



## Being a family member of a burn survivor – Experiences and needs

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### ABSTRACT

**Background:** Family members are important in the recovery process of persons with severe burns; however, few previous studies have focused on how this group experiences care and rehabilitation.

**Objective:** To explore family members' experiences and needs, during the time in hospital and after discharge.

**Methodology:** Explorative study with a qualitative descriptive design. Ten semi-structured interviews with family members of injured persons treated at the national burn centres were recorded digitally, transcribed verbatim, and analysed using content analysis.

**Findings:** Five categories were related to experiences during care: Experiencing excellent treatment and support, Experiencing mistrust and a rejecting attitude, Feelings of chaos and shock, Being the hub of the family network, Feeling hope and thankfulness. Three categories were related to experiences during rehabilitation: Ambiguous feelings, Multifaceted support and Handling the situation.

**Conclusion:** The experiences of the time in hospital and during rehabilitation are individual and comprise a mixture of positive and negative experiences and a diversity of needs. The results suggest that health-care professionals should be proactive and identify specific needs for support as well as provide individualized treatment of family members.

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### 1. Introduction

Severe burn injuries are complex and often treated in burn-specific intensive care units for a period of a few days up to several months, followed by rehabilitation that might last for more than two years [1,2]. Survivors of severe burns are at risk of long-lasting psychological and physiological consequences such as post-traumatic stress disorder, depression [3,4], skin-related problems, pain and loss of function [2,5]. A severe burn is a distressing experience not only for the injured person but also for family members, for whom hospital admission is considered especially traumatic [6]. In addition, its consequences can lead to economic and social negative effects [7] for the family.

Family centred care has gradually been established as a concept, mainly within paediatric, oncologic and critical care during the last decades. In family-centered care family members participate in care, share information and decision-making at the level they choose [8]. It has been established that family members play a

key role during the care of critically ill persons within intensive care [9,10]. Family members also continue to be of vital importance after hospital discharge. They are frequently relied upon to care for the injured person, who is often discharged from hospital before full recovery [11]. Within burn care it is known that social support is of fundamental importance in the recovery process of the injured person [12,13]. Studies have also shown that persons with burns consider support from family members to be vital during recovery, and that psychosocial needs are believed to be of higher priority than physiological needs [13,14]. Since family members are nowadays acknowledged as key persons during hospitalisation, it has been proposed that they should also be included in the care after discharge from burn care [15,16]. Positive experiences of including adult family members in burn care procedures such as wound dressings, have been reported [17].

The well-being of family members of critically ill persons have been of interest to researchers since the late 1970s [18]. Within burn care, family members have been reported to worry about pain and the effect the burn survivor's changed appearance will have on returning to society [19–21]. It has also been reported that family members experience guilt in relation to the accident [22,23] and that spouses might have to assume a new role after the injury

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[24]. Uncertainty regarding the hospitalized person's condition is experienced as difficult [25,26] and even when there is little optimism concerning recovery, family members need to feel hope [25,26]. It is important for family members to be present in the ICU in order to strengthen the integrity of the patient, as well as to be close to and watch over the sick individual [25–27]. During hospitalisation family members of patients with burns value social support provided by family and friends [21]. Other needs that have been reported involve the wish to be close to the patient, support in meeting personal needs, understanding the person's condition, and financial assistance [21,28]. Family members may worry about how to manage the situation after hospital discharge [29], and it has been found that they need to be prepared concerning psychological aspects of the recovery process [30].

When a loved one is critically ill, family members tend to put the injured person's wellbeing before their own, and it is sometimes difficult for this group to articulate their own needs [31]. Ågård & Harder [27], point out that even though family members might be vulnerable, they are still resourceful and try to find their place while experiencing turmoil. The need considered to be of most importance to family members varies in different studies, and cultural background may have an impact on how needs are valued. However, the need to receive information is often ranked highly [32].

Although the importance of family members is acknowledged, burn care in Sweden is not organized according to the principles of family centered care. Knowledge about how family members of burn survivors experience the time in hospital and after discharge could be beneficial when improving support for these individuals. As Sundara [6] concludes, the experiences of family members need to be further explored, especially the rehabilitation process at home. It has also been pointed out that ways to assess and meet the needs of family members in both the short and the long term should be developed within general critical care [32]. 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 [31,33].

## 2. Objective of the study

The aim of this study was to explore family members' experiences of burn care during the time in hospital and after discharge.

## 3. Materials and methods

### 3.1. Design

The study was explorative with a qualitative descriptive design [34] in order to gain a deeper understanding of the family members' experiences.

### 3.2. Participants

The catchment area comprised all of Sweden as it involved the two national burn centres where admission criteria are based on the recommendations of the American Burn Association [35]. Participants were recruited using a convenience sample method. Inclusion criteria were (1) family members of persons with burns who were present during hospitalisation and rehabilitation, (2) burn incidents at least one year before inclusion, (3) burns covering 10% or more of the total body surface area 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 who were admitted to the burn centres between 2009 and 2010 were contacted by author JB and asked whether they had a family member that the research team could contact. If the former patient agreed, the family member was contacted and informed about the study. Nine of the patients who were contacted did not respond or did not return the written consent form, and two did not consent to the study. Two family members did not want to participate in the study. Eleven family members originally agreed to take part, but one was unable to participate due to personal reasons, which left 10 family members as participants in the study. They were 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 burned of the patients varied between 12.5% and 70.0% and the range for length of stay in the Burn Centre was 9–227 days. Participants are referred to as family members, while the burn injured persons are referred to as patients or injured persons.

### 3.3. Data collection

Data was collected using a semi-structured interview guide. One of the authors (JB) was responsible for conducting all the interviews. Pre-interviews with non-family members did not indicate a need to change the interview guide. Data collection took place between November 2011 and June 2012 and focus was on two main questions, the general experience of the time in hospital and after discharge, and of support during the same phases. The interviewer asked follow-up questions in order to help participants to elaborate on their answers. The interviews lasted between 14 and 55 min (mean 41 min) and took place at locations chosen by the participants, in most cases the participant's home.

### 3.4. Data analysis

The interviews were recorded and transcribed verbatim and included comments on non-verbal emotional expressions. 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 [36] and a qualitative content analysis was conducted in the following steps [37]: (1) The authors identified meaning units related to the family members' experiences of burn care and support. (2) The meaning units were coded with labels representing different experiences. (3) Codes were organised into categories of experiences representing the manifest content level.

### 3.5. Rigour

As family members' experiences in burn care have been explored to a limited extent, a qualitative descriptive design with a purposeful sampling strategy was used [34]. An in-depth interview technique [34] resulted in rich data. A strength of the study is that respondents were recruited through persons treated at the two national burn centres in Sweden. This resulted in participants who represented different parts of the country geographically with experience from different facilities for specialist care and after care.

Trustworthiness was established by the researchers' experience in qualitative research (credibility), there was stability in the data collection procedure (dependability), the data was analysed by two of the researchers who were not involved in burn care and was thereafter discussed frequently with the other researchers (confirmability). This decreases the potential prejudice and the associated risk for misinterpretation of the interviews.

### 3.6. Ethical considerations

The study was conducted according to the principles of the Helsinki Declaration [38] and was approved by the Regional Ethical Review Board. The former patients, as well as the associated family members, were informed both verbally and in writing about the purpose of the study, and that participation was voluntary, before the family member agreed to participate in the study. Information that would make it possible to identify a respondent or person was removed from the transcribed interviews.

## 4. Findings

The interviews resulted in a total of 8 categories regarding experiences of burn care and support. Five categories were related to experiences during care: *Being the hub of the family network*, *Experiencing excellent treatment and support*, *Experiencing mistrust and a rejecting attitude*, *Feelings of chaos and shock*, *Feeling hope and thankfulness*. Three categories were related to experiences during rehabilitation: *Ambiguous feelings*, *Multifaceted support*, *Handling the situation*. The categories are presented with illustrative citations and interview numbers.

## 5. Experiences during inpatient care

### 5.1. Being the hub of the family network

The family members described themselves as being the hub of the family network. Some perceived that they assumed a new and involuntary role in relation to the family member, for example by giving care to the injured person while he or she was temporarily home from the hospital. Some described concerns about not being able to help the injured person after discharge. The new situation resulted in increased responsibility concerning practical arrangements, as arranging for childcare as well as taking care of children and other relatives who were affected by the incident. Family members observed what was being done with the injured person, passed on information to relatives and friends, were obliged to contact insurance companies and the health insurance office.

“Of course there were so many practical things, I mean if you're... if you're a little practical, and I guess I am, then there's so much that has to be done, the children have to be supported, I feel like I'm the hub of the family network... (Participant 1)”

### 5.2. Experiencing excellent treatment and support

Experiences included satisfaction with the quality of care, the atmosphere in the unit and individualized treatment such as flexible visiting hours. Family members appreciated when the staff did things above and beyond their ordinary duties, e.g. directing special attention to festive occasions, and helping out with childcare during visits.

“...when I got there [to the burn unit]...” they took the [original] chair away and brought in a better armchair for me, well that's such a little thing but I noticed it, it meant a great deal to me. (Participant 4)”

All professions within the specialist burn care provided support, and so did employers of the injured person or family member. In addition, family members experienced support consisting of assistance with living accommodations, doctor's certificates and financial issues. Friends and other family members also provided important support, for example, relatives with professional knowl-

edge regarding hospital care could be of assistance when there were language barriers.

“There were two of us (family members), and so we cried and we laughed and we hugged (giggle) and got ourselves through that time, so we supported each other. (Participant 7)”

### 5.3. Experiencing mistrust and a rejecting attitude

Family members sometimes experienced an impersonal and rejecting attitude and lack of information at the specialist care unit. There were experiences of lack of flexibility e.g. concerning visiting hours, feelings of being a burden, neglected, and lacking acknowledgement of the difficult situation. Support provided by medical social workers was experienced as not beneficial, or that it was only available to the injured person. Staff focused on the injured person and relied on the patient to pass on important information to family members. Family members were encouraged to seek psychosocial support somewhere else. Family members wished for proactive and individualized support from professionals.

“If you didn't ask yourself, there wasn't anyone who asked you ‘What do you want? Can we help you? (Participant 9)”

Some noticed an unprofessional attitude towards the injured person, which resulted in a need to check on the staff's work. Family members experienced difficulties related to discharge from specialist care, e.g. lacking communication between the specialist burn care and the local hospital. The care provided by the local hospitals was perceived as inflexible and incompetent compared to specialist care, which not only made the family members feel insecure, it also frightened the injured person.

“We just sat right down there on the floor in the corridor and didn't know where to go, we just put our heads between our knees and sat there. (Participant 7)”

### 5.4. Feelings of chaos and shock

The family members felt vulnerable and exposed during the acute phase in the hospital. They experienced distress related to the burn incident such as feelings of chaos and shock. The situation was described as unreal, like being a robot with total focus on the injured person. They described themselves as being in a state of unpleasant waiting, and time went by very slowly.

“...I'm not used to seeing my beloved [spouse] just lying there like he's in a vegetative state. (Participant 3)”

The family members experienced frustration, disappointment, anger and irritability related to feared possible consequences that the burn might have, such as issues regarding sexual functioning and even death.

“... we were just counting the hours... or I only counted quarter hours, I thought ‘maybe he'll make it until Dad comes... but the whole time it was this crisis that he wasn't going to make it. (Participant 2)”

### 5.5. Feeling hope and thankfulness

Although they were in a difficult situation after the burn incident, family members expressed feelings of hope and thankfulness, which emerged when the injured person's condition improved. They gained hope from staff members and persons in their social network and some relied on a higher power in the new and difficult situation.

“Yes, that’s what held me up, I thank God that all of us got out, and I thank God that we all survived, and... that supported me in some way. (Participant 1)”

Being hopeful was also described as an approach that the family member chose to adopt in order to handle the situation.

“... in some way you just keep going ... it didn’t matter what the doctors said or anything, you just ... ‘this has to work out’ ...he just has to live through this’. (Participant 2)”

## 6. Experiences during rehabilitation

### 6.1. Ambiguous feelings

Discharge from the hospital was associated with ambiguous feelings in the family members. Family members experienced thankfulness that the injured person had survived and that things had gone as well as they had. Initially, discharge from hospital was something positive that the family had looked forward to. However, when leaving the hospital, they experienced a lack of coordinated support and felt stranded and forgotten, while not trusting the outpatient care.

“I looked forward to that [the discharge] very much, it was like ‘Oooh, now he’s coming home, oh how wonderful!’ But no, it wasn’t wonderful at all (laughs)! (Participant 4)”

The situation was experienced as chaotic. Feelings of being diminished, powerless, stressed and dejected emerged. They had to deal with lack of hope, financial consequences, lack of sleep, as well as the injured person’s pain and medication-related withdrawal symptoms. In addition, it was demanding having unknown carers at home, experiencing lack of personal space and fulfilling obligations such as having to go to work. Family members experienced feelings of reluctance towards caring for the injured person, stated that it was hard to know what support might be available, and that the needs of family members are clearly underestimated by healthcare staff.

“... ‘I have to be in charge of his medications, make sure he has the right medications in this pill dispenser, and I have to help him get dressed, feed him, wash him and do everything’, I said, ‘because otherwise nothing works’. And the look that I got...she [a care professional] turned around and looked at me, you know, and I got the feeling that ‘oh my God, is this one of those whining bitches?’, just that look... she didn’t say anything, she just looked at me. (Participant 10)”

### 6.2. Handling the situation

The family members expressed several ways of handling the new situation: focusing on the injured person, not focusing on their own needs, trying to go on like before, holding back negative feelings and thoughts, and trying to make the best of the situation.

“... I didn’t say it **then**, but it wasn’t long before I thought ‘Oh how I wish he could simply have stayed at the specialist care center a few months longer’... (Participant 4)”

“So... as I said, things didn’t turn out as I’d planned, and then... you always make the best of the situation... (Participant 6)”

### 6.3. Multifaceted support

The family members experienced the most important support from significant others, friends and fellow employees. Insurance

companies and health care professionals within primary health-care and the municipality were other sources of support. Being on sick leave allowed the family members to focus on the injured person’s needs without having to go to work. Organized home health care could relieve the family members of the need to perform professional care.

“We received such a huge amount of support, and for me support was that I knew that [the injured person] was being taken care of, then I could stop worrying...he got all the help you could possibly imagine. (Participant 5)”

In addition, some experienced that talking repeatedly with the injured person about the incident and the new situation was supportive. Relief was also found in religion and support from religious organisations. Family members wished for support from others in the same situation and searched for blogs on the topic on the Internet. Generally, family members wished for proactive support after discharge.

“... the churches here in town got together and...so the children and I moved into these flats that they’d furnished...put up wallpaper, furnished, everything from knives and forks to TVs to sofas to beds, in other words we moved into furnished flats, and that’s what the Christians in town did for us. (Participant 1)”

## 7. Discussion

Family members reported a turmoil of negative and positive emotions and reactions and had mixed experiences of excellent as well as inadequate care. They experienced a lack of support both during care and after discharge. During care the lack of support involved insufficient knowledge about available support as well as uncertainty concerning who was entitled to existing sources of support. Some family members could not recall any offers of support at all. Family members were sensitive to negative attitudes among the staff, including subtle expressions of negativism, inappropriate language, and inflexible and impersonal attitudes concerning visiting hours. Previous studies within general intensive care have demonstrated that family members are appreciative when staff provide emotional support [39] and when visiting hours are flexible [31]. Although it has been established that family members should be included in intensive care and burn care [9,10,17], respondents in this study experienced that the staff sometimes relied on the injured person to pass on relevant information to family members, which can be seen as contradictory to a family centred approach.

After discharge, a lack of support was experienced mainly as being forgotten and as having problems getting support, even when the family member had contacted the public healthcare organisation. Notably, experiences of being rejected were not limited to the period after discharge when family members needed to talk to someone about strains associated with the new situation, but were also experienced by some family members during in-hospital care. Patients nowadays are discharged from hospital earlier than previously to reduce costs associated with inpatient care [11]. Early discharge could contribute to the lack of support experienced by the respondents in this study. The family members stated that needs of significant others within burn care are underestimated by the staff, something that has also been concluded regarding other intensive care settings [31,33]. Family members also stated that even if they had not needed specific support themselves, they thought it was important that no family member in the same situation should be left without support.

Support is not restricted to having a professional person to talk to. Family members of critically ill persons find it of value to

receive accurate information concerning the injured person's condition [18,31], something that was also experienced by the respondents in this study. Being put on the sick list provided relief from their own job responsibilities, allowing family members to focus on and be near the injured person, which has been demonstrated as important in previous studies [26,27].

After discharge a few respondents experienced receiving all the professional back-up from the public sector that they could wish for. It is notable that family members also experienced support from the injured person's employer, mainly through financial assistance and help with insurance matters. Similar interventions in rehabilitation processes have previously been demonstrated to facilitate return to work [40]. Family members expressed a wish for proactive support from the healthcare staff both during the time in hospital as well as after discharge, and some experienced that support was only offered if they asked for it. Previous studies have pointed out that within intensive care family members might have difficulty expressing their own needs and actually tend to suppress them, which could result in their receiving little attention [26,27,31].

Verhaghe et al. [31] concluded that it is unclear to what degree family members need the presence of other family members or friends during the inpatient care phase. The family members in this study experienced such support and in accord with previous research [21], they considered this support to be of most importance. This indicates that it may be of value for professionals to examine and encourage contacts within the family members' social networks.

After discharge, friends and family provided support through practical help and by spending time with the injured person outside the home. Furthermore, family members experienced that discussing strains related to the new situation with the injured person was supportive and that the burn survivor's positive attitude towards recovery was important. Educating patients about possible needs of their loved ones in relation to the new situation after a burn could possibly benefit the social situation of the family and encourage family members to support one another.

In accordance with previous studies, family members in this study experienced support when staff members did something beyond what was expected of them [41,42], they valued being emotionally validated by the staff [39], and those with spiritual affiliations found support through religion or religious groups very helpful [21]. The findings support the concept of family centred care; where patients are seen as a part of a family context and health care staff need to support the persons around the patient to facilitate recovery.

As demonstrated in this and previous studies, the consequences following a severe burn have a great impact not only on the injured person but also on family members. Family members strive to take control and find their place in the new situation, and they express a need for health professionals to be pro-active. Hence, a family centred approach in traditional as well as in innovative ways, could have positive effects.

## 8. Study limitations

A majority of the respondents in this study were females and partners of the injured persons, which can be seen as a reflection of the fact that a majority of individuals with severe burns in high-income countries are male. Another limitation is that the participants were recruited through the associated injured persons, which may have excluded family members that were not possible to contact using this strategy. Altogether, a different sampling strategy might have included family members with other perspectives on burn care and rehabilitation.

## 9. Conclusions

The results of this study indicate that the experiences of family members of persons with burns are individual and personal, which makes caring for family members a complex task for healthcare professionals. The results emphasize the importance of family centred care, i.e. that the injured person should not be seen as an isolated island, but as a part of a social context, which is greatly affected by the injury and treatment. Health care staff need to include family members in planning and be pro-active in offering support also to family members to gain optimal conditions for recovery.

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## Conflict of interest

There are no conflicts of interest to declare.

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## References

- [1] Willebrand M, Kildal M. Burn specific health up to 24 months after the burn-A prospective validation of the simplified model of the Burn Specific Health Scale-Brief. *J Trauma* 2011;71:78–84.
- [2] Öster C, Willebrand M, Ekselius L. Burn-specific health 2 years to 7 years after burn injury. *J Trauma Acute Care Surg* 2013;74:1119–24.
- [3] Van Loey N, Van Son M. Psychopathology and psychological problems in patients with burn scars: epidemiology and management. *Am J Clin Dermatol* 2003;4:245–72.
- [4] Dyster-Aas J, Willebrand M, Wikehult B, Gerdin B, Ekselius L. Major depression and posttraumatic stress disorder symptoms following severe burn injury in relation to lifetime psychiatric morbidity. *J Trauma* 2008;64:1349–56.
- [5] Esselman P, Thombs B, Magyar-Russell G, Fauerbach J. Burn rehabilitation: state of the science. *Am J Phys Med Rehabil* 2006;85:383–413.
- [6] Sundara DC. A review of issues and concerns of family members of adult burn survivors. *J Burn Care Res* 2011;32:349–57.
- [7] Peck M, Molnar J, Swart D. A global plan for burn prevention and care. *Bull World Health Organ* 2009;87:802–3.
- [8] Institute for Patient- and Family-Centered Care, What is PFCC?. <http://www.ipfcc.org/about/pfcc.html>. 2018. (Accessed 1 May 2018).
- [9] Schmidt M, Azoulay E. Having a loved one in the ICU: the forgotten family. *Curr Opin Crit Care* 2012;18:540–7.
- [10] Davidson JE, Powers K, Hedayat KM, Tieszen M, Kon AA, Shepard E, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. *Crit Care Med* 2007;35:605–22.
- [11] McLeod LA. Patient transitions from inpatient to outpatient: where are the risks? Can we address them? *J Healthc Risk Manag* 2013;32:13–9.
- [12] Park S-Y, Choi K-A, Jang Y-C, Oh S-J. The risk factors of psychosocial problems for burn patients. *Burns* 2008;34:24–31.
- [13] Sproul JL, Malloy S, Abriam-Yago K. Perceived sources of support of adult burn survivors. *J Burn Care Res* 2009;30:975–82.
- [14] Liang CY, Wang HJ, Yao KP, Pan HH, Wang KY. Predictors of health-care needs in discharged burn patients. *Burns* 2012;38:172–9.
- [15] Watkins PN, Cook EL, May SR, Still JM, Luteran A, Purvis RJ. Postburn psychologic adaptation of family members of patients with burns. *J Burn Care Rehabil* 1996;17:78–92.
- [16] Blakeney PE, Rosenberg L, Rosenberg M, Faber AW. Psychosocial care of persons with severe burns. *Burns* 2008;34:433–40.
- [17] Bishop SM, Walker MD, Spivak IM. Family presence in the adult burn intensive care unit during dressing changes. *Crit Care Nurse* 2013;33:14–24.

- [18] Molter NC. Needs of relatives of critically ill patients: a descriptive study. *Heart Lung* 1979;8:332–9.
- [19] Goyatá S, Rossi L. Nursing diagnoses of burned patients and relatives' perceptions of patients' needs. *Int J Nurs Terminol Classif* 2009;20:16–24.
- [20] Phillips C, Fussell A, Rumsey N. Considerations for psychosocial support following burn injury—a family perspective. *Burns* 2007;33:986–94.
- [21] Thompson R, Boyle D, Teel C, Wambach K, Cramer A. A qualitative analysis of family member needs and concerns in the population of patients with burns. *J Burn Care Rehabil* 1999;20:487–96.
- [22] Bowden M, Feller I. Family reaction to a severe burn. *Am J Nurs* 1973;73:317–9.
- [23] Cella DF, Perry SW, Kulchycky S, Goodwin C. Stress and coping in relatives of burn patients: a longitudinal study. *Hosp Community Psychiatry* 1988;39:159–66.
- [24] Simmons D. Family adjustment when the breadwinner is burned. *Occup Health Nurs* 1983;31:38–40.
- [25] Eggenberger S, Nelms T. Being family: the family experience when an adult member is hospitalized with a critical illness. *J Clin Nurs* 2007;16:1618–28.
- [26] Engström Å, Söderberg S. The experiences of partners of critically ill persons in an intensive care unit. *Intensive Crit Care Nurs* 2004;20:299–308.
- [27] Ågård AS, Harder I. Relatives' experiences in intensive care—finding a place in a world of uncertainty. *Intensive Crit Care Nurs* 2007;23:170–7.
- [28] Ablon J. Reactions of Samoan burn patients and families to severe burns. *Soc Sci Med* 1973;7:167–78.
- [29] Bowden M. Helping the burn patient return home. *AORN J* 1971;13:69–72.
- [30] Maaser BW. Early psychologic interventions with adult burn survivors and their families. *Top Emerg Med* 1995;17:50–6.
- [31] Verhaeghe S, Defloor T, Van Zuuren F, Duijnste M, Grypdonck M. The needs and experiences of family members of adult patients in an intensive care unit: a review of the literature. *J Clin Nurs* 2005;14:501–9.
- [32] Paul F, Rattray J. Short- and long-term impact of critical illness on relatives: literature review. *J Adv Nurs* 2008;62:276–92.
- [33] Maxwell KE, Stuenkel D, Saylor C. Needs of family members of critically ill patients: a comparison of nurse and family perceptions. *Heart Lung* 2007;36:367–76.
- [34] Patton MQ. *Qualitative research & evaluation methods*. London: SAGE Publications Inc; 2015.
- [35] American Burn Association. *Burn Center Referral Criteria*. <https://ameriburn.org/public-resources/burn-center-referral-criteria/>. 2018. (Accessed 1 May 2018).
- [36] ICT Services and System Development and Division of Epidemiology and Global Health. *OpenCode 4.0*. Umeå: Umeå University. <http://www.phmed.umu.se/english/units/epidemiology/research/open-code/>. 2018. (Accessed 1 May 2018).
- [37] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24:105–12.
- [38] WMA. *Declaration of Helsinki – Ethical principles for medical research involving human subjects*. Adopted by the 18th WMA General Assembly, Helsinki, June 1964. Latest update Seoul October 2008. 2013.
- [39] Schwarzkopf D, Behrend S, Skupin H, Westermann I, Riedemann N, Pfeifer R, et al. Family satisfaction in the intensive care unit: a quantitative and qualitative analysis. *Intensive Care Med* 2013;39:1071–9.
- [40] Franche R-L, Cullen K, Clarke J, Irvin E, Sinclair S, Frank J, et al. Workplace-based return-to-work interventions: a systematic review of the quantitative literature. *J Occup Rehabil* 2005;15:607–31.
- [41] Arman M, Rehnsfeldt A. The 'Little Extra' that alleviates suffering. *Nurs Ethics* 2007;14:372–86.
- [42] Haugh KH, Salyer J. Needs of patients and families during the wait for a donor heart. *Heart Lung* 2007;36:319–29.