA-FT) and Length of Stay in the ICU (LOS) were collected from the medical records of the associated patients.

Socio-demographic data

The following variables were registered: gender, age at the time of the burn, number of years of education and family member-patient relationship (1 = married/co-habiting, 2 = parents, 3 = children, 4 = siblings and 5 = friend).

Participants were 37 women and 7 men, with a mean age of 42 years at the time of the burn. Thirty-four were partners of the patients, three were siblings, three were parents, three were children and one was a friend. As all but one participant were family members, the participants will be referred to as family members.

Table 1. *Characteristics of the family members and their injured relatives in Papers I and II.*

| Family members | | | | |
|-------------------------------|--------|------|------|------------|
| | Median | Mean | S.D. | Range |
| Age of family members (years) | 43 | 42 | 14 | 17 -80 |
| Years of education | 12 | 12 | 3 | 7 – 20 |
| Patients | | | | |
| TBSA burned (%) | 27.5 | 29.8 | 22.8 | 0.5 – 80.0 |
| TBSA-Full Thickness burns (%) | 6.0 | 13.0 | 16.4 | 0 – 63.0 |
| Length of stay (days) | 15.0 | 25 | 28 | 1 – 144 |

Symptoms of anxiety and depression

The Hospital Anxiety and Depression Scale (HADS) [145] was used to assess symptoms of general anxiety and depression. The HADS consists of 14 items divided into two subscales, Anxiety and Depression. Each item is rated on a scale of 0 to 3, where 0 equals no symptom, and 3 equals severe symptom. The possible scores range from 0 to 21 for each subscale, and symptom levels are classified in three categories: non-cases (<8 points) which refers to normal symptom levels, doubtful cases (8–10 points) which refers to mild symptom levels, and definite cases (>10 points) which refers to moderate and severe symptom levels. HADS is considered a reliable instrument for use in both somatic and psychiatric populations as well as the general population [12].

Health-related quality of life

The EuroQol Five Dimensions (EQ-5D) [46] was used to assess health-related quality of life. The EQ-5D includes five questions that define health in five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension includes 3 response categories: 1 = “none”, 2 = “moderate”, and 3 = “extreme problems”. The responses can be transformed into an index which is based on population norm values [36] and varies from -0.594= “death or worse than death” to 1= “full health”. The EQ-5D also includes a vertical visual analogue scale (VAS), graded from 0 = “worst possible health state” to 100 = “best possible health state”, where the respondents mark their perceived current state of health. The EQ-5D has been validated in a Swedish general population [20] and is also validated for assessment of HRQoL in adult patients with burns [147]. The EQ-5D index and the VAS scores were used for analyses.

Symptoms of Posttraumatic Stress Disorder

The Impact of Event Scale-Revised (IES-R) was used to assess symptoms of posttraumatic stress disorder. The IES-R consists of 22 items assessing frequency of the associated symptoms [134]. Each item is rated 0, 1, 3 or 5 and the total maximum score is 110. The Swedish version of the IES-R has been validated among patients with burns and showed excellent psychometric properties [119].

Stressful life events

The List of Threatening Experiences-Questionnaire (LTE-Q) [18] was used during care to assess previous stressful life events in the family members. The LTE-Q questionnaire consists of 12 categories of common life events that are likely to be considered threatening. The total number of events is calculated.

Coping strategies

The Coping with Trauma Questionnaire (CTQ) [140] was administered during care to assess general coping styles, i.e. not specifically related to the recent burn. The CTQ contains 33 items rated on a scale of 1–4 (1 = does not apply/not used, 2 = used somewhat, 3 = used quite a bit and 4 = used a great deal). The items are divided into six subscales: Reevaluation/adjustment, Avoidance, Emotional support, Optimism/problem solving, Self-control, and Instrumental action.

Social support

The Social Support Questionnaire-Short Form (SSQ-6) was used to assess the family members' perceptions of social support during care. The SSQ-6 consists of six items assessing amount of social support and perceived satisfaction with this support [108]. Only the subscale assessing satisfaction with social support was used. Each item is rated on a scale from 1 = "very dissatisfied" to 6 = "very satisfied".

Assessments and measures in Papers III and IV

Injury characteristics of the patients

Data concerning the associated patients, gender, LOS, age and TBSA, were collected from medical records.

Socio-demographic data

In connection with the interview, the following variables concerning the family members were collected: gender, age at the time of the interview, working status, and family member-patient relationship.

The participants consisted of nine women and one man (mean age 49 years, range 29-63). Eight respondents were partners of the patients (married/cohabiting), one was a parent and one was an adult child of the patient. TBSA of the patients varied between 12.5% and 70% and the range for LOS in the Burn Center was 9-227 days. The participants are referred to as family members.

Qualitative interview

In order to gain a deeper understanding of the family members' experiences, interviews were explorative and qualitative descriptive [102]. The same researcher conducted all interviews. A semi-structured interview guide [94] was evaluated by means of interviews with two persons who were not family members, and the evaluation did not indicate a need for revision. Focus was on the general experience of inpatient care and rehabilitation, and of support during the same phases. The interview questions were: (1) How did you experience the acute phase of care while your family member was in the hospital? (2) How did you experience the phase after discharge from the hospital? (3) What support were you offered during the time in hospital, and how did you experience this support? (4) What support were you offered during rehabilitation, and how did you experience this support? (5) Were there any subjects that you feel were taboo or not ok to bring up with the staff? (6) Did you experience support from any organization or person outside the hospital? (7) What did you experience as the most important support? (8) What support would you have wished for during the time in hospital as well as after discharge? The interviews lasted between 14 and 55 minutes (mean 41 minutes).

Data analyses

Statistical analyses

Analyses were performed with the statistical package IBM SPSS Statistics. In Paper I, average levels of anxiety and depression, respectively, were compared over time in repeated measures ANOVAs. Bivariate correlations were used to analyse the associations between relevant independent variables collected during care on the one hand, and the HADS scores at 3, 6 and 12 months on the other. Each of the HADS subscales was then used as a dependent variable in three separate sets of multiple regression analyses, one for each time point. The three variables with the strongest bivariate associations with the HADS scores were selected as independent variables in each regression analysis. As this study was explorative, all three variables were first analyzed in an enter model. In a second step, a final model was obtained by backward elimination.

In Paper II, the five dimensions of the EQ-5D were analysed separately using Cochran's Q to detect changes over time. For these analyses the sample was dichotomized into: 0 = "none", and 1 = including both "moderate" and "extreme problems" according to the response levels on the EQ-5D. Bivariate correlations and multiple regression analyses were performed using a similar strategy for analysis as in Paper I.

Qualitative analyses

In Papers III and IV, the interviews were recorded digitally and transcribed verbatim in Swedish, and notations concerning non-verbal emotional expressions were also made. As the method was qualitative descriptive, qualitative content analysis was chosen for analysis [107]. The authors read the transcribed data multiple times and listened to the recordings when needed to gain an optimal understanding of the content. The transcribed interviews were imported to Open Code 4.0 [58], software designed for coding and organizing qualitative data generated from text, such as transcribed interviews. The analyses were conducted in the following steps, influenced by the approach described by Graneheim and Lundman [54]. (1) The authors identified meaning units related to the family members' experiences of inpatient care and rehabilitation (Paper III), and of support and views of support (Paper IV). (2) The meaning units were coded with labels representing different experiences and views. (3) Codes were organized into subcategories and categories (Paper III) or directly into categories (Paper IV) that represented the manifest content level. (4) In Paper IV, findings that were not related to the *experience* of support but that comprised responses to specific questions regarding support in the interview guide (no. 5, 7, and 8) were reported in running text under the heading "Specific views on support". The

authors discussed the coding and categorization until consensus was reached and quotes illustrating the categories were chosen as an illustration of the results.

Table 2. *Examples of meaning units, codes, subcategories and categories as applied in Paper III.*

| Meaning unit | Code | Subcategory | Category |
|--|---------------------------|--------------------|-------------------------------------|
| But it's a miracle of God that we're here today. | A miracle of God | God | Being thankful |
| ... then we had to decide how to travel down to X [the specialist care center] | Making decisions | Responsibility | Being the hub of the family network |
| And I understand why there are visiting hours, I really do, but I don't understand why they aren't individualized. | Inflexible visiting hours | Dissatisfaction | Being treated in an insensitive way |

Ethical considerations

The studies were conducted according to the principles of the Helsinki Declaration [143] and were approved by the Uppsala University Ethics Committee (Papers I and II) and the Regional Ethical Review Board in Uppsala (Papers III and IV). Participation was voluntary for family members as well as for the associated patients; all received written and oral information before agreeing to participate. Participants were informed regarding the possibility to discontinue participation in the study at any time, without having to explain why. In Papers III and IV, details that would make it possible to identify a respondent or patient were removed from the transcribed interviews, the quotations and the manuscript. As all but one of the participants in Papers III and IV were female, all participants were reported in a female context to avoid the risk of identification.

Summary of results

Paper I: Prediction of psychological symptoms in family members of patients with burns 1 year after injury

Psychological symptoms

The average levels of psychological symptoms of the family members were low. The mean scores for the HADS anxiety subscale varied from 8.3 (SD = 4.3) during care down to 5.7 (SD = 3.8) at 12 months, and the HADS depression subscale varied from 6.0 (SD = 3.8) during care down to 3.1 (SD = 2.9) at 12 months. Both Anxiety and Depression decreased significantly from the assessment during care to the assessment at 12 months. Furthermore, symptoms of anxiety decreased between the assessment during care and at 3 months, and for symptoms of depression there was a significant decrease between the 3- and 6-month assessments.

Table 3. *Distribution of family members demonstrating normal, mild and moderate/severe symptom levels during care and at 12 months.*

| Symptom levels assessed with HADS | | | |
|--|--------|------|---------------------|
| | Normal | Mild | Moderate/ Severe |
| Anxiety | | | |
| During care | 21 | 8 | 15 |
| 12 months | 27 | 7 | 5 |
| Depression | | | |
| During care | 27 | 12 | 5 |
| 12 months | 35 | 4 | 0 |

Prediction of psychological symptoms

In bivariate correlations, both Anxiety and Depression were highly associated with the corresponding psychological symptom at the previous assessment. Furthermore, there were associations with Avoidant coping, life events, age and LOS.

In the final multiple regression models, between 47% and 54% of the variance in the Anxiety subscale was explained by previous life events and

previous anxiety symptoms at the three assessment time points. For Depression, between 29 % and 50 % of the variance was explained by previous life events, previous depressive symptoms, age and Avoidance.

Paper II: Health-related quality of life in family members of patients with burns

Health-related quality of life

The mean EQ-5D index varied between 0.80 and 0.86 across the assessments and did not change over time. However, there was a significant change in the Anxiety/depression domain where the frequency of responses “moderate” or “extreme” problems decreased during the first six months post burn (Figure 2). The mean EQ-5D VAS scores increased significantly from 71.6 during care to 81.2 at twelve months.

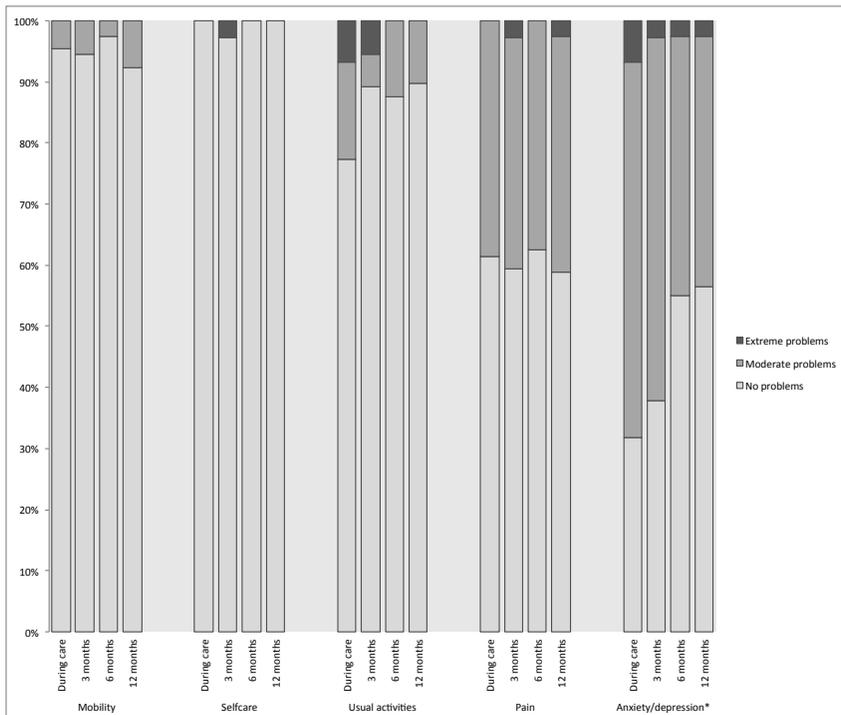


Figure 2. Distribution of scores in all dimensions for the EQ-5D health scale at all assessments.

* The frequency of responses denoting moderate/extreme problems decreased while the responses denoting no problems increased between the 3-month assessment and 6 months post burn ($p < 0.05$).

Prediction of Health-related quality of life

In bivariate correlations the EQ-5D index and the VAS scores at the 3-, 6- and 12-month assessments were significantly associated with the corresponding assessment during care. Furthermore, both index- and VAS scores were negatively associated with symptoms of PTSD during care and earlier life events. There were modest associations with LOS and Social support, but most were not statistically significant.

In the final multiple regressions for the EQ-5D index scores the range of adjusted variance was between 21 % and 29 %. Overall the strongest predictors were earlier life events and EQ-5D index during care. For the EQ-5D VAS scores, the explained adjusted variance varied between 18 % and 28 %. Earlier life events together with concurrent symptoms of PTSD, EQ-5D VAS during care and working/non-working were remaining predictors.

Paper III: Family members of patients with severe burns: Experiences during care and rehabilitation

The interviews resulted in seven categories related to family members' experiences during inpatient care and six categories related to experiences during rehabilitation after hospital discharge. A summary of the results is given below. For detailed descriptions of categories together with illustrative citations and interview numbers, see Paper III.

Experiences during care

The hospitalization had a negative impact on the family members, as judged by their experiences. In the category *Feeling distress* these experiences were mainly related to the acute character of the incident and included feelings of chaos and shock. A total focus on the injured person was experienced and it was hard having to endure waiting, while at the same time some family members were already worrying about what the situation would be like after discharge. Negative feelings such as anger and irritability were also present. There were negative experiences related to the health care provided in hospital, described in the category *Being treated in an insensitive way*. Family members sometimes felt neglected by the staff, felt as if they were a burden, and were frustrated about the lack of flexibility concerning visiting hours. When they noticed instances of unskilled care and unprofessional behaviour this was experienced as difficult. Frustration emerged when the injured person was discharged to a local hospital, where family members experienced problems due to a lack of competent burn care. Some family members were clearly reluctant towards being expected to act as care providers at times when the burn survivor was temporarily home from hospital, which is de-

scribed in the category *Reluctance towards giving care*. The respondents needed to coordinate practical arrangements and the handling of information and decisions related to the incident, described in the category *Being the hub of the family network*. Positive experiences during care were also found and these comprised the categories *Receiving excellent care*, *Feeling hope* and *Being thankful*. Individualized treatment, a positive atmosphere in the unit and flexible visiting hours were noted as positive experiences. Hope was experienced as a way to cope with the situation and it was found through the staff and the existing social network, and when the injured person's condition improved. In the overwhelming situation, some family members found strength in relying on a higher power, and feelings of thankfulness were expressed in relation to the care and the recovery of the injured person.

Experiences during rehabilitation

The time after discharge from hospital was challenging for the family members. *Ambiguous feelings* were experienced after hospital discharge. The patient's return home was something that the family had looked forward to; however, negative aspects of the discharge soon emerged. Respondents experienced emotional and practical *Difficulties after discharge*. The situation was experienced as chaotic, with feelings of being diminished, powerless, stressed and dejected. Worries concerning financial consequences, a lack of sleep and of hope, as well as a lack of personal space were demanding. Being affected by the injured person's pain and withdrawal symptoms related to medications, and in some cases having to fulfil their own professional duties at the same time was hard. Family members experienced that they were *Being forced to take responsibility* in the form of involuntary nursing of the injured person. They experienced being overwhelmed by responsibilities, dealing with communication problems between the hospital and outpatient clinics, and experiencing a lack of support from the healthcare system. Experiences in the category *Handling the situation* included focusing on the injured person and not on their own needs, trying to go on like before, holding back negative feelings, and trying to make the best of the situation. The family members were *Gaining support* from friends, healthcare professionals, and insurance companies. Being on sick leave allowed the family members to focus on the injured person's needs without having to go to work. Some of the family members expressed their thankfulness that the injured person had survived, and some did so by praising God, described in the category *Being thankful*.

Paper IV: Family members' experiences of support during care and rehabilitation of patients with severe burns

The interviews resulted in five categories related to experiences during care and five categories related to experiences during rehabilitation. A summary of the results is given below. For detailed descriptions of categories together with illustrative citations and interview numbers, see Paper IV.

Experiences of support during care

During care, family members experienced a lack of support or negative experiences that were classified into the category *Nonsupport*. Family members were unaware of what support was available or did not expect any support at all. A rejecting attitude among staff members as well as being told to seek help elsewhere were experienced as unsupportive. Some thought they were not expected to need support and that counseling by a medical social worker was not experienced as beneficial. Inflexible and impersonal attitudes among the staff and a lack of information were considered unsupportive, along with experiencing that they were a burden. Family members experienced that the staff focused only on the injured person and that they relied on the patient to communicate important information to the family. Some had tried to seek support from the primary care center but felt rejected.

However, family members also experienced *Professional Support* from members of all professions involved in the care, as well as from employers of the family members. This support was of a practical nature and could include assistance with living accommodations and doctor's certificates. *Support from family and friends* was also experienced. Respondents expressed a wish for proactive support from professionals involved in the care, as well as acknowledgement of the difficult situation in which they found themselves, described in the category *A wish for support*. Finally, family members experienced support when staff members did *That little something extra*, above and beyond their ordinary duties.

Experiences of support during rehabilitation

After discharge family members also experienced a lack of support or had negative experiences that were classified into the category *Nonsupport*. Family members found themselves being stranded and forgotten. They felt insecure and did not trust outpatient care. They experienced a lack of coordination between care providers, and it was up to the family member to find adequate support after discharge. It was difficult to know what support might be available, and some stated that the needs of family members were

clearly underestimated by healthcare staff. There were also experiences of *Professional support*, such as that provided by social workers within primary health care. Some respondents received all the support they needed from primary health care and the municipality. The category *Support from family and friends* consisted of support from friends, fellow employees and significant others. Family and friends assisted with practical arrangements including providing food and replacing things that were missing after the fire, and they also acted as social support for both the family member and the patient. Talking repeatedly with the injured person about the incident and the new situation comprised the category *Support from the injured person*, and some family members found strong support through *Religion* such as when the local parish prayed for the family member and the injured person.

Specific views on support

Subjects that were taboo

Only a few respondents experienced that there were subjects that were taboo during the time in hospital or after discharge. Instead, they related examples of touchy subjects they had brought up such as questions concerning how the burn would affect sexual capacity and concerning future reproduction. Some experienced that it was taboo to question the organization in the ICU. There was also a wish for more time to prepare at home before hospital discharge, but some respondents did not dare to raise this issue.

The most important support

A majority of the family members stated that other family members and social contacts such as colleagues provided the most important support. One respondent stated that the injured person's positive attitude towards rehabilitation had been of most importance.

Wish for support

During the time in hospital the family members stated that they wished for practical assistance such as financial advice and childcare. They also wished to be emotionally validated by the nursing staff, and they preferred a proactive approach from professionals. Other needs were to be sick-listed and to have visitors at home to avoid loneliness. A number of family members in this study clearly stated that they did not receive any offer of support at all and some did not remember if they were offered any support. Some family members did not need or want extra support.

During rehabilitation the family members stated that they wished for financial support and organized practical assistance in the home, for example cleaning and relief from nursing duties. They also wished for a care coordinator for the patient, as well as a better rehabilitation plan and medical follow-up. Although some did not consider themselves in need of support, they

recognized that others probably were, and stated that no family member should be left without support in such a situation. Some respondents searched for informal support after discharge, including blogs.

Discussion

The main aim of this thesis was to increase and deepen the understanding of the situation for family members of patients with burns, both during the time in hospital and during rehabilitation. The task was approached in two ways: 1) by quantitative studies using well-known questionnaires to describe and predict psychological symptoms and HRQoL during care and up to 12 months after the incident, and 2) by qualitative studies revealing the family members' overall experiences of the time during care and rehabilitation, as well as their experiences of support during the corresponding times.

Psychological symptoms in family members

The family members expressed low to moderate levels of anxiety and depression, and the symptoms decreased during the first three and six months, respectively. The low level of symptomatology is in contrast to earlier research in general ICU settings, which has shown that relatives of ICU patients often demonstrate high levels of both anxiety and depression [34; 78; 90; 100; 101]. This discrepancy might be explained by the timing of inclusion. As the family members were recruited once the patients were considered medically stable, the first assessment did not take place during the most acute phase of hospitalization when symptoms could be expected to be at the highest level. As seen in this study and in previous research [5; 27; 90; 125] symptoms seem to decrease over time. Nevertheless, one third of the family members reported moderate or severe symptoms during hospitalization, and early psychological symptoms were found to be the strongest predictor of symptoms of anxiety and depression at all assessments. This implies that early assessment might help in identifying family members who could benefit from counselling.

Health-related quality of life in family members

The family members demonstrated a HRQoL similar to the general Swedish population [20], assessed with the EQ-5D index, at all assessments. In the Anxiety/depression dimension, HRQoL improved over time during the first six months, a finding that corresponds with earlier research on family mem-

bers of patients with burns [24; 114] and with Paper I in this thesis [22]. An improvement was also found when the EQ VAS scores were analysed from the assessment during care until 12 months post burn. These findings indicate that family members experienced HRQoL-related problems during the first months after injury, followed by an improvement during the first year post injury.

Earlier life events and HRQoL assessed during care were predictors of HRQoL in family members the first year after a burn, where earlier life events played a more central role closer to the injury. Symptoms of traumatic distress early in the care process might have an impact on HRQoL, since symptoms of PTSD during care both correlated strongly with HRQoL at each assessment and were a significant predictor of lower HRQoL during care and at three months.

Experiences during care and rehabilitation

Family members found themselves exposed and vulnerable in the situation when their loved one was hospitalized after the burn. The experiences of distress, such as frustration, anger and disappointment, might be reactions that could be linked to psychological symptoms previously reported in family members of patients within burn care, as well as within general intensive care [6; 24; 78; 101; 114], and as seen in Paper I of this thesis [22]. Seeing the injured person physically changed can be shocking [43], which was also described by respondents in this study. The respondents appreciated flexible visiting hours, being treated in an individualized manner and receiving support. Simultaneously, and in accord with previous findings [17; 56; 112; 117; 131], there were experiences of being treated in an indifferent manner, including being subjected to restricted visiting hours and a lack of areas designated for visitors. Respondents experienced a lack of communication between specialist care and the local hospital, which has been pointed out as a challenge for the health care system in general [66; 81].

Family members in this study described a total focus on the injured person, which has also been described by others [43; 131], when becoming the hub of the family network in practical matters. Hope is vital for family members during critical care [43; 131] and respondents in this study experienced hope when the patient's condition improved, and through interaction with the nursing staff. Receiving information without excluding hope is important to family members in intensive care [33; 51; 82]. It might also be important to acknowledge spiritual needs, since in accordance with other research [51; 82; 124] some respondents in this study found their belief in a higher power to be meaningful.

Despite positive expectations concerning the patient's homecoming, negative consequences related to the injured person's medical status soon became

evident. Family members need time for themselves in order to gain strength [43], findings supported by results in this study indicating that respondents experienced a lack of sleep and a lack of their own space. Family members' strategies for handling the situation after discharge, such as disregarding their own needs and negative feelings and focusing on the injured person, are in accord with previously identified strategies characterized by sacrificing oneself and volunteering [59]. Finding strength in faith, as experienced by some respondents, has been described as an effective way of coping by family members in other care settings [130].

Family members' experiences of support

Family members experienced a lack of support both during care and after discharge. There was a lack of knowledge concerning available support, as well as uncertainty concerning who was entitled to existing sources of support. Some could not recall any offers of support at all. Negative attitudes among the staff, for example inflexible attitudes concerning visiting hours, were experienced as unsupportive. Previous studies within general intensive care have demonstrated that family members are appreciative when staff members provide emotional support [112] as well as flexible visiting hours [131]. Flexible visiting hours within general intensive care have been recommended [11]. Previously reported needs of family members, such as flexible visiting hours and feeling accepted by the staff, might not be fully met within the ICU environment [17], as also experienced by respondents in this study. Family members should be included in intensive care [31; 110]; however, some respondents in this study experienced that the staff sometimes relied on the injured person to pass on relevant information to them.

After discharge, family members experienced problems in getting support. The respondents stated that the staff underestimated needs of significant others within burn care, findings that are in accord with previous research [77; 131]. Receiving accurate information concerning the injured person's condition is important to family members of critically ill patients [82; 121; 131], which is something that was also highlighted by the respondents in this study. Being sick-listed allowed family members to focus on their loved one, which has been demonstrated as important in earlier studies [43; 146]. Respondents expressed a wish for proactive support from the healthcare staff both during the time in hospital as well as after discharge, findings that correspond with results of previous research [60]. The family members experienced and greatly valued support from family and friends both during the time in hospital and after discharge. This has also been shown before [124], which is why it may be important for professionals to support individuals with weaker social networks. In agreement with previous research [4; 55], respondents in this study experienced support when staff

members did something beyond what was expected. Being emotionally validated by the staff was experienced as supportive and is also something that has been reported in research within other intensive care settings [112]. Support through religion was greatly valued by family members with spiritual affiliations, findings which are also in accord with earlier research [82; 124].

General discussion

Although being a family member of a patient with a burn injury is a distressful experience, the majority of family members expressed low to moderate levels of problems with psychological symptoms and health-related quality of life. The decreasing symptoms of anxiety and depression and the increased perceived overall health state, assessed with EQ-5D VAS-scores, during the first year post burn may be a reflection of the recovery process for the patient. As stated in the introduction, physical recovery after a severe burn is generally quite rapid during the first year post burn, followed by a slower rate of recovery involving minor improvements in function as well as skin- and appearance-related problems [141]. The findings indicating low symptomatology are in some respects contrary to early studies in the field. One possible reason is the timing of the assessment, as mentioned above, and another is potential changes in burn care that have taken place after publication of the previous studies on family members of patients with burns [24; 114].

In both Papers I and II, earlier life events were found to be a predictor of higher levels of symptoms of anxiety and depression, as well as a lower HRQoL. These findings are in accord with research on patients with burns demonstrating that previous psychological symptoms and life trauma experience predict psychopathology after burn injury [75]. Overall, the severity of the burn injury, reflected by length of stay and total burn size, did not have a strong influence on HRQoL or on symptoms of anxiety or depression. The results, indicating that HRQoL and psychological symptoms in family members can be predicted in part, could be important contributions to the ongoing work of reducing the negative impact a stay in the ICU may have on family members [23; 79]. The findings could form a basis for development of interventions focusing on the wellbeing of the family.

The findings in Papers III and IV demonstrate that family members often experience the time in hospital and after discharge as distressful and burdensome, and that many lack support after discharge. Previous research [42; 120] has found that nurses often have a positive attitude towards family members in intensive care, however there may be individuals in this group who are less committed. Possible differences in ward atmosphere, as discussed in other care settings [126], and possibly the lack of a general approach to the care of family members in the workplace [10], might contrib-

ute to the understanding of these results. Family members appreciated flexible treatment and found individualized treatment supportive, findings that are supported by earlier research on family members of critically ill patients [60; 131]. Family members can experience even minor transfers of the patient as frightening [57], and the respondents in Papers III and IV experienced the transition to local hospitals and to the home as distressful. There was a perceived lack of support during these episodes.

The findings in Papers I-IV emphasize that the consequences following a severe burn have a great impact not only on the injured person but also on family members. Reactions in the form of psychological symptoms, HRQoL and the general experience are individual. The findings therefore suggest that support directed towards family members of patients with burns should be individualized. Family members seek control and need to find their place in a situation that can be chaotic. Several factors are suggested to contribute to the family members' experience of burden and chaos, including the fact that patients are discharged before fully recovered, and that communication between care givers is deficient [66; 81]. One way for professionals to support family members in their new role and in taking control over the situation might be to facilitate empowerment in family members. The concept can be described as the means to attain power, the ability to create or resist change, and empowered individuals may be able to make life changes that have a positive affect on their health [68]. Empowerment within burn care could include helping family members attain control by inviting them to take an active part in care planning for the injured person, and to stay informed concerning discharge, thereby helping them to prepare mentally and practically.

Methodological discussion

Papers I and II share most strengths and limitations as they are based on the same data collection. The longitudinal design with repeated testing is perhaps the most important strength. The restricted sample size and the fact that the large majority of participants were women are limitations of the studies. A larger sample would have allowed more predictors in the models in both studies and would have permitted relevant subgroup analyses, such as regarding potential gender differences. The over-representation of women was not unexpected, since the majority of individuals with burns in the developed world are men. Nevertheless, this fact may lead to difficulties when it comes to generalizing the results to other less homogeneous populations, as the prevalence of anxiety and depression can be expected to be higher among women in general [65], and as women generally report lower HRQoL than men [20; 26].

Only 49 of 76 (64 %) patients in Papers I and II could name a person who was close to them and who could be approached concerning the study, which in itself is an important finding. Although the exact reasons for the small number of eligible family members are not known, it is possible that a large proportion of the patients lacked a strong social network. Psychiatric disorders such as depression and substance use disorders have been reported to be prevalent in patients with burns [37; 47], and social problems have been described as a risk factor in this context [38]. Considering these facts, the proportion of family members identified in the study might actually reflect the proportion of available family members. Of the 48 family members who agreed to participate, all but four completed the study, which is a strength. Thus, although the sample is small and the patients may not be representative of patients with burns in general, it is reasonable to believe that the current sample may be quite representative of existing family members in the study population.

As the experiences of family members of patients with burns have been explored to a limited extent in previous research, a qualitative descriptive design was used in Papers III and IV [102]. Qualitative content analysis, aiming to describe the meaning of the material in a systematic way [111], was chosen as the method for analysis, as it is suggested to be appropriate when the approach is qualitative descriptive [107]. In this method the concepts credibility, confirmability, dependability and transferability are of methodological importance [54; 71]. The relatively few included participants are compensated for by an in-depth interview technique with follow-up questions [94], resulting in rich data. The respondents were recruited through patients treated at the two national burn centres in Sweden. This resulted in participants who geographically represented the whole country, as well as potentially different ward routines, which can be considered to enhance credibility [54]. As in Papers I and II, the majority of respondents in Papers III and IV were females and partners of the patients. The interviewer and one of the senior researchers involved in the entire research process were not involved in burn care, decreasing the preunderstanding and risk for misinterpretation of the interviews, which may increase the confirmability of Papers III and IV [71].

The dependability [54] of Papers III and IV may have been strengthened by the choice of using the semi structured interview guide and also by transcribing the interviews verbatim. Transferability [54] of the results from Papers III and IV to other contexts or conditions seems possible, especially with respect to family members of critically ill persons in situations where a longer rehabilitation process can be expected. Taken together, the results can be considered credible and worth being taken into account in the context of care and support given to family members of persons with severe burns. However, transferability is something for the reader to decide, based on the

description of the different parts of the research process and the results [54; 71].

A strength of all the Papers in this thesis is the long-term perspective. As pointed out by Paul & Rattray [95], a majority of studies on family members of critically ill patients have been performed during the time in hospital, and research focusing on the time after discharge therefore fills a gap in global research. The use of both quantitative and qualitative methods has likely added insights to the situation of family members that might have been difficult to achieve using a single method [61].

Future aspects and clinical implications

Family members of patients treated within general intensive care have been studied during recent decades; however, there are gaps in the research, especially concerning the time after discharge, methods for assessing needs of family members, and effective interventions [95; 118]. The results in this thesis demonstrate that being a family member of a burn survivor is a distressful experience not only during care but in many cases also after discharge. The results indicate that some individuals are more vulnerable than others and that it might be possible to identify those in need of support while the care phase is still ongoing. A routine assessment of early psychological symptoms, previous life events and HRQoL in family members should be implemented within burn care settings.

Nurses play an important role in providing psychosocial support for family members of critically ill patients. Studies [42; 120] have pointed out that this profession often has a positive approach to family members of patients receiving care. An understanding of how family members experience the time in hospital and after discharge could contribute to the further development of supportive interventions directed towards these individuals. Results in this thesis show that during care, family members wished for a proactive and individualized approach from the staff, although more research is needed with regard to which supportive interventions should be offered.

Findings in this thesis strongly indicate that family members experienced distress and a lack of support in conjunction with the injured person's discharge to the local hospital and to the home. Routines with focus on information and relieving practical burdens should be developed and implemented, both within specialist care and in local hospitals. Further research is needed to develop and further explore the outcome of such interventions.

Finally, previous research has drawn attention to the fact that healthcare professionals tend to underestimate the needs of family members of critically ill persons, and that nurses tend to underestimate the importance of their role in relation to the needs of family members [77; 131]. Further research on how healthcare staff within burn care experience the interaction with

family members is therefore needed in order to develop interventions matched by the needs of this group. Social support has proven crucial in the recovery process of burn survivors [91; 98; 116], and it is possible that family members who experience support themselves might have better resources to provide support for the patient.

Conclusions

Being a family member of a person with a severe burn is a distressful experience. In this thesis, psychological symptoms and HRQoL in family members have been explored, together with how they experience the time and support in hospital and during rehabilitation. The main conclusions are:

- In general, family members demonstrate low to mild levels of psychological symptoms during the first year after the burn. However, one third demonstrate moderate to severe symptoms during care. Overall, the symptoms decrease over time and can be predicted in part by early symptoms, which is why screening might be useful in identifying individuals who may benefit from counselling.
- Family members' report of HRQoL is similar to that of the general population. An improvement is seen over time, but only in the anxiety/depression dimension. HRQoL could be predicted in part by earlier life events and psychological symptoms, which is why it may be possible to identify those with impaired HRQoL using a validated instrument.
- The time in hospital is stressful for family members, and they might benefit from being cared for in a more individualized way. Positive experiences during hospitalization were related to the perception of excellent care, feeling hope and thankfulness. However, improvements could be made in the communication between healthcare providers and family members, especially when planning and executing transitions to other hospitals and at discharge. Support should be offered at discharge, as family members may feel overwhelmed by new responsibilities.
- Family members' experience of support is individual and there were experiences both of sufficient support and of lack of professional support. Support from family and friends was valued and there was a wish for professionals to be proactive in offering support. Treatment of these individuals should be modified according to personal circumstances and it is important to actively include family members in the care process both before and after discharge.

Sammanfattning på svenska

Närstående utgör en viktig del av det sociala stödet för människor som genomgår en lång rehabilitering, exempelvis efter en svår brännskada. Trots detta har få tidigare studier fokuserat på närstående till personer med brännskador, särskilt ur ett längre tidsperspektiv. Den aktuella avhandlingen utgör en del av ett större interdisciplinärt samarbetsprojekt mellan Institutionen för neurovetenskap och Institutionen för kirurgiska vetenskaper vid Uppsala universitet, samt Brännskadecentrum vid Akademiska sjukhuset i Uppsala och Brännskadeavdelningen vid Universitetssjukhuset i Linköping. Fokus för avhandlingen är psykiska symtom och hälsorelaterad livskvalitet hos närstående till personer med svåra brännskador, närståendes upplevelse av tiden när den brännskadade vårdades på sjukhus samt tiden efter utskrivning. Ytterligare ett område som utforskats är hur närstående upplevt stöd, samt vilket sådant de erbjudits, mottagit och önskat under ovanstående faser. Resultaten kan utgöra underlag till utveckling av omhändertagandet av närstående inom brännskadevård, samt vid andra sjukdoms- och skadetillstånd som medför långvarig fysisk och psykisk påverkan för den drabbade. I avhandlingen ingår fyra delstudier och de övergripande slutsatserna är som följer:

- Generellt visar närstående låga till milda symtom på ångest och depression under året efter brännskadan. En tredjedel uppvisar dock måttliga till svåra symtom under vårdtiden. På gruppnivå minskar dessa symtom över tid och kan prediceras av tidiga symtom, varför screening kan vara användbar för att identifiera individer som skulle kunna ha nytta av ökat stöd.
- Närstående visar en hälsorelaterad livskvalitet (HRQoL) jämförbar med den generella populationen i Sverige. En förbättring sker dock över tid gällande oro/nedstämdhet. HRQoL kan prediceras av tidigare livshändelser och närvaro av psykiska symtom, varför det kan vara möjligt att identifiera individer som riskerar lägre HRQoL med hjälp av ett validerat instrument.
- Tiden när den skadade vårdas på sjukhus är påfrestande för närstående, vilka skulle kunna gynnas av att tas om hand på ett mer individualiserat sätt. Tiden på sjukhus innefattar även upplevelser av positiv karaktär,

men kommunikationen mellan vårdgivare och närstående kan förbättras, särskilt i anslutning till planering och genomförande av förflyttning till annan vårdinrättning eller utskrivning. Stöd bör erbjudas vid utskrivning, då närstående kan uppleva sig tyngda av ansvar.

- Närståendes upplevelse av stöd är individuell. Upplevelser av såväl tillräckligt som bristande professionellt stöd beskrevs. Närstående värderade stöd från familj och vänner högt. Bemötandet av närstående bör anpassas efter individens personliga omständigheter och det är viktigt att aktivt inkludera närstående i vårdprocessen, så väl före som efter utskrivning. Det är viktigt att hälso- och sjukvårdspersonal tillämpar ett proaktivt tillvägagångssätt vid erbjudande om stöd.

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