Support needs of parents of children with burns

A qualitative study of parents' experiences and need for support in relation to their child's burn injury during hospitalisation and after discharge

Lina Sophie Toft Lernevall

Thesis for the degree of Philosophiae Doctor (PhD)
University of Bergen, Norway
2022

UNIVERSITY OF BERGEN

Support needs of parents of children with burns

A qualitative study of parents' experiences and need for support in relation to their child's burn injury during hospitalisation and after discharge

Lina Sophie Toft Lernevall

Thesis for the degree of Philosophiae Doctor (PhD)
at the University of Bergen

Date of defense: 07.11.2022

Year: 2022
Title: Support needs of parents of children with burns

Name: Lina Sophie Toft Lernevall
Print: Skipnes Kommunikasjon / University of Bergen

Scientific environment

This doctoral thesis, conducted between 2017 and 2021, originates from
the Department of Global Public Health and Primary Care, Faculty of Medicine, University of Bergen, Norway and
the Department of Plastic, Hand and Reconstructive Surgery, National Burn Centre, Haukeland University Hospital, Bergen, Norway.

During my whole PhD period, I have been a member of the following research groups and international research environments:

– The Research Group for Phenomenological Studies in Health Sciences at the Department of Global Public Health and Primary Care, Faculty of Medicine, University of Bergen, Norway.
– The Research School in Public Health and Primary Health Care, Department of Global Public Health and Primary Care, Faculty of Medicine, University of Bergen, Norway.
– The PhD-Seminar for Danish Nurses doing a PhD, the Department of Public Health, Section of Nursing, Aarhus University, Denmark.
– The research group Patient-reported Outcomes and Patient Safety in acute and/or critical illness (POPS) at Western Norway University of Applied Sciences in Bergen, Norway.
– EANS Summer School at the European Academy of Nursing Science (EANS) from 2018-2021.

Permission has been obtained to use logos from all organisations.

As a PhD student, I had the opportunity to go abroad and visit different international research environments:

- School of Health Sciences (Sydney Campus), University of Tasmania, in Sydney, Australia. I spent 4 weeks in 2018 as an international student researcher visiting Associate Professor Rachel Kornhaber and Professor Michelle Cleary who are co-authors on my first PhD paper.
- Department of Public Health, Section of Nursing, Aarhus University, in Aarhus, Denmark. I spent 2 + 2 weeks in 2019 and 2021 as an international research student where I wrote my second and fourth paper.
- CERN - the European Organization for Nuclear Research in Geneva, Switzerland. I spent 2 ½ weeks in 2020 of writing retreat progressing on the analysis for my third paper.

The supervisors of this PhD study were:

Main supervisor: Professor Pia Dreyer, RN, PhD
Department of Public Health, Section of Nursing, Aarhus University, Aarhus, Denmark and Professor II Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway.

Co-supervisor: Professor Asgjerd Litleré Moi, RN, PhD
Department of Health and Caring Sciences, Western Norway University of Applied Sciences, Bergen, Norway and Department of Plastic, Hand and Reconstructive Surgery, National Burn Centre, Haukeland University Hospital, Bergen, Norway.

Co-supervisor: Professor Emerita Eva Gjengedal, RN, PhD
Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway.

Acknowledgements

I want to thank the Western Norway Regional Health Authority [Helse Vest] for granting me a fully paid PhD grant. Thank you for believing in me and in this project. Without your scholarship, this project would not have been feasible.

A profound thank you to the participating parents. I sincerely thank you for your participation in this study. I thank you for prioritising your time to talk to me, for opening up to me and sharing your story with me. I am grateful for the trust you showed me by agreeing to meet me twice and share your experience. I must admit that I am deeply touched by your story, and I sincerely wish you all the best in the future to come.

A profound thank you to the participating staff members and leaders. I am very grateful that despite a busy workday, you all took the time to participate and shared your knowledge with me.

A sincere thank you to the four parents who were my parring partners in user involvement. I am very grateful for our talks, discussions and your input.

Thanks to the psychologists for including parents to this study and to the burn centre for letting me collect data there. Thanks to my retired leader Kari Lybak for good conversations and essential support.

Dear Pia, Asgjerd and Eva. What an incredibly supervisor team you have been, and what a great time we have had together. Thank you for believing in me, for supporting me, for the flexibility of your contact hours and for the incredible effort you have put into your supervising. You have followed me during the creation of this PhD, and the life events that have happened alongside. This has meant a lot to me and my family, and I am very grateful for this. Hopefully, our collaboration can continue in the future with new projects.

Thank you to Australian co-authors Associate Professor Rachel Kornhaber from School of Health Sciences (Sydney Campus), University of Tasmania and Professor Michelle Cleary from School of Nursing, Midwifery & Social Sciences, Central Queensland University for an unforgettable time in Sydney, for fruitful discussions and international collaboration.

Thank you to Associate Professor Morten Pilegaard from Aarhus University for editing the manuscript of the whole dissertation for proper English language, grammar, punctuation, spelling and overall style. I appeciate our collaboration, your comments, advice and punctual response. May we continue this collaboration in the future with new manuscripts.

Thanks to my mentors during the Norwegian Research Grand Prix 2017, deputy communications manager and senior adviser Aleksander Valestrand and senior advisor Synnøve Vindheim Svardal, and the rest of the Research Grand Prix team 2017, Gunn Janne Myrseth, Ingvill Rosenlund, Kjetil Myhren-Berge, Per Olav Sølvberg and Silje Vik Pedersen. I have learned invaluable presentation techniques.

Thanks to the European Academy of Nursing Science (EANS) Summer School 2018-2021 for teaching me about the MRC framework of complex interventions and for the international collaboration with my classmates.

Thanks to persons who have influenced my nursing career:
– The Danish registered nurse Inger Yde from Egå Medical Centre for the impact you had when you said: “Lina, you have a very special energy. If you come to a department that does not appreciate you and your energy, you need to leave that place and find another where they see the great potential you have”.
– To my bachelor supervisor Associate Professor Pia Koustrup for guiding me during my bachelor in nursing and for inspiring me to continue my academic education.
– To my master supervisor Professor Pia Dreyer, who is now my main-supervisor, for inspiring me to pursue a career in academia.
– The Norwegian nursing philosopher Kari Martinsen for inspiring me with you work and for many cosy meetings and good talks.

Thanks to beloved friends in Denmark and Norway for all the support you have given me. To mention a few: Signe Mosbjerg Wengel, Jonas Hjortshøj Sørensen, Anne Holck, Sophie Lauridsen, Inge Birkeland, Kine Tveten, Tone Lill Mathisen, Andrea Mathisen and Linda Kleppe.

Last but not least I wish to thank my family. I wish to thank my parents Laura Jette Lernevall and Karl Anders Lernevall for supporting me my whole life, for always being there for me and for being good role-models. I love you. To my brother Fredrik Lernevall for good support, for being the best brother and always being there fore me. Dear Anders Toft Lernevall, my beloved husband. You are my love, my rock, my support and my travel agent (you ordered all flight tickets, rental cars and hotel stays throughout this PhD). Thank you for your outmost valuable support. “Dig og mig”.

Saint-Genis-Pouilly, 30 November 2021

Abstract

Background: A paediatric burn injury affects the whole family, especially the parents who play a crucial role in supporting their child. However, little attention has so far been payed to the parents' needs for support during a burn trajectory.

Aims: The overall aim of this thesis was to gain a deeper understanding of parents' lived experiences and need for support both when their child was hospitalised with an accidental burn injury and during the time following discharge; and to inform the development of a future support intervention for this parental group. The specific aims of the four studies were: 1) To systematically synthesise the literature focussing on support needs of parents of burn-injured, hospitalised children. 2) To explore staff members' lived experiences of supporting parents with children hospitalised at a burn centre due to a burn injury. 3) To explore parents' lived experiences of their need for support when having a child admitted to a burn centre. 4) To explore the lived experience of parents caring for their burn-injured child at home after being discharged from a burn centre.

Methods: The four studies were structured by the development phase of the Medical Research Council's framework for complex interventions, and a phenomenological hermeneutic approach was chosen using a Ricoeur-inspired textual analysis method. The data collection methods included an integrative review, focus group interviews and individual semi-structured interviews.

Results: In this thesis, six parental needs for support were identified; Parents of burn-injured children need to be treated as a whole family; need help to process feelings of guilt, shame and blame; need to receive information to get a sense of control; need to be met with trust by staff members; need time to see to their own fundamental personal needs; and need to obtain the right skills necessary after discharge.

Conclusions and implications: Each of the six parental needs for support ought to be addressed by burn staff members, through a care programme guided by a family-centred care approach.

List of Publications

Paper I

Lernevall, L. S. T., Moi, A. L., Cleary, M., Kornhaber, R., & Dreyer, P. (2020). Support needs of parents of hospitalised children with a burn injury: An integrative review. *Burns*, *46*(4), 771-781.
https://doi.org/10.1016/j.burns.2019.04.021

Paper II

Lernevall, L. S. T., Moi, A. L., Gjengedal, E., & Dreyer, P. (2019). Staff members' experience of providing parental support in a national burn centre. *Open Nursing Journal*, *13*, 211-219.
https://doi.org/10.2174/1874434601913010211

Paper III

Lernevall, L. S. T., Moi, A. L., Gjengedal, E., & Dreyer, P. (2021). Parents' lived experiences of parental needs for support at a burn centre. *Int J Qual Stud Health Well-being*, *16*(1), 1855749-1855749.
https://doi.org/10.1080/17482631.2020.1855749

Paper IV

Lernevall, L. S. T., Moi, A. L., Gjengedal, E., & Dreyer, P. Parents' lived experience of caring for their burn-injured child after discharge from hospital. (In review).

As the author of Paper I, I retain the right to include it in a thesis or dissertation; permission for which is therefore not required. Paper II and Paper III are published with Open-Access License permitting unrestricted use, distribution and reproduction.

Abbreviations

FCC – Family-centred care

MRC – Medical Research Council

NFFB – The Norwegian Society for Burn Victims [Norsk Forening For Brannskadde]

PTSS – Posttraumatic stress symptoms

REC – The Norwegian Regional Committees for Medical and Health Research Ethics

TBSA – Total body surface area

WHO – World Health Organization

Contents

FIGURES AND TABLES

Figures:

Tables:

1. INTRODUCTION

The ambition behind this research was to gain a deeper understanding of parents' lived experiences and need for support when their child was hospitalised with an accidental burn injury and after discharge.

Burn injuries in children are known to be extremely traumatising for the whole family and cause psychological effects in parents (Bakker et al., 2013a; Bayuo & Wong, 2021). Parents of burn-injured children have a higher risk of sustaining physical and mental disorders than the general population (Dorn et al., 2007; Enns et al., 2016). In burn-injured children, the outcome is closely associated with parental health and optimal family functioning (Bakker et al., 2013a; De Young et al., 2014; Landolt et al., 2002; Lieberman, 2004; Sheridan et al., 2012; Simons et al., 2010). In 1989, the United Nations' convention on the rights of the child stated that a child has the right to "the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health" (United Nations, 1989, p. 11) and "that a child shall not be separated from his or her parents [unless it] is necessary for the best interests of the child" (United Nations, 1989, p. 4). Thus, a burn-injured child has the right to receive burn treatment and have his/her parents present while hospitalised. In Norway, since 2000, one parent has been entitled to stay together with his/her hospitalised child during the institutional stay; during serious or life-threatening diseases, this right applies to both parents (Helse- og omsorgsdepartementet, 2000). When one or both parents are hospitalised with the child, the healthcare professionals must adapt the given care to the child and parent(s) alike (Harrison, 2010). However, being present is not only positive for parents who may feel powerlessness when for instance witnessing their child's reactions to medical procedures (Egberts et al., 2018a; McGarry et al., 2015).

Within the field of burn injuries, medical improvements in the 1970s regarding early excision and skin grafting improved burn patients' survival and shortened the time they spent at hospital (Jeschke et al., 2020). Thus, the main goal of treatment changed from immediate survival to goals for mental health, quality of life, addressing scarring and long-time well-being (Jeschke et al., 2020). Up to ~ 96% of paediatric burn patients are discharged home with family (Luce et al., 2015), putting an extra pressure on the parent(s) who has to attend to the child's needs (McGarry et al., 2015). As parental health affects the burn-injured child's recovery (Bakker et al., 2013a; De Young et al., 2014; Simons et al., 2010), parents' wellbeing is extremely important, and knowledge about how hospitalisation and the time after discharged are experienced by parents is critical to helping them obtain the best possible level of parental health.

The thesis consists of a synopsis and four papers, which all illuminate the overall aim of the study. After a brief introduction to the subject (Chapter 1) follows an updated review of research about the support needs of parents of burn-injured children (Chapter 2). Literature searches have been done continuously throughout the whole PhD period in order to remain updated on the support of parents of burn-injured children. Newer research published during the PhD period is included in the discussion section. The last literature search was completed on 30 November 2021. The overall aim of the thesis is to cover existing knowledge gaps regarding parental support (Chapter 3). The methodology and methods of the studies are explained and illustrated with concrete examples (Chapter 4). Findings from the four studies are presented briefly and the discussion highlights how the individual parts of the thesis are connected and form a comprehensive work. The findings are further discussed in light of previous research and relevant theory. Thoughts about methodological considerations are also mentioned (Chapter 5 and 6). At the end of this synopsis, a summary is presented leading to recommendations for clinicians and suggestions for further research (Chapters 7, 8 and 9).

2. BACKGROUND

2.1 Burn injury

Burn injuries are called ‘combustio’ in Latin (Lindholm, 2005). They are defined as injuries to skin or other tissues caused by heat, friction, electricity, radiation, radioactivity or chemicals (World Health Organization, 2018). Based on their origin, they are divided into three categories: thermal (scalds, fire), chemical and electrical burn injuries (Mani, 2003). Among adult burn injuries, men account for 55%–75% of the cases, which are often work related, caused by flames, scalds or contact burns (Brusselaers et al., 2010). The paediatric burn injuries account for 40%–50% of the population of severe burn injuries and are most often caused by scalds (Brusselaers et al., 2010). Burn injuries are classified based on their severity (size and depth) (Figure 1); first-degree (superficial thickness involving the outer layer of the skin/epidermis), second-degree (superficial and deep partial-thickness involving epidermis or epidermis and dermis), third-degree (full-thickness which extends through the full dermis), and fourth-degree (deeper injury involving muscle or bone) (Jeschke et al., 2020).

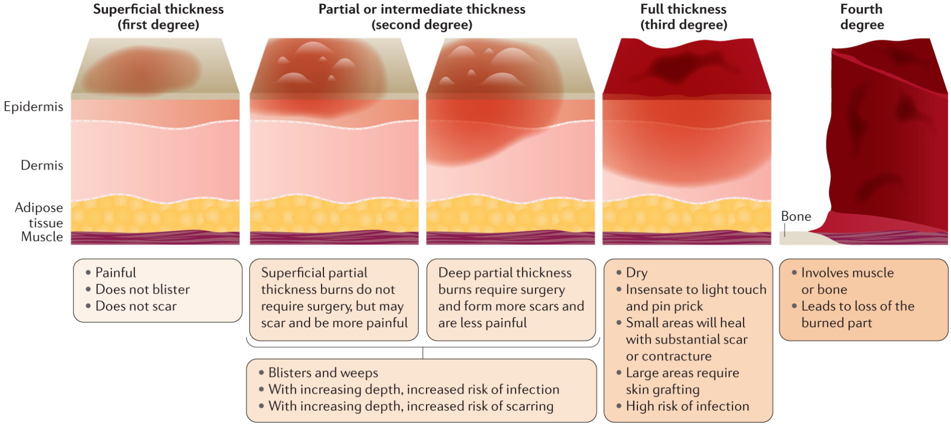


Figure 1. An illustration of burn depth

Reprinted by permission from Springer Nature (Copyright) (Jeschke et al., 2020)

First-degree and superficial second-degree burns often heal without surgery, whereas deep second- and third-degree burns often need surgery; and in fourth-degree burns, the body part is often lost (Jeschke et al., 2020). In addition to destruction of tissue, an inflammatory response occours, and severe burn injuries are associated with “an immediate systemic and local stress response” (Jeschke et al., 2020, p. 2).

2.1.1 Treatment of burn injuries

The immediate first aid to a burn injury is to remove the person from what causes the burn injury into a safe area, remove any clothes and cool down the burned area (Jeschke et al., 2020). Most specialist agree on the ‘20/20’ rule, meaning to cool the burned area with 20 °C (lukewarm) water for 20 minutes (Figure 2) (Bennett et al., 2019; Guttormsen & Brekke, 2021; Lindholm, 2012; National Health Service (NHS), 2021; Norsk Brannvernforening [The Norwegian Fire Protection Association], 2021).

Figure 2. An illustration of first aid for burns, rule ‘20/20’

Reprinted by permission from Norsk Brannvernforening [the Norwegian Fire Protection Association] (Copyright) (Norsk Brannvernforening [The Norwegian Fire Protection Association], 2021).

The flushing of water on the burn wound reduces heat and pain (Jeschke et al., 2020). Thereafter, emergency services can be contacted and the patient should be seen by a doctor (Jeschke et al., 2020). Minor burn injuries are often treated at outpatients’ facilities, whereas large burn, burn on specific body parts and severe burn injuries require specialised burn intensive care at specialised centres (Jeschke et al., 2020; Lindholm, 2012). A burn centre is a specialised department that treats patients in the acute phase but also in the early stages of rehabilitation.

The purpose of hospital treatment is to save the patient's life, treat pain and other bodily reactions to the burn injury, restore skin surface by removing dead tissue and transplanting intact skin (operations) and then to restore functionality through physical and occupational therapy to achieve optimal functioning, appearance and patient recovery and return to a pre-burn life style (Jeschke et al., 2020). The total body surface area (TBSA) is calculated, i.e. how much of the body's surface has been burned percentage wise. The percentage of the TBSA burned is normally equivalent to the length of stay in days at the hospital, i.e. the normal rule is one day of hospitalisation per TBSA% (Greenhalgh, 2019). Deep-dermal or full-thickness injuries requiring skin grafts will lead to scarring, and children in particular will often need life-long outpatient follow-up because of scarring and skin contractures while growing up (Celis et al., 2003). Thus, burn injuries have a high cost both economically and, indeed, personally for both the children and the families afflicted (Mirastschijski et al., 2013; Sheridan et al., 2000). In one study, parents of burn-injured children reported overall satisfaction with the quality of paediatric burn care, suggesting improvements in the form of easier access to the burn centre, better information about department routines and more involvement in treatment and planning (Willebrand et al., 2018).

2.2 Paediatric burns

According to the World Health Organization (WHO), around 11 million people were so severely burned in 2004 that they needed medical attention, with children being the most vulnerable group (World Health Organization, 2018). In Europe, almost half of all severe burn injuries affect children. Among all childhood burns, children under five years are overrepresented (50%–80%) (Brusselaers et al., 2010). Children under two years are particularly vulnerable to burn injuries caused by scalds (Brusselaers et al., 2010). Scalds account for 60%–75% of the hospitalised paediatric burn injuries followed by injuries caused by flames and contact burns (Brusselaers et al., 2010). From 1985 to 2009, paediatric patients' length of hospitalisation in Europe was reported to be 15-16 days and their survival rate 98%–100% (Brusselaers et al., 2010). The majority (80%–90%) of paediatric burn injuries happen at home (Brusselaers et al., 2010); 47% in the kitchen/dining room and 12% in the bathroom (Pardo et al., 2008). In many cases, a parent or relative is present witnessing the accident; mothers (26%), other relatives (18%) and both parents (12%) (Pardo et al., 2008). The parents often experience shock, panic and fear from witnessing the accident and doing first aid (Egberts et al., 2019; McGarry et al., 2015). During the first weeks after the burn accident, they relived the accident and first aid provided (Egberts et al., 2019) and many ruminated over how the accident could have happened and how they acted in the given situation (McGarry et al., 2015).

In Norway, with a population of 5 million people, around 14,000 people were registered with a burn injury in 2017 (3,480 from specialist health services and 11,000 from primary healthcare) (Ohm et al., 2019). In 2012, most burn-injured patients were treated by outpatient services, and 620 patients had to be hospitalised for a minimum of 24 hours (Onarheim et al., 2016). Each year, around 100-150 patients need specialised professional burn care at Norway's national burn centre (Helse Bergen - Haukeland universitetssjukehus, 2021; Onarheim et al., 2016). One third of these patients are children. In 2012, children below the age of three years made up 34.8% of the burn patients at the national burn centre (Onarheim et al., 2016). A population-based Norwegian study found that the risk of being hospitalised with a burn injury was twelve times higher for children under three years than for all other age groups (Onarheim et al., 2016). A study from 2007 of paediatric burn injuries treated at the Norwegian national burn centre found that most injuries happened between 15:00-19:00 o'clock, at home indoors in the kitchen or the living room (Brudvik et al., 2011). The injuries were caused by contact with an oven (27%) or stove (18%), scalds with hot food/drinks (33%) or other hot liquids (11%), and affected the hand (47%), legs/seat (13%), chest/stomach (13%), arm (9%) and face (7%) (Brudvik et al., 2011).

2.3 Parental inclusion in hospitals

Recent years have seen a growing focus on letting parents participate in paediatric wound care procedures (Egberts et al., 2018a; Smith et al., 2011) and on improving communication between parents and staff members (Brown et al., 2020). This represents a change in focus since the 1970s where parents visiting their children at paediatric burn departments were often left to witness how their child suffered without being able to help their child (Abramson, 1975; Doctor, 1994). Earlier insights produced in the 1950s and 1960s by John Bowlby and James Robertson documented the negative psychological consequences of separating the mother from the child (Alsop-Shields & Mohay, 2001). Bowlby and Robertson's work also affected paediatric nursing and laid the groundwork for the development of family-centred care (FCC) (Alsop-Shields & Mohay, 2001). FCC is an approach according to which the hospitalised child's family is key to its life (Foster et al., 2016). The child and the family are included in the planning of the care processes (Harrison, 2010) as "the family members are recognised as care recipients" (Arabiat et al., 2018, p. 39). FCC yields higher quality of child care (Harrison, 2010) and ensures a better health outcome for both child and family (Foster et al., 2016).

2.4 Parents' experiences

A paediatric burn injury is known to affect the whole family (Brodland & Andreasen, 1974; Phillips et al., 2007). Positive parental behaviour can reduce the child's medical procedural distress, improve its recovery outcomes and reduce its psychological and long-term physical problems (Brown et al., 2018; Francis, 1990). Parents' anxiety could increase the burn-injured child's distress (Francis, 1990). If parents are depressed due to the accident, the child's self-image will mirror parents' negative feelings (Cahners, 1988). The way a parent reacts to a child's accidental burn injury therefore profoundly affects the child's psychosocial and physical recovery (Sheridan et al., 2000). Many parents witness the burn accident (Pardo et al., 2008), and one study reported that 71.4% of the mothers felt “directly responsible for the accident” (El Hamaoui et al., 2006, p. 118).

2.4.1 Reactions to hospital treatment

If parents are suffering from accident-related psychological distress, they will encounter more difficulty being supportive of their child during medical care (Brown et al., 2019a). Parental posttraumatic stress symptoms, guilt and general depression affect their behaviour and have a negative impact on the child’s coping with burn wound care (Brown et al., 2019a). During hospitalisation, a child undergoes many medical procedures, and the presence of parents changes depending on the procedure performed and departmental rules. Being present during wound care procedures can make parents feel distress, disgust, fear, concern and helpless when witnessing their child’s distress and pain (Brown et al., 2020; Egberts et al., 2019; Morley et al., 2016). Staff members have been reported to be unaware of parental distress during wound care procedures, which hindered parents from being supported (Smith et al., 2011). Parents reported feeling physical and emotional isolation while hospitalised with their child, and over time the isolation changed, becoming more psychological than physical, and it was reinforced due to limited or absent communication with spouse or family (Heath et al., 2018). During acute inpatient treatment, many parents felt that they lost control as a primary caregiver because treatment was performed by the health professionals (Andrews et al., 2018). Some parents became so occupied tending to their child’s every need that they put themselves aside, making it difficult to detect the difficulties they were experiencing (Griffiths, 2017; Heath et al., 2018). Although being present affected them negatively in many ways, parents also had some positive experiences as a result of good care, reassurance from health professionals and the progression of wound healing (Egberts et al., 2019). Still, some parents relived the experience of the dressing change up to six months after the burn (McGarry et al., 2015).

2.4.2 Reactions to returning home

After having been treated for their burn injury, the children and their parent(s) are discharged to their own home, which involves transferring reponisibility for after-care to the parent(s) (Luce et al., 2015). The transition from being hospitalised with supportive burn staff members to being discharged to their home leaves many families isolated and frightened as they are alone with a child who has become more dependent on them (Cahners, 1979; Oster et al., 2014). For some parents, returning home was a positive experience (McGarry et al., 2015; Oster et al., 2014), but for most, being discharged included many challenges, for instance in respect of providing correct after-care (Brady et al., 2020; McGarry et al., 2015; Oster et al., 2014; Ravindran et al., 2013a), tackling challenges in their child and themselves (McGarry et al., 2015; Oster et al., 2014) and handling others' reactions to their child's burn scars (McGarry et al., 2015; Ravindran et al., 2013a; Rimmer et al., 2015). Supporting parents and family functioning also after discharge from hospital is therefore vital to improve functional outcomes in children after burns (Sheridan et al., 2000) and ensure a good quality of life for the child (Landolt et al., 2002). Teaching parents to perform correct burn wound care can promote adequate recovery after returning home (Egberts et al., 2018a). One study investigating important factors for optimal outcome in the children found that a well-functioning family together with early reintegration to pre-burn activities and consistent follow-up from a multidisciplinary burn team were important (Sheridan et al., 2000). Because the interaction between the child and its parents is so vital to the child's development and health (Stokkebæk, 2007), all burn team members should offer parents evidence-based support throughout the burn care trajectory (Sheridan et al., 2000).

2.4.3 Guilt

Feelings of guilt have been reported to affect parents of burn-injured children for years, also in the cases where the burn accident was completely unintentional (Mason, 1993). Studies report parents experiencing feelings of guilt during the in-patient phase, i.e. while the child was hospitalised (Horridge et al., 2010; McGarry et al., 2015), with parents thinking "Whose fault is it?" (Mason, 1993, p. 496). One month after the accident, 45% of mothers and 46% of fathers reported to experience feelings of guilt (Egberts et al., 2017). Parents still experienced feelings of guilt six months after the accident (Egberts et al., 2019; Mason, 1993) and 2.5 years after the accident (Horridge et al., 2010); even 11 years later, guilt haunting mothers of burn-injured children was reported to cause higher stress scores (Bakker et al., 2010). One study found a correlation between parental guilt and the child's age, with younger age causeing more parental guilt (Hawkins et al., 2019). Some couples experienced marital tension which could led to divorce or the parents coming closer together as a couple (Cahners, 1979). For some, partner conflict added to the pressure they already experienced (McGarry et al., 2015). Mothers were also found to have a statistically significantly higher guilt score than fathers up to 5.6 years after the accident (Sveen & Willebrand, 2018), and mothers reported higher guilt scores than fathers up to 14 years after the accident in another study (Rivlin & Faragher, 2007). This shows that guilt is a feeling that affects parents immediately after the burn but also much later.

2.4.4 Anger, blame, anxiety and shame

Within the first months after the burn accident, feelings of anger were reported by 57% of mothers and 59% of fathers (Egberts et al., 2017). Anger was sometimes directed towards the other parent involved in the accident (Verity, 1995) or toward the person whom they held responsible for the accident, which, in turn, resulted in feelings of blame (McGarry et al., 2015). Some parents also blamed themselves (McGarry et al., 2015; Ravindran et al., 2013b), which lead to feelings of guilt (Kornhaber et al., 2018); and the shame they felt could lead to depression and anxiety (Hawkins et al., 2019). Some had to deal with the anxiety and fear of losing their child (Brodland & Andreasen, 1974; Ravindran et al., 2013a). During the inpatient period, 69% of parents reported clinically significant anxiety, declining over time to 33% up to 2 years after the burn (Phillips & Rumsey, 2008). Nine years after the burn accident, 25% of parents reported exceeding the anxiety cut-off score (Willebrand & Sveen, 2016b). Some parents were blamed by others for the accident, which made them unsecure about their parental abilities (Ravindran et al., 2013a; Ravindran et al., 2013b). When questioning their own ability to be a good parent, they overcompensated by being overprotective towards their child, thereby restraining the child’s freedom (Horridge et al., 2010). Other studies also report parents becoming overprotective (Cahners, 1979; Egberts et al., 2019; Fowler, 1978; McGarry et al., 2015), hypervigiliant or avoidant (Bakker et al., 2012; Egberts et al., 2019; Willebrand & Sveen, 2016a).

2.4.5 Posttraumatic stress and depression

Within the first month after the burn accident, 49%–50% of mothers of burn-injured children showed symptoms of posttraumatic stress (PTSS) (Bakker et al., 2013b; Egberts et al., 2020; Egberts et al., 2018b), declining to 31% three months after the burn (Egberts et al., 2018b) and 18% after 18 months (Bakker et al., 2013b; Egberts et al., 2020). Six months after the burn, 72% of mothers experienced PTSS which declined to 56% up to three years after the burn (Rizzone et al., 1994). The latter study is older than the previously mentioned studies, which may indicate that the prevalience of parental PTSS has declined somewhat. During a 10-year period, PTSS in mothers dropped from 42% one year after the burn to 19% 11 years after the burn (Bakker et al., 2010). This shows that even though PTSS decline over the years, some mothers still struggle in the long term.

For fathers, PTSS was 24%–27% one month after the burn (Bakker et al., 2013b; Egberts et al., 2017; Egberts et al., 2018b), declining to 14% three months after the burn (Egberts et al., 2018b) and 4%–6% after 18 months (Bakker et al., 2013b; Egberts et al., 2017). Even though the percentage of paternal PTSS is lower than among mothers, this shows that also fathers are affected by the burn injury to their child.

Studies including both mothers and fathers found that parents of burn-injured children experienced significantly more PTSS one week after the burn accident than the comparative general population (McGarry et al., 2013). During the first weeks after the burn accident, some parents experienced intrusive involuntary vivid memories from when their child got burned including static or visual moving images and sounds (Egberts et al., 2019). These images faded with time for most parents, but some still experienced this three to six months after the burn (Egberts et al., 2019). One study of parents to adolescents (8-18-year olds) found that 18 months afte the burn, mothers' PTSS correlated with higher parental concern, whereas fathers' PTSS correlated with the child's itching and low appearance (Pan et al., 2014). Parents' PTSS may also influence re-epithelisation of their child's burn wound (the time it takes for the surrounding skin to cover the burn wound) (Brown et al., 2019b). One study found that 22% of parents had a probable diagnosis of posttraumatic stress disorder one month after the burn, declining to 5% after six months (De Young et al., 2014). It has also been reported that even parents of children sustaining a minor-to-moderate burn injury report clinically significant levels of PTSS (Odar et al., 2013), indicating that the size of the burn injury does not determine if parents develop any symptoms.

A burn injury can also lead to depressive symptoms among parents (Cella et al., 1988). One study found that parent's clinically significant depression was between 44% at the inpatient stage and 22% at the outpatient stage (6-24 months after the burn) (Phillips & Rumsey, 2008). Up to nine years after the burn, 10% of parents exceed the cut-off score for depression (Willebrand & Sveen, 2016b). Among burn-injured children's mothers, 31% had depressive symptoms one month after the burn; a figure that declined to 7% after 18 months (Egberts et al., 2020). One study found major depressive disorder in 35.7% of these mothers (El Hamaoui et al., 2006). One month after the burn, fathers showed lower total depression scores than mothers (Seivert et al., 2019).

2.4.6 Support interventions

Some older studies suggest ways in which burn centres and staff members may help parents. Brodland and Andreasen claimed that burn units should aid the family members of burn-injured patients by providing them with a pamphlet on arrival with information about visiting hours, daily routines, treatments and procedures, usual course of recovery and glossary of unfamiliar terms (Brodland & Andreasen, 1974). They should also establish group support meeting with other relatives (Brodland & Andreasen, 1974). Another study stressed that parents needed support specifically from a social worker (social and financial problems), clinical psychologist (child's progress) and specialist burn aftercare nurse (physical and psychological consequences); and from the usual team consisting of nurses, doctors, physiotherapists, occupational therapist, clinical psychologists, social workers and play leaders (Francis, 1990). A third study suggested that burn staff professionals should address the family's emotional needs, provide therapeutic intervention to relieve parents of their guilt and enhance their coping skills (Cahners, 1988). In addition, burn centres should offer one-to-one mental treatment and weekly group meetings with other families (Cahners, 1988). The use of support groups with parents of burn-injured children has also been reported (Abramson, 1975; Barnett et al., 2017; Cahners, 1979; Fowler, 1978; Frenkel, 2008; Leeder, 1979; McHugh et al., 1979; Rivlin et al., 1986).

Today, the European Burn Accociation guideline on working with parents of burn-injured children suggests, among others, to give appropriate information, normalise reactions, involve parents in care, provide couple advice, support family coping strategies, family care and family support, and influence burn-outcome expectations (European Burns Association, 2017).

Many countries, such as England (Heath et al., 2019), Norway (Helse Bergen - Haukeland universitetssjukehus, 2021) and Sweden (Sveen et al., 2017), have recently worked on improving online information about burn injuries for parents of burn-injured children. In the United Kingdom, an information website for parents/carers of burn-injured children was developed and launched in 2018 to aid parents of burn-injured children seeking information and health-related support on the Internet (Heath et al., 2019; Heath et al., 2020). In Norway, the national burn centre has a website with information to patients and relatives about treatment of burn injuries (Helse Bergen - Haukeland universitetssjukehus, 2021). In Sweden, a six-week internet-based information and support program has been tested (Sveen et al., 2017). Even though there were no proven beneficial effects on parental post-traumatic stress of these initiatives, parents found it supportive and meaningful (Heath et al., 2019; Sveen et al., 2017).

One study from the United Kingdom investigated how experienced psychosocial specialists provided psychosocial support (Guest et al., 2018). All specialists highlighted the importance of providing support to the whole family (Guest et al., 2018). In one study, nurses in Swedish national burn centres told how they identified family members' need for support and how the support they provided changed depending on which approach they used (Bäckström et al., 2019). Still, little is known about how different burn staff members support parents of burn-injured children.

To help the burn victims and their families, many countries arrange burn camps, a week's summer camp; and since 2019, a Norwegian burn camp for families has been offered (NFFB - Norsk Forening For Brannskadde [The Norwegian Society for Burn Victims], 2021a). Parents attending an English family burn camp found attending beneficial for themselves and the whole family (Armstrong-James et al., 2019).

Even so, many years ago, a study raised the question of how to effectively support and help parents help their child (Cahners, 1979). In light of this, there is still a gap of knowledge and more research is needed on how both support providers and parents of burn-injured children experience the support they provide/receive and ask them what the needs for parental support are.

2.4.7 Summary

As shown above, much research has explored the psychological reactions of parents of burn-injured children (Bakker et al., 2013a). Rather less attention has been devoted to study their lived experiences and needs for support during hospitalisation and after hospital discharge. Equally sparse is knowledge of different support initiatives and what staff members do to support parents who are hospitalised with their child and the time following their discharge from hospital. Parents are psychologically much affected by their child's burn injury, and their reaction affects the child and burn-related outcomes (De Young et al., 2014). Therefore, more knowledge of parents' experiences and needs is required.

3. AIMS

The overall aim of this study was to gain a deeper understanding of parents' lived experiences and need for support both when their child was hospitalised with an accidental burn injury and during the time following discharge; and to inform the development of a future support intervention for this parental group. The aims of each of the four studies are as follows:

Study I

To systematically synthesise the literature focussing on support needs of parents of burn-injured hospitalised children. How is support for parents of these children perceived by these parents, and what are the contents and context of the given support?

Study II

To explore staff members' lived experiences of supporting parents with children hospitalised at a burn centre due to a burn injury.

Study III

To explore parents' lived experiences of their need for support when having a child admitted to a burn centre.

Study IV

To explore the lived experience of parents caring for their burn-injured child at home after being discharged from a burn centre.

4. METODOLOGY AND METHODS

The overall long-term aim of the present project was to develop a support intervention, the guiding framework of which was the development phase of the Medical Research Council's (MRC) framework for complex interventions (Bleijenberg et al., 2018; Craig et al., 2008). In accordance with the development phase, a thorough review of existing literature was conducted to obtain information on "how to proceed or whether additional data collection is needed" (Bleijenberg et al., 2018, p. 88). Thus, Study I is an integrative review of current knowledge. It became evident that knowledge about this specific topic was very sparse, and more time was therefore spent on understanding the problem. For this purpose, qualitative methods are particularly useful (Bleijenberg et al., 2018). Especially focus group interviews and individual in-depth interviews are highlighted as means "to analyse the specific nature of the problem, ascertain who is involved or affected by the problem, and how the problem is perceived from different perspectives" (Bleijenberg et al., 2018, p. 88). Consequently, focus group interviews were conducted in Study II to understand what burn staff members do to support parents of hospitalised burn-injured children and in-depth individual semi-structured interview were used in Study III and IV to explore parents' lived experiences and need for support both during hospitalisation and after discharge.

A phenomenological hermeneutic approach is recommended to explore providers and parents' perceptions, which is "highly important in this early stage [in the development phase] and should not be underestimated" (Bleijenberg et al., 2018, p. 88). Qualitative research methods are recommended as appropriate to the integrative review method "allowing for iterative comparisons across primary data sources" (Whittemore & Knafl, 2005, p. 550). We therefore chose a qualitative phenomenological hermeneutic method, and a Ricoeur-inspired textual analysis method was found suitable in the integrative review. Since the participants' perspective emerged through interviews which, in turn, were transformed into text (via transcription), Ricoeur's theory of interpretation became crucial. Thus, this thesis has a phenomenological hermeneutic methodological approach.

First, a short introduction to the development phase of the MRC framework for complex interventions is given. This is followed by an introduction to phenomenological hermeneutics.

4.1 Development phase of the MRC framework for complex interventions

The MRC framework for complex interventions was introduced in 2000 to guide researchers on what to be aware of when developing and evaluating complex interventions (Medical Research Council, 2000), understood as "interventions that contain several interacting components" (Craig et al., 2008, p. 979). The MRC framework was later updated to consist of four phases: Developing complex interventions; assessing the feasibility of complex interventions and piloting them; evaluating complex interventions, and implementing complex interventions (Craig et al., 2008; Richards et al., 2015). More recently, four elements were added to the development phase emphasising the need to avoid 'research waste' due to poor, insufficient, inadequate questioning, attention, reporting or description in the process (Bleijenberg et al., 2018). The framework is particularly popular within nursing and medical research as it helps to "develop interventions systematically, using the best available evidence and appropriate theory" (Craig et al., 2008, p. 980).

This thesis sought to obtain an in-depth understanding of parents' experiences and needs for support while being hospitalised with their burn-injured child and in the time after being discharged from hospital. The starting point of the development phase is 'Problem identification and definition', a process that started when I worked at a burn centre wondering about and searching for literature on how best to support the parents. Thereafter, the first thing to do was to make a review, reading all the literature I could find, resulting in Study I. This refers to 'Systematically identifying the evidence' (Bleijenberg et al., 2018). Then interviews, both focus group interviews

(Study II) and individual semi-structured interviews (Study III and IV) were carried out to understand needs seen from different perspectives, which is similar to 'Determine the needs' (Bleijenberg et al., 2018).

4.2 Phenomenological hermeneutic approach

Phenomenological hermeneutic is the main methodological approach in this thesis. The following section will therefore briefly introduce the thinking of phenomenological hermeneutic. After the sections on Setting, User involvement, Sample and Data collection, phenomenology will be further described in relation to the phenomenological hermeneutic analysis method introduced in the section Data analysis method.

The German philosopher Edmund Husserl (1859-1938), the founding father of phenomenology, "considered phenomenology to be all three - a philosophy, an approach and a method" (Morse, 1994, p. 118). The word phenomenology comes from the Greek word phenomenon and means "to show itself". Phenomenological epistemological inquiry is to seek, understand and describe "the essential structure of the lived world" (Morse, 1994, p. 119) and describe things as they show themselves. A successor, but also a critic of Husserl, the German philosopher Martin Heidegger further developed phenomenology in a hermeneutic direction. Drawing on these early versions of hermeneutics, the French Philosopher Paul Ricoeur (1913-2005) developed phenomenological hermeneutic further in an interpretive direction. He argued that "the belongingness to the world is the interpretive experience itself and that all understanding is mediated by interpretation" (Morse, 1994, p. 121). Meanings, understanding and new knowledge have to be found in the text. Therefore, an in-depth analysis will lead to a comprehensive understanding with new facets of 'being-in-the-world' (Ricoeur, 1976).

Therefore, a phenomenological hermeneutic method (Dreyer & Pedersen, 2009) was used to analyse the conducted interviews (to be described later in the section Data analysis method).

4.3 Setting

Study II and III were conducted at a burn centre in Norway. The burn centre has five highly specialised intensive care rooms with a total of five intensive care burn unit beds. The burn centre can treat eight hospitalised burn patients simultaneously of whom five can be in intensive care. The centre treats about 150 burn patients yearly, including 50 children. The median stay is 20 bed days. Patients are treated by a multidisciplinary and multispecialty team with many years of expertise from the burn speciality. The team includes intensive care nurses, anaesthesiology nurses and registered nurses without any speciality, plastic surgeons, anaesthesiologists, physiotherapists, hospital clowns, social workers, psychologists, psychiatrists, priests, kitchen workers, cleaning assistants, a secretary and a hospital service worker.

In addition to providing medical and nursing care, all parents to burn-injured children are offered a consultation with a psychologist soon after admission, preferably within the first 2-4 days. The burn centre has access to operation theatres and to a 24-hour laboratory. The burn centre runs an outpatient clinic for both children and adults once a week, where patients may consult a plastic surgeon and a physiotherapist, among others. The burn centre also arranges educational courses for Norwegian and Nordic health personnel and has on-going international collaboration and responsibility for knowledge development and dissemination about burn care through research and quality improvement projects. In addition, together with the national burn patient organisation (NFFB - Norsk Forening For Brannskadde [The Norwegian Society for Burn Victims], 2021b), the burn centre arranges separate burn camps for adults, children and families once a year.

4.4 User involvement

User involvement is an “approach to research” (Abma et al., 2018, p. 7) rather than a research method, and it encompasses involving people in the research process, “people whose lives are at the centre of research” (Abma et al., 2018, p. 7). Users’ involvement in a research process heightens the chance that any new knowledge generated will be useful to the health service targeted by the research (Haugen, 2013). Many names are used to designate the inclusion of someone with first-hand experience in a research process. The most often used terms are participatory research (Abma et al., 2018), user participation (Haugen, 2013) and user involvement (Feiring et al., 2017; Nolan et al., 2011). The word ‘user involvement’ will be used in this thesis since this terminology is used in the MRC framework (Craig et al., 2019). According to the MRC framework, “appropriate ‘users’ should be involved at all stages” (Craig et al., 2019, p. 15) of both the development process and the outcome analysis as this will heighten the relevance of the process of developing an intervention and make it more likely that the intervention will be implemented (Craig et al., 2019).

During my PhD, I collaborated with two couples (four parents) who served as my sparring partners. They were the first parents to respond to my invitation published on the Facebook page of the Norwegian burn patient organisation (NFFB - Norsk Forening For Brannskadde [The Norwegian Society for Burn Victims], 2021b). The couples were different in age and their children had different genders (girl/boy) and burn aetiologies. By the choice of the parents, we met 2-4 times annually on Skype or corresponded via e-mail. We never met in person. They had personal experience with the topic of my PhD and could therefore be viewed as ‘experts’, and their help in the early research project was priceless. They helped develop the interview guide used for Study III and commented on article drafts and the discussion of findings, for instance by saying what affected them most or what they found most important.

4.5 Sample

Data for Study I consist of published articles focusing on parents and caregivers to burn-injured children. Participants in Study II are burn staff members and leaders from a Norwegian burn centre. In Study III, the participants are parents to hospitalised burn-injured children interviewed in the acute phase during hospitalisation or shortly after being discharged. In Study IV, the same parents participated again; only this time their child had been discharged from hospital to their home.

Study I included seven peer-reviewed articles (four qualitative studies and three surveys) from six different countries with a total of 521 parents/caregivers (390 females and 118 males); for 13 parents/caregivers, no gender was mentioned. The inclusion criteria were as follows:

- Studies describing support for parents with care provision during hospitalisation of their burn-injured child (< 18 years old).
- All years of publication.
- Articles published in English.

Participants in Study II were 21 burn staff members and leaders (18 females and 3 males) (Table 1). The inclusion criteria of burn staff members and leaders were:

- Burn staff members who regularly cared for burn-injured children and their parents.

Table 1. Participants in focus group interviews

	Group 1	**Group 2**	**Group 3**	**Group 4**
Participants, n	5	8	3	5
Data collection period	May 2017	May 2017	June 2017	October 2017
Professions (n)	Hospital clown (1), intensive care nurse (3), physiotherapist (1)	Anaesthesia nurse (1), burn surgeon (1), hospital clown (1), intensive care nurse (3), physiotherapist (1), social worker (1)	Intensive care nurse (2), psychologist (1)	Five leaders representing four professions
Burn experience: years, mean (min-max)	11.1 (5.5-24.5)	15.9 (10 months-25)	7.2 (2-15)	18.5 (6-35)

Length of interview	1 hour 48 min	1 hour 54 min	1 hour 45 min	1 hour 52 min

Recruitment of burn staff members and leaders started by identifying the professions involved in the care and treatment of children and their parents, resulting in eight professions: Anaesthesiology nurses, doctors, hospital clowns, intensive care nurses, physiotherapists, priests, psychologists and social workers. The leaders of all eight professions received an invitation letter (Appendix I) and forwarded this by e-mail to the employees. Consent to participate was returned to me by e-mail, and an appointment for the interview was made. To promote good conversation and dialogue among the participants, three groups with different staff members and one group of leaders were created. In total, four focus group interviews were conducted from May to October 2017, three with burn staff members representing seven professions and one with leaders of four different professions. The total working experience with burns spanned from 10 months to 35 years; the median time of experience was 14 years (total 297.8 years of experience/ 21 persons).

In Study III, the participants were 22 parents (12 mothers, 9 fathers and 1 stepfather) to burn-injured children who were either still hospitalised or had recently been discharged. Twenty-one of the same parents and three new parents (12 mothers, 11 fathers and 1 stepfather) were interviewed again in Study IV around the time of their child’s three-month follow-up appointment at the burn centre’s outpatient clinic. Participants in Study III and IV are presented in Table 2. The inclusion criteria of parents were:

- Parents to burn-injured children <12 years old, in order to have a homogeneous age group. Parents who spoke and understood Norwegian. Language restrictions were removed 11 months after recruitment had started, and an interpreter would be used if needed.
- Minimum 24-hour stay at the burn centre.
- Only accidental burn injuries.

Table 2. Participants in Study III and IV

	First interview	Second interview
Parents, n	22	24
Mothers/fathers/stepfather, n	12/9/1	12/11/1
Age mother, mean (min-max)/ age father, mean (min-max)	32 years (21-40)/ 35 years (24-46)	31 years (21-39)/ 35 years (24-46)
Interviewed together/ alone, n	12 (6 couples)/10	12 (6 couples)/ 12
Living together/ alone, n	18/4	22/2
Employed, n	22	24
Having one child/more children, n	8/14	8/16
Norwegian/European, n	16/6	18/6

Recruitment of parents started within the first days after they had arrived at the burn centre where all parents were seen by a department psychologist. Parents participating in Study III and IV were invited by three licenced psychologists and specialists in clinical psychology for children and youth, and one psychiatrist/ psychotherapist (Appendix II). The parents were invited to participate in two interviews; first during hospitalisation (Study III) and, second, around the time of their three-month follow up (Study IV). Each invited parent(s) was given an envelope containing an information letter (Appendix III), a letter of consent and a free-post return envelope. If the parent(s) wanted to participate, he/she/they sent a signed letter of consent by airmail to one of my supervisors. I collected the unopened letters, contacted the parents and scheduled an appointment for the interview at the hospital in a meeting room near the burn centre; or if the parents had been discharged, I travelled to their home(town) to conduct the interview.

All participating parents were contacted again for the second interview (Study IV) and a date and place was agreed upon. One mother declined to participate, finding the whole situation too traumatic and emotional. When interviewing three parents in their homes, their spouse (not previously interviewed) questioned why they were not being interviewed. They had parental experience and wanted to participate even though for different reasons they had stayed at home and had not been hospitalised with their child but only visited the burn centre. They were therefore also interviewed.

4.6 Data collection

A review was chosen for Study I and qualitative interviews were chosen for Study II, III and IV.

The aim of a review, Study I, is to examine previous literature within a specific field to gain a more comprehensive understanding of that particular field (Whittemore & Knafl, 2005). The goal is to *own* the topic and thereby become an expert within the field (Polit & Beck, 2017). In this thesis, an integrative review was conducted in Study I to obtain all available knowledge about support for parents of burn-injured hospitalised children. An integrative review is a method within the systematic mixed studies reviews that includes literature deploying diverse methodologies (Whittemore & Knafl, 2005). In order to minimize systematic bias and error, it is recommended to use a well-developed method for conducting integrative reviews, and thus the method described by Whittemore and Knafl was chosen (Whittemore & Knafl, 2005).

The integrative review method described by Whittemore and Knafl has five stages: problem identification, literature search, data evaluation, data analysis and data presentation. In February 2017, a systematic search was conducted in five electronic databases: Cumulative Index of Nursing and Allied Health Literature (CINAHL), Excerpta Medica dataBASE (EMBASE), PsycINFO, PubMed and Scopus. It was updated again in May 2018. The search produced 469 papers based on the keywords and Medical subheadings (MeSH): adaption, adolescen*, burn*, caregiver*, child*, coping, paediatric*, parent* and support. The selection process followed the PRISMA 2009 Flow Diagram (Moher D et al., 2009); and in the end, seven article were included in the integrative review.

In Study II, data collection was done in four focus groups; three groups with staff members and one with leaders. A homogeneous focus group, including staff members caring for the same patients (despite having different professional backgrounds), strengthens the group dynamic as focus group members can identify with each other (Malterud, 2012a), share their different points of view and discuss one or more specific topics (Brinkmann, 2014; Polit & Beck, 2017). The leaders were in one homogeneous group for themselves as a mix of both staff members and leaders would create a too heterogeneous group likely to be affected by power play, which would affect communication negatively (Malterud, 2012a). Three to eight participants were included in the groups, which is in accordance with recommendations for focus group sizes (Halkier, 2012; Kitzinger, 1995; Krueger & Casey, 2015; Malterud, 2012a). The focus group is a particularly suitable format with which to explore "people's knowledge and experiences" (Kitzinger, 1995, p. 299) because the group process facilitates clarification and exploration of participants' views on the spoken topic, which would have been more difficult in a face-to-face interview between one participant and the interviewer (Kitzinger, 1995). In the literature, the number of groups needed depends on the study (Halkier, 2012). In Study II there were four groups.

In a focus group interview, the interviewer functions as a 'moderator' whose role differs from that of an interviewer in a face-to-face interview (Halkier, 2012). In the focus group interview, all participants first stated their name and years of experience within burn care. The aim of the session was then explained and the moderator thereafter took a silent stance, listening actively, letting the participants discuss, as recommended (Kitzinger, 1995). The focus group interviews in Study II were facilitated by one of my co-supervisors who had worked as an intensive care nurse but had no experience from the burn centre. The co-supervisor was chosen as a moderator to uphold a distance between the participants and the focus group moderator, as I had working experience from the burn centre and knew all the participating staff members. I was present during all focus group interviews, serving as an observer and summing up the interview at the end. All four focus groups interviews were digitally recorded with three digital voice recorders. I transcribed all interviews verbatim immediately after the interview had taken place. The interviews were conducted within normal working hours. The participants were all on duty but not providing patient care and could hence participate without being interrupted or forced to leave. The interview took place in a meeting room outside the burn centre. Coffee, tea, soft drinks, chocolate and candy were available for everyone to provide a good atmosphere and acknowledge their participation. The main topic for the participants to discuss was what they did to support and help parents of hospitalised burn-injured children. The interview guide can be found in Appendix IV.

In Study III and IV, semi-structured interviews were used for data collection. The parents in Study III and IV were encouraged to talk about their experiences of what they needed when being at the burn centre but also at home after being discharged. In this type of interview, the interviewer seeks answers to a topics and will encourage the participant to tell his/her story and speak freely about all predefined topics (Polit & Beck, 2017). The parents were informed that I knew the department, so they did not need to explain or describe the special features of the burn centre. I have a nursing background with clinical experience from a burn centre, which gave me useful knowledge about this field. This, in addition to user involvement, helped me during the interviews to ask follow-up questions about certain statements to get more detailed answers. The semi-structured interview allows the interviewer to better utilize the potentials of the dialogue and allows for follow-up questions on particular issues raised by the participant (Brinkmann, 2014). ‘Dialogue’ originates from the Greek words ‘logos’, to speak and ‘dia-’ which means forth and back between people (Brinkmann, 2014). Conversation, in Latin ‘conversari’, means to live together or to keep company with one another (Brinkmann, 2014). ‘Interview’ comes from French ‘entrevue’ which means between and to see, which means to see each other and to exchange points of view (Brinkmann, 2014). Because we speak, communicate and engage in dialogue with each other in daily life, some might think that it is easy to do a scientific interview because we use the same techniques (Brinkmann, 2014). People thinking like this will be fooled by this illusionary simplification of an interview, especially within research where interviewing requires preparation, ethical consideration, execution of the interview and thereafter transcribing and analysing the empirical material (Brinkmann, 2014).

In Study III, questions were asked such as; Can you explain what happened (burn injury)? How did you experience arriving at the burn centre? What was meaningful for you while hospitalised at the burn centre? Can you recall a/some situation(s) where you felt supported/not supported? See Appendix V for the interview guide. Parents in Study IV were asked how things had been since the last interview and how they experienced their time at the burn centre (positive/less positive memories) (Appendix VI). The interviews at the hospital took place in a meeting room near the burn centre. Otherwise, the interviews took place in the parents' homes or at another place where it was possible to withdraw to a quiet place for a confidential talk. To create a relaxed, trustful atmosphere, all parents were offered tea/coffee/soft drinks and chocolate. Information about the interviews is found in Table 3. Interviewees were given no monetary compensation for their participation.

Table 3. Interview data of Study III and IV

	Study III	**Study IV**
Data collection period	April 2017 – July 2018	June 2017 – November 2018
Interviews, n	16	18
Days since accident, mean (min-max), n	17 (9-27)	130 (74-195)
Length of interview: minutes, mean (min-max), n	75 (33-175)	66 (38- 155)
Total interview time: hours and minutes	20 hours and 12 min	19 hours and 56 min
Place of interview, (n)	At the hospital near the burn centre (8), local hospital (1), home (5), hotel (2)	At the hospital before or after their three-month follow-up appointment (5), local hospital (2), home (10), café (1)

4.7 Data analysis method

4.7.1 Study I

In Study I, the method by Whittemore and Knafl was chosen because it is open for inclusion of different sources of literature and allows the use of different methodologies. We accordingly searched for both qualitative and quantitative studies. Whittemore and Knafl themselves argue that ‘data analysis’ is the least developed and weakest part of the integrative review method, for which reason they recommend to use primary research methods “developed for mixed-method and qualitative designs” (Whittemore & Knafl, 2005, p. 550). For this reason, a Ricoeur-inspired method developed by Dreyer and Pedersen (Dreyer & Pedersen, 2009) was chosen (to be described below). This method deploys textual analysis and I have used this method previously (Lernevall et al., 2017). The same method was used in Study II, III and IV.

4.7.2 Study II, III and IV

A phenomenological hermeneutic approach was found appropriate for exploring both staff members and parents’ perspectives.

The lived experience of both staff members and parents are captured in the transcribed interviews. To obtain a deeper understanding of the transcripts, a textual in-depth analysis method was chosen inspired by Ricoeur (Dreyer & Pedersen, 2009). The phenomenological hermeneutic was found highly relevant as a methodological approach as the focus was on understanding both staff members and parents’ lifeworld and their lived experience. A story told by a person, a ‘narrative’, consists of a beginning, a middle and an ending and contains the meaning of the story itself (Dreyer, 2019). Through the narrative, the person remembers the past and interprets the past in light of the the present, bearing in mind all what has happened since the narrative happened (Dreyer, 2019). This means that a narrative is never a true rendition of reality because it always contains an interpretation by the one who is telling the story (Dreyer, 2019). When another person interprets the narrative, it is important to discover the significant elements in the narrative (Dreyer, 2019); what is the narrative about, what does the ‘author of the text’ talk about (Dreyer & Pedersen, 2009)? The person who interprets a narrative will always be influenced by his/her own context, and so be affected by what he/she finds meaningful (Dreyer, 2019). This means that there can never be a true, definite interpretation of a narrative, but one interpretation can be more suitable or appropriate than another (Dreyer & Pedersen, 2009).

4.7.3 Ricoeur and his interpretation theory

The present thesis draws on the philosophical work of Jean Paul Gustave Ricoeur (1913-2005), a French philosopher (Ricoeur, 1976).

Ricoeur’s interpretative theory and use of textual analysis is explained in the book *Interpretation theory: Discourse and the Surplus of Meaning* (Ricoeur, 1976). According to Ricoeur (Ricoeur, 1976), a text can be many things inclusing, for instance, a face-to-face interview, a focus group interview, an observation, a text, a story or something similar (Dreyer & Pedersen, 2009). In Ricoeur’s interpretation theory, a dialectic relation exists between explanation and understanding in relation to language as a work, for instance a text (Ricoeur, 1976). When something is explained to someone and understood, that person can, in turn, pass it on by explaining it to yet another person. This illustrate how explaining and understanding melt together and overlap. “Understanding is the goal of explanation and explanation is the means to understanding” (Reagan, 1996, p. 46). Ricoeur highlights that explanation unfolds the meaning, whereas understanding grasps the meaning as a whole (Ricoeur, 1976). Meaningfulness is therefore central and can be found in something written, be it documents, monuments, gestures or vocal expressions (Ricoeur, 1976).

Ricoeur writes that a text is mute (Ricoeur, 1976). When a text has “left” the author, it is released from its original addressee (Ricoeur, 1976) and thereby the text becomes independent from both the author and the situation (Reagan, 1996). To understand the text, one cannot repeat the written, but must instead create a new event from the text. One therefore needs to interpret. The text is ‘pluviosity’ and consists of many layers.

Therefore, the text cannot be understood by simply reading a single sentence (Ricoeur, 1976). “The literary texts involve potential horizons of meaning, which may be actualized in different ways” (Ricoeur, 1976, p. 78). According to Ricoeur, there is no true interpretation of a text because, as he argues, “there is always more than one way of constructing a text” (Ricoeur, 1976, p. 79) and therefore more than one way of interpreting it. When reading a text, the reader enters a place “where the text stands”. The text thereby has an interior, but no exterior. “The meaning of a text is open to anyone who can read” (Ricoeur, 1976, p. 93). The sense of the text is “in front” of the text (Ricoeur, 1976), and the intention of the author is behind the text (Ricoeur, 1976). By distancing oneself from the author and letting the text talk instead, one lets the horizon of the text unfold and open up to “being in the world” in front of itself (Ricoeur, 1976).

Ricoeur writes about a structural approach to a text that combines a naïve interpretation (surface interpretation) with a critical interpretation (depth interpretation) (Ricoeur, 1976). According to Ricoeur, ‘a whole work’ consists of (meaning of) elements (Ricoeur, 1976). The process/action of dividing the text into these elements/segments (called the horizontal aspect) is called structural analysis by Ricoeur (Ricoeur, 1976). These segments are then put together to integrated parts that constitute the whole (Ricoeur, 1976). Through this process, a narrative structure appears and the underlying narrative logic becomes evident (Ricoeur, 1976). The narrative parts of the text are then put together “to form a whole” (Ricoeur, 1976, p. 85).

4.7.4 Ricoeur-inspired analysis methods

Ricoeur wrote about interpretation in a philosophical way and provided no specific procedural advice. Over the years, different researchers have developed Ricoeur-inspired interpretation methods for analysing empirical data (Dreyer & Pedersen, 2009; Geanellos, 2000; Lindseth & Norberg, 2004; Wiklund et al., 2002). These methods are all based on Ricoeur’s work and the hermeneutic arc (Singsuriya, 2015), but have developed differently. Geanellos introduces a two-step model, where the findings and interpretation decisions have to be justified by interview excerpts; she argues that according to Ricoeur, there is “a single, correct (or best) interpretation” (Geanellos, 2000, p. 117). Wiklund et al. also propose a two-step method and write that the interpreter’s preunderstanding is influential during the first step (Wiklund et al., 2002). In step two, the findings are validated against the results of step one, and “the story is rewritten to reflect the researcher’s validated understanding” (Singsuriya, 2015, p. 352). Both Lindseth and Nordberg, and Dreyer and Pedersen propose a three-step method with a similar first step – a naïve reading – where the material is read to grasp the “meaning as a whole” (Dreyer & Pedersen, 2009, p. 67; Lindseth & Norberg, 2004, p. 149). They propose different methods for the second step of the analysis which they both designate ‘structural analysis’. The goal for both approaches is to examine the parts to understand the whole; Lindseth and Norberg through four steps and Dreyer and Pedersen through three steps. Dreyer and Pedersen focus on narration and rewrite the story of the interview transcripts by using different literary genres (Singsuriya, 2015).

4.7.5 The Ricoeur-inspired interpretation method by Dreyer and Pedersen

The Ricoeur-inspired interpretation method by Dreyer and Pedersen was used in all four studies. This method was chosen for Study I, as mentioned earlier, because it is systematic, partly resembles the integrative method used and was familiar to two authors of Paper I. The ‘Dreyer and Pedersen’ method was also used for Study II, III and IV to get a deeper understanding of the participants’ lived experiences. It is a method where the participants’ words are central; and although the researcher interprets the transcribed interview, ‘what is said’ is not changed. The method requests the researcher to be true to what the participant has said. The three levels of the method allow the analysis to move from a surface interpretation to a depth interpretation.

The first level of the interpretation model is a naïve reading where the total material is read “to grasp its meaning as a whole” (Dreyer & Pedersen, 2009, p. 67), representing a surface interpretation. Ricoeur describes this first encounter with the text as follows; “understanding will be a naïve grasping of the meaning of the text as a whole” (Ricoeur, 1976, p. 74). A naïve reading has been conducted in all four studies, but is presented only in Study III and IV. The naïve reading for Study II is displayed in Table 4.

Table 4. Level 1. Naïve reading. Example from Study II

Support for parents of burn-injured children starts as soon as they arrive at the burn centre with their child. Everyone is conscious about how they approach the child and its parents; e.g. their body language and what they say. They want parents to feel safe and secure. Within this first meeting, the different persons and their tasks are introduced and the course of events about to happen is explained. When staff members are doing painful things, e.g. taking blood samples or giving injections, they and particularly the anaesthesia nurse try to make it as swift and painless as possible.

Giving information is highlighted throughout the interviews as the most important way of providing parental support. All the different professions agree upon this. Parents are orally informed about the routines on the burn unit such as the strict hygienic rules, and that they are not allowed in the kitchen or to use the cupboards in the corridor. Instead, they are encouraged to ask for things that they need. The burn centre has a pamphlet that is in the process of being revised. Some think the old one is still useful and hand it out to parents, while others find it outdated and wait for the new version that might be online. Whether or not they give out the pamphlet, they agree that oral information should be repeated because parents forget the information they receive. However, not all information should be given in the beginning or at the same time. Therefore, the different professions work closely together to give the same information. There is also a “main contact nurse” for each family to ensure the right flow of information. To ensure that knowledge amongst the experienced staff members is passed on to new staff members, some propose the development of a checklist on which information to give. Not everyone agrees on this as they are afraid it might restain the information flow. Some ask for more systematic routines that might make multidisciplinary work easier. They do not agree on this either.

The hospital clowns, however, are the only ones who do not give the parents any information. Instead, their job is to create an “emotional break” both for the child and for the parents. By doing this, the parents relax, and the other staff members can more easily do their job.

In the beginning, it is very important to the doctors to determine if the burn injury is due to an accident or abuse. They try to do this in the best possible way, thinking about where to talk confidentially, who should be present and how to address this subject. They use the time they need to have a good conversation, to calm down the parent(s) and to get the information needed to start treatment. They also agree that nearly all parents suffer from guilt and on how essential it is to talk with the parents about these feelings. Everyone thinks about his or her approach to the parents throughout their stay at the burn centre, and they try to take and make time for the different caring acts. Even though they try to keep appointments, they find it difficult to have time for everything. From the beginning, they see parents as "super users" with knowledge about their child. Parents are encouraged and guided to be the main career of their child, for instance changing the diaper and monitor the temperature. Because a child has a right to have his/her parents nearby at all times, the parents are told to stay with their child. All leaders agree that only one parent needs to sleep at the burn centre with the child. Sometimes, the staff members nanny the child for a short time to relieve the parents, but there are no systematic relief arrangements on the burn centre.

They wonder if they could improve the transition from the burn centre to the other hospital departments (e.g. children department, the hospital hotel).

Just before being discharged, it is important that one parent is participating in the wound treatment to facilitate treatment at home. Some staff members raise the question if the parents are educated well enough before discharge. Before leaving, the parents are orally informed about compression, sun protection and the offer about a summer camp for burn victims called Burn Camp. They are given the telephone number to the burn centre and encouraged to take contact if needed. Wishes for the future are more follow-up options like travelling nurses, more systematic phone calls after discharged and to meet parents at the three-month follow up. They wish for more space, a playroom for children and a parent's room with facilities like a sofa, television, shower and toilet. When wishing freely, they wanted their own hospital with burn unit beds, out-patient clinics and an operation theatre. Everything at the same place.

The second level in Dreyer and Pedersen's method is the structural analysis consisting of three steps; 1) What is said – finding quotations; 2) What the text speaks about – creating a narrative story and, lastly, 3) Creating themes (and subthemes) (Table 5) (Dreyer & Pedersen, 2009). According to Ricoeur, "comprehension will be a sophisticated mode of understanding, supported by explanatory procedures" (Ricoeur, 1976, p. 74). A table showing the structural analysis process has been published in Study II, III and IV.

Table 5. Level 2. Structural analysis. Example of one theme in Study II

Meaning-bearing units (What is said in the text?)	**Significance-bearing units (What does the text talk about?)**	**Theme**
“In relation to guilt, think we are very open, that we are there to help them regardless of what has happened. That's the thought most of us have. That we are quite open minded. We are there to help, and everything that might have happened and has happened… we let others take care of. They [the parents] must be observed, of course, if there is any suspicion, we must describe what we see. But I think we… we all support just as much, I hope so, regardless of what nationality and how it has happened, then everyone gets the same care, I think we give that (No. 15)”. “But we talk about it several times, right. Raise the issue several times, and then, point out if there is a child in age of one year, right, that a lot of things happen in that age group. They [the children] develop so fast, right. So, it's quickly done, you're not paying attention (No. 2)”. “But I think it's like [name] said, also like you [name] said to reassure the parents. That you get trust, build that trust already in the first meeting. And then, at least, I notice it within myself, one of the first things I say to them is “That an accident can occur to all of us”, that it has happened to other parents before and will happen to other parents in the future. To show them that this is actually true. And then explain a little that we have had many patients before, and how the road has been for them. That it turned out very well and that they are back to their normal lives. That life continues, also after all of this (No. 6)”. “But I think in relation to guilt and the fact that it has happened. You have to admit that an accident has happened and often because you have been inattentive or careless. But then the question is, how can one present this to the parents, that “Okay, what you might have to say to yourself is that it actually was your mistake, because of what you did. But a mistake is something everyone can make. This has had a consequence, but it won’t help your child or yourself if you go around criticising yourself in the future. There comes a time where you have to say “Okay, this happened” and move on” (No. 1)” …	In order to try to help parents with their feelings of guilt, staff members report taking the initiative to talk about the guilt openly and on many occasions. They explain that accidents can happen to everyone. Some staff members explain in general terms what they have seen before and how it turned out for those families. By sharing this information, they try to help parents deal with their guilt and live with it. Sometimes, they have to tell parents to focus on their child instead of the guilt. All professions except the hospital clowns report approaching the issue of guilt. The hospital clowns avoid the issue of guilt and instead shift the focus from guilt to the child. The other professions listen to the parents and inform them about normal reactions for parents and children. Staff members explain that they always try to acknowledge the parents’ feelings and meet and care for each parent equally and that they try to be open-minded and unprejudiced towards the parents despite the course of the accident and what they might think themselves. …	Helping parents deal with feelings of guilt.

Finding the right name for a theme is essential as the reader should be introduced to the 'what is to come'. An example of the process of naming the four themes in Study II is presented in Table 6.

Table 6. Level 2, step 3. Creating themes. The evolution of theme names in Study II

How to secure information throughout the whole stay →	How to make parents secure →	Secure and safe from the beginning →	Confidence-building activities from day one →	Confidence-building approach from the second they enter the burn centre →	Ending with: **creating a safe, secure and trusting environment from the moment parents enter the burn centre**
How to address parental guilt →	Guilt-reducing measures →	Helping parents deal with their feelings of guilt →	Ending with: **helping parents deal with feelings of guilt**		
Creating a break →	Relieve the parents and give them a break →	Helping the parent to continue being the parent of their child →	Enabling them to continue being the parent →	Ending with: **helping parents navigate in their daily routines while continuing to be a mother or father**	
Giving back control →	Gradually give back control to the parents →	Gradually educating parents in taking over the wound care of their child →	Gradually giving caring responsibilities back to the parents →	Gradually involving them in the treatment in preparation for discharge →	Ending with: **gradually involving parents in wound treatment as preparation for discharge**

The final and third level is a critical analysis and discussion "where the researcher, with other relevant literature and pre-understanding, discusses and argues in favour of one or several suitable interpretations" (Dreyer & Pedersen, 2009, p. 69). In all studies and in this synopsis, this third step is displayed in the Discussion section. About these three levels, Ricoeur writes “structural analysis as one stage – albeit a necessary one – between a naïve interpretation and a critical one, between a surface interpretation and a depth interpretation” (Ricoeur, 1976, p. 87), showing how they are linked together.

4.8 Ethical considerations

The four studies of this thesis were conducted in accordance with the Helsinki Declaration (World Medical Association, 1964/2013) and approved by the leaders at the Norwegian burn centre, where the study took place. The protocol for this study was also approved by the Norwegian Regional Committees for Medical and Health Research Ethics (REC) (REC, 2021), project number: 2017/54/REK (Appendix VII and VIII).

Participation in all interviews was voluntary and unpaid. All participating staff members and parents had received both written and oral information (Appendix I and III) about the study and their right to withdraw from the project without explaining themselves. Parents were additionally informed that the professional care and treatment of their child would be the same regardless of their choice to participate or not. Parents were given a stamped, addressed envelope so that they could send a signed letter of consent if they wanted to participate. This was done to ensure anonymity so that nobody besides me knew which parents were participating in this study, and to ensure that all children and parents were treated equally no matter if the parents participated in this study or not.

In January 2018, 10 months after recruitment of the parents had started, a request was sent to the ethical committee to change the inclusion criteria due to a low number of recruited parents. One third of the families with paediatric burn injuries were not Norwegians and did not speak Norwegian fluently (which was one of the inclusion criteria). In February 2018, this request was granted to enable inclusion of all parents regardless of their nationality (Appendix IX). An English information letter was made and handed to eligible parents (Appendix X.). An interpreter would be used if parents needed one in order to express themselves fully. No interpreter was, however, needed as parents mixed English, the little Norwegian they knew and got help from their spouse.

The digital audio records of all interviews, both focus group interviews and individual semi-structured interviews, are kept in a secured research server at the university hospital and will be deleted when the project ends. In the transcripts, all names of places and individuals were removed. The deidentified list of contact information including the transcribed interviews will be kept in the secured research server for five years after the study has ended to allow data to be available for a follow-up study. Five years after the project has ended, the information will be deleted in accordance with the requirements from REC.

Much consideration was given how to take care of parents in the interview situation, as it is known that an interview can cause the participant to become emotionally distressed, albeit this only happens infrequently (Alexander, 2010). The asymmetrical power that lies in the relationship between an informer and the interviewer (Haahr et al., 2014) was also taken into account. The parents were seen as extra vulnerable given the situation where their child had an accidental burn injury and because the first interview took place in the acute phase shortly after the accident (9 to 27 days). But being vulnerable did not mean that their voices were less important to hear, as clearly brought out by another study (Alexander, 2010). Therefore, parents of burn-injured children needed to be heard to gain more knowledge about their perspectives. A study of interviewing family members of critically ill patients at intensive care units raised the dilemma that an interview could create a need for therapeutic intervention (Burr, 1996). To accommodate any parental needs for extra therapeutic help, the department psychologists served as backups if any parents should need extra counselling as a result of the interview. This was, however, not necessary in any case, as all parents declined to talk to the psychologist when offered the opportunity to do so. Interviewing vulnerable persons can also affect the interviewer, and it is therefore recommended that the interviewer has some training within the field (Dickson-Swift et al., 2008). I had experience of conducting interviews, and a debriefing was done with one of my supervisors after each interview. In Study III and IV, the parents said that they were happy to talk to someone who knew the department and the specialised medical field. This mirrors findings of another article where participants were happy for the opportunity to talk about their illnesses or experiences to someone who was neither friend nor family (Alexander, 2010). One can call this “The listening ear of the researcher” (Burr, 1996, p. 174). Some parents said that it had helped them process their experience in a positive way. No one regretted that they participated, even the mother who only participated in Study III. I was genuinely surprised by how much it meant to the parents to see me again and tell their story once more while stongly emphasising how well their child was developing, but also how they themselves struggled in different ways.

5. SUMMARY OF FINDINGS

The findings in this thesis originate from four separate studies. Study I summarised knowledge about support for parents through previously published research, and Study II examined what staff members do and think is important in order to support the parents. In Study III and IV, the parent's experience of needs for support were studied while hospitalised (Study III) and at home (Study IV).

5.1 Study I – Support needs of parents of hospitalised children with a burn injury: an integrative review

The aim of this study was to gain a comprehensive understanding of the support needs of parents with burn-injured hospitalised children through systematically synthesising the existing research. Seven articles focusing on support needs of parents of burn-injured children were included in the integrative review displaying the sparse knowledge within this field. Four themes were derived from the analysis (Table 7).

Table 7. Themes and subthemes of Study I

Themes:	**Subthemes:**
Emotional distress	– Fear of losing child and fear of medical treatments – Staying strong and accepting the situation
Guilt and blame	– Blaming oneself or blaming the partner – Blame from family members and hospital staff
Information is central	– Information from the healthcare professionals – Missing information
Having someone to lean on or being alone	– The healthcare system – Support from others – Being alone

The parents were deeply emotionally affected by the burn injury, and the fear of losing their child was so severe that it affected their appetite and their ability to participate in dressing changes. Many parents were affected by feelings of guilt either self-afflicted or because they were blamed by their partner, family members or hospital staff. Self-blame made it hard to forgive themselves and made some change their behaviour. Being blamed for the accident by others made them feel terrible, distrust their ability as a parent and made it hard for them to talk to others about it. Receiving all necessary information could partly relieve them of some of their anxiety. This made them cope better and gave them a sense of control. Too much information on the other hand could cause panic in some parents. Feeling misinformed made them question the quality of care and made them stressed, worried, anxious and out of control. The feeling of being supported by health professionals and group sessions gave them a sense of comfort, relief and made them feel at ease, resulting in a high satisfaction with the quality of care and confidence in the medical treatment. Some parents formed a dyad and experienced this as the most important support. Experiencing lack of support made the parents feel alone and some turned to their religion for consolation.

5.2 Study II – Staff members' experience of providing parental support in a national burn centre

The aim of Study II was to gain knowledge about staff members' experience of supporting parents of burn-injured children while hospitalised at a burn centre. Burn staff members described their experiences of supporting parents of burn-injured children in different ways. In the analysis, four themes were found that describe how the support was provided from the perspective of burn professionals (Table 8).

Table 8. Themes of Study II

Themes:
Creating a safe, secure and trusting environment from the moment parents enter the burn centre
Helping parents deal with feelings of guilt
Helping parents navigate in their daily routines while continuing to be a mother or father
Gradually involving parents in wound treatment as preparation for discharge

Creating a good relationship with the parents during their first meeting was described as very important by the staff members. Therefore, they tried to make the parents feel secure and trusting them by introducing themselves and their role while being aware of their oral and body language. They described how they were attentive to the parent's wellbeing by trying to calm them down, alleviate their anxiety and giving specific information with the purpose of making parents less confused and disorganised. The staff members wanted to reduce child and parental stress. Therefore, each family was given a primary or contact nurse to ensure continuity. The staff members also experienced that guilt was a main topic; and to help parents, the staff members described how they listened, explained, shared experiences and acknowledged the parents' feelings but also told them when to stop ruminating about it. In order to maintain or strengthen the parental role, they encouraged parents to be included in the care of their child and to continue with their normal family routines. They also clarified their expectation to the parents being present during hospitalisation while offering them small breaks to see to their personal needs. To prepare the parents for the caring for their child at home, the staff members wanted parents to actively participate in wound treatment prior to being discharged.

5.3 Study III – Parents' lived experiences of parental needs for support at a burn centre

The aim of this study was to explore parents' lived experience of their need for support while their child was hospitalised with a burn injury. In Study III, the parental needs for support are displayed in four themes (Table 9).

Table 9. Themes of Study III

Themes:
Being in it together—for their child
Being taken care of by professionals makes you feel calm and safe
Trying to have some control in an uncertain situation
Getting time to be yourself and see to personal needs

Staying together during the hospital stay was experienced as extremely important for the parents as they could process the traumatic and chaotic event of the accident as a team and support each other. Being separated added extra pressure on them, making them stressed, sad and unneeded; an example of this is not being allowed to spend the night together at the burn centre. Divorced parents, however, did not share the need to be together as it made them exhausted, frustrated and irritated. Being met by awaiting, caring and professional staff members upon arrival to the burn centre was described as extremely important for the parents as it made them feel relaxed, comfortable and cared for. Something that was experienced as particularly helpful in processing their feelings of guilt was the way staff members approached, reacted to and commented on these feelings. Getting information throughout the hospital stay was important for the parents. It made them less afraid and more optimistic, trustful, relaxed and better prepared for discharge. Conversely, they felt irritated, frustrated, hampered, confused, despaired and distrusted the staff when experiencing lack of information or miscommunication. Divorced parents did not share information between them and therefore lacked information. Having some breaks alone was experienced as extremely important to the parents as it was strenuous being at the burn centre.

5.4 Study IV – Parents' lived experience of caring for their burn-injured child after discharge from hospital

The aim of this study was to explore parents' lived experiences of caring for their burn-injured child at home after discharge from a burn centre. The analysis in Study IV resulted in four themes presenting how the challenges in everyday life at home were experienced by the parents (Table 10).

Table 10. Themes of Study IV

Themes:
Embodied feelings that will stay forever
Discharged to continue treatment at home without necessary skills
Grieving over the lost past and fearing the unknown future
Longing to reunite with familiar staff members

The feelings experienced from the accident had been embodied within the parents and made them mentally and physically exhausted. They experienced loss of body control as their body could suddenly react on its own. Feelings of guilt were still inside them and some had accepted that this would not disappear. Some even felt shame. Leaving the burn centre without proper training was experienced as chaotic and stressful, and it made the parents struggle executing the medical treatment at home. This made them feel insecure, uninformed, tired, sad, ignorant, sweaty, exhausted and crazy. At home they had concerns and fears for their child's future, while trying to process, grieve and accept the changes in their child. The relation to staff members who had treated them was so important that the parents described a profound need to be reunited with them at the three-month follow-up appointment. Meeting a staff member whom they knew made them emotional, extremely happy and relieved as the reunion was experienced as almost therapeutic and as a closure. Meeting only new staff made them disappointed and lacking answers to their questions. When calling the burn centre with questions, they also wanted to be answered by someone who knew them. A phone call from the burn centre, for instance two weeks after discharge, would make them feel seen, taken care of, less insecure and more safe.

5.5 Comprehensive understanding

Together all four studies generate one overall comprehensive understanding; i.e. that parents of burn-injured children have specific needs and that these needs must be catered for the parents to come through it all as a family, both while hospitalised and after discharge. The parents need help in order to process their post-burn emotions, feelings related to the injury like guilt, shame and blame, while constantly trying to understand what is happening at the burn centre, demanding to be informed. Staff members play a crucial role in supporting parents. In order to help with the care and treatment of their child, the parents need to have their own fundamental needs fulfilled, have the right training and skills to execute and succeed with the prescribed treatment, and get help to stop their fear about the future.

6. DISCUSSION

The overall aim of this study was to gain knowledge about the needs for support of parents of burn-injured children both during hospitalisation and follow-up to inform the development of a support intervention for these parents. To achieve this goal, it was important to get a deeper understanding of both parents' and staff members' experiences of parental needs for support throughout the whole burn trajectory. Drawing on the Ricoeur-inspired method, we elicited these needs and display them in the comprehensive understanding, which will be discussed in the following text, illustrated in Figure 3. This critical analysis and discussion is the third and final level of the Ricoeur-inspired interpretation method by Dreyer and Pedersen (Dreyer & Pedersen, 2009).

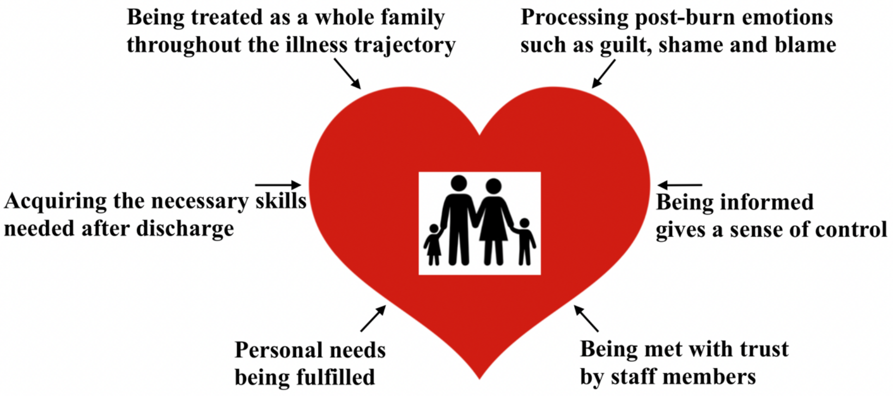


Figure 3. Illustration of parental needs for support

The figure is a heart with a family inside. The heart symbolises the warmth, caring and love that exist within the families. Around the heart are parental needs for support derived from the comprehensive understanding. The core of the heart is the family, which can be either strengthened or weakened depending on whether the needs are met or not.

In the following, the parental needs for support will structure the discussion and be discussed in light of other literature and theory.

6.1 Being treated as a whole family throughout the illness trajectory

The need to be treated as a whole family appears as important in all studies as everyone in the family is affected by the burn accident: the child, the mother and the father. Another study also found that the whole family was affected by the burn injury (Oster et al., 2014). Especially when returning home, parents were being challenged to care for the whole family including any siblings (Oster et al., 2014), which required much energy and time from the parents (De Sousa, 2010). The siblings' perspectives, however important, were not included in the studies of this thesis, which focused on both mothers and fathers, finding that fathers wanted to be included and considered as an equally important parental figure for the child. Thus, the family wanted to be treated as a unity. In another study, it was only the mother and not the father who was given an information leaflet upon arrival (Heath et al., 2019). The mother and father of the burn-injured child needed each other during hospitalisation as they provided pivotal support for one another, as presented in Study I and III. Even staff members talked about the parents as if they were both present at the burn centre, as shown in Study II. After being discharged, the parents expressed other needs and concerns than being together, displayed in Study IV, which suggests that the need for having each other was already fulfilled being reunited as a family at home. Looking back in history from the beginning of the last century, recent decades have seen a gradual liberalisation internationally, allowing parents to be present together with their hospitalised child (Alsop-Shields & Mohay, 2001; Sundal, 2014; Sundal et al., 2019). From being completely excluded from the hospital (Sundal, 2014; Sundal et al., 2019), parents are now allowed to be present during the hospital stay; a right that has been encoded in several countries including Norway (Helse- og omsorgsdepartementet, 2000). Today, parental presence is expected during medical examinations, treatment, care and other procedures of their child (Harrison, 2010; Sundal et al., 2019). But even today, only one of the parents is hospitalised at the burn centre together with the child, as reported in study III, and often that parent is the mother, while the father arrives later and sleeps elsewhere. One may, indeed, question if they are welcomed to the same extent and receive the same flow of information. In many countries, such as India, Malawi and South Africa, the cultural norm is that mothers are responsible for the child’s care and upbringing (Frenkel, 2008; Holden et al., 2020; Ravindran et al., 2013b; Van Niekerk et al., 2007), explaining why they often are blamed for burn accidents to their child occurring in the home (Frenkel, 2008; Ravindran et al., 2013b). According to the WHO, inadequate adult supervision and young girls being in charge of households while taking care of small children are major risk factors in paediatric burn injuries (World Health Organization, 2018). This indicates that mothers are still the main carers of children in some cultures, as supported by a newer study (Holden et al., 2020). In the Nordic countries, however, it is natural to see fathers being present to the same extent as mothers in their child’s first years of life (Cederström, 2019). Even though cultural differences may apply from country to country and indeed within national subcultures, the findings of the studies in this thesis show a fundamental need to be cared for as a family.

All the studies of the present dissertation show the lived experiences related to parental needs for support. In the parents’ world of lived experiences, they find themselves in a dependency relationship to the other parent, the child and the health professionals. As human beings, we form interdependent relationships with each other, or as the Danish theologian, philosopher and phenomenologist Knud Ejler Løgstrup (1905-1981) puts it, “The individual never deals with another human being without holding some of its life in his hand” (own translation) (Løgstrup, 2010, p. 25). In the situation following their child’s burn accident, parents’ relationship with the health professionals is particularly important, and one might argue that the success of the parents’ outcome is much influenced by the relationship they have with the health professionals, especially because “we are each other's world and each other's destiny” (own translation) (Løgstrup, 2010, pp. 25-26). In other words, we are in the world together and affect each other’s life and lived experience. Therefore, it is extremely important that the health professionals see the whole family because they are fundamentally responsible for helping the family come through it all in the most positive way. For instance, allowing both parents to sleep at the burn centre the first nights to let the parents process the traumatic event and take turns sleeping and being awake monitoring the child, as presented in Study III.

With history in mind and in light of the parents’ need for being together and to be treated as a whole family, we might ask ourselves how far we have come when it comes to including parents in burn departments? In a quantitative prospective study of parental-child relations after a paediatric burn event, the authors recommended to implement a family system perspective when supporting, monitoring and educating the burn-injured child and the parents (Bakker et al., 2014). Which limitations apply to parental access to operations, wound treatment and spending the night? How can parents be included when they are at the burn centre all the time? The answers to these questions may be found within the theory of family-centred care (FCC), a philosophy and approach used within paediatric nursing (Harrison, 2010). The most central element in FCC is ‘a relationship between the family and health care professionals’ (Harrison, 2010). FCC has four core concepts; dignity and respect, information sharing, participation, and collaboration (Institute for patient- and family-centred care, 2021). The findings from the four studies in this thesis confirm that at least one parent was hospitalised together with the child and that the parent was involved, to a variable degree, in the care and treatment of the child. To practise FCC successfully, the healthcare system needs to change from being professionally centred to being more collaborative, giving the family a key role in the care of the child (Shields et al., 2007). Staff members should treat the parents as a whole family throughout the illness trajectory.

6.2 Processing post-burn emotions such as guilt, shame and blame

Following an accidental burn injury to their child, all parents in the four studies were psychologically and physically affected, and their feelings manifest themselves both bodily and emotionally. Feelings of guilt were a particularly prominent emotion in all four studies, and often guilt was related to anger and blaming someone for the accident. Parental feelings of anger could emerge when touching their child’s scars, as found in Study IV, but also when blaming the other parent whom they held responsible for the accident, as shown in Study I. This could develop into a conflict between the parents, as reported in Study I and II. Guilt, shame and blame have long been mentioned in the burn literature of parents with burn-injured children (Barnett et al., 2017; Bayuo & Wong, 2021; Bowden & Feller, 1973; Brodland & Andreasen, 1974; Cahners, 1988; Cook, 1982; Coy et al., 2019; Egberts et al., 2017; Egberts et al., 2019; El Hamaoui et al., 2006; Fowler, 1978; Francis, 1990; Frenkel, 2008; Hawkins et al., 2019; Heath et al., 2018; Horridge et al., 2010; Kornhaber et al., 2018; Mason, 1993; Oster et al., 2014; Rivlin & Faragher, 2007; Suurmond et al., 2020; Sveen & Willebrand, 2018; Van Niekerk et al., 2007; Verity, 1995), with guilt being the most prominent feeling.

Across the four studies, feelings of guilt and self-blame were most noticeable in the acute phase following the burn accident; but as reported in Study IV, guilt was also present during rehabilitation after discharge. This shows that the feelings affect the parents to a variable degree through the burn trajectory. Parental guilt and self-blame have also been reported three months to three years after the burn injury (Egberts et al., 2019; Heath et al., 2018; Horridge et al., 2010). Such long-term feelings of guilt and self-blame may lead to self-doubt causing parents to become overprotective and overcompensating toward their child (Horridge et al., 2010). This shows that the intensity of guilt and self-blame may decrease over time. Using ‘The shifting perspective model” by the Canadian professor Barbara L. Paterson (Paterson, 2001), one may argue that guilt and blame are in the foreground of the parents’ lived world, but the feelings step back to let life be in the foreground as time passes.

Since guilt, shame and blame keep reappearing in the literature, it might be important to get a deeper understanding of these feelings to determine how they affect a person. In Study I, II and III, some parents blamed themselves or they were blamed by others for the accident, and in all studies parents report feelings of guilt that may cause them to be ashamed for what has happened to their child, as reported in Study IV. Guilt, shame and blame are often used together, but according to the Danish psychologist Lars J. Sørensen, they are phenomenologically different (Sørensen, 2013). Guilt is related to something outside of the self, i.e. actions for which I am responsible, what I did wrong (Sørensen, 2013), seen in a relation to the other person (Martinsen, 2012). Responsibility means that one always has the possibility and the ability to react differently – easily visualised when the word is split into two: response and ability (Sørensen, 2013). Shame, on the other hand, is a very painful inner feeling, often hidden inside (Sørensen, 2013), and it is closely associated with identity and personality (Martinsen, 2012). Sørensen argues that a shameful person "can never be happy with himself" (own translation) (Sørensen, 2013, p. 71), which makes it difficult to care for oneself, whereas a guilty person has a need to be cleansed from the guilt and made un-guilty (Sørensen, 2013). Study III shows an example of a mother who felt that staff members removed her guilt by telling her that a burn injury can happen to anyone. Blame is both private and public; private in the sense that it leads to self-judgement and public/social in the sense that someone may express blame and pass judgement on another person for doing or causing something wrong (Malle et al., 2014). This knowledge about guilt, shame and blame is important for health professionals who try to address these feelings, as the feelings should be dealth with differently. The burn staff members seem to have a unique role in helping parents process and deal with these feelings because they see the parents quickly after the accident has happened owing to their professional role. Guilt is the easiest feeling to treat because the feeling is open for debate (Sørensen, 2013). Feelings of guilt should be addressed and spoken openly about with the parents in order to ease their feelings of guilt. According to the model of shifting perspectives (Paterson, 2001), staff members should assist parents in identifying and understanding guilt. There are cases, though, where an accident is not accidental but deliberately inflicted upon the child. However, even though child abuse is necessary to investigate and treat, it was neither the case nor the focus of the studies in this thesis as only accidental injuries were included. Blame regulates the behaviour of a person to prevent similar negative outcomes (Malle et al., 2014). Blame and self-blame should also be discussed and talked about. Shame on the other hand is more difficult to treat as it is hidden, secret and just there (Sørensen, 2013). Sørensen writes that shame can only be defeated if "one allows oneself to be seen with loving eyes" (own translation) (Sørensen, 2013,

p. 72). This means to feel seen, acknowledged and accepted for the one I am, which means that I have nothing to hide (Sørensen, 2013). In Study III, some parents suffered alone as they did not share their feelings of guilt; for some parents, the guilt would never completely disappear as it was hard to forgive themselves, as reported in Study I and IV. This guilt could easily turn into shame if it remained hidden within the person and remained unaddressed. For parents with this kind of shame feeling, it is understandably difficult or maybe nearly impossible to put these feelings aside, allowing other people such as staff members to look at you with loving eyes. This makes it much harder for staff members to help ease feelings of shame. Staff members have to create a trustful relationship and look at the parent with loving eyes, so that the parents open up and allow themselves to see those loving eyes and the love and forgiveness that is embedded within the look. Staff members should, in other words, aid parents in processing post-burn emotions such as guilt, shame and blame.

6.3 Being informed gives a sense of control

Receiving enough information is also a central parental need found across the four studies. Getting enough information alleviated stress and gave parents a sense of control, as reported in Study I and III. This is supported by another study where parents emphasised the importance of receiving adequate information about their child's psychological and medical condition in order to be able to deal with the scars and understand the treatment (Suurmond et al., 2020).

The amount of information was proportional to how calm or upset the parents became (McGarry et al., 2015). An example of this is seen in Study II where staff members limit information sharing during admission and gave parents only as much information as they were able to absorb in a crisis situation. The importance of getting information about the medical situation has also been reported elsewhere (Egberts et al., 2019). Staff members in Study II explained that they took the time needed to talk with and inform the parents, regardless of how busy they were, but that they were also aware of not using too much time out of consideration for the tired parents. Here, one may argue that staff members take account of the parents' experienced lived time. The parents' lived time is affected and disturbed by the events happening in relation to their burn-injured child and their lived time is not touched by the time of the clock that continues to move forward in the same undisturbed rhythm. The Norwegian nursing philosopher Kari Martinsen writes that if the nurse lets herself use the time, she can come to understand the patient and help ease their discomfort (Martinsen, 2012). The staff members' approach to time is therefore essential in caring for the parents. According to Martinsen, healthcare professionals can be challenged in their meeting with the patient and the relatives as they are controlled by the measurable objective clock-time that exists within the healthcare system (Martinsen, 2012). Clock-time affects the person without the person having something to say, but it is the lived time inside the body that counts "For it is not the clock, but the heart that stops when time is out" (own translation) (Martinsen, 2012, p. 134). This means that staff members should be more attentive to the lived time of the parents, their needs, instead of being controlled by the clock-time, and possibly end up being too busy. In Study III parents highlighted time as particularly important and said that despite the staff members being busy, they still had time for them and their questions. This show how vital it is for parents that staff members have enough time to inform them and answer their questions. For some parents not speaking the native language used at the burn centre, it was difficult to obtain all necessary information and they wished for the staff members to use a more active communication style towards them (Suurmond et al., 2020). One could argue that the staff members should take charge of the information and communication as the parents are in a very vulnerable situation. The parents are emotionally overwhelmed by what has happened to their child as displayed in Study I, III and IV. Moreover, they depend on the care and treatment offered by the staff members, and some might be afraid of doing something wrong, why staff members helped them navigate as found in Study II. Receiving regular advice on what to do, however, limited parental independent decisions and diminished their parental role (Horridge et al., 2010). Not feeling informed or experiencing miscommunication directly affected the parents and made them stressed, worried and question the quality of care, as displayed in Study I, III and IV. Missing crucial information could give parents catastrophic thoughts, which could bother them with worry for years (Suurmond et al., 2020). It is important for staff members to balance giving enough information and having the time to deliver the information in a manner parents understand. The FCC concept of 'information sharing' is highly relevant here (Institute for patient- and family-centred care, 2021). Staff members should provide information that gives the parents a sense of control, for example by asking if the information has been adapted to the parents' needs and how the parents heard and understood the given information.

6.4 Being met with trust by staff members

Across all four studies, the impact that staff members had on parents of burn-injured children was noticeable. Being met by competent staff members was highlighted across the four studies as highly important for the parents' wellbeing. The way they were met and received care by staff members impacted their entire experience. In another study, parents reported that meeting certain staff members was experienced as very beneficial, as they could support, comfort, offer advice and help them distract their child (Heath et al., 2018). In all four studies, the staff members were mentioned as unique to the parents in being there for them when they most needed it and were at their most vulnerable.

Staff members in Study II highlighted the importance of establishing a good relationship with the parents and that the parents could trust them, which would benefit the collaboration between them and ultimately benefit the child. Parents reported experiencing staff members as trustful, a finding in both Study III and IV. These statements about trust in the meeting between parents and staff members can be interpreted as being evidence of a trustful relationship between the two parties. A cornerstone in Kari Martinsen's phenomenological philosophy is trust (Martinsen, 2006). Martinsen bases her thinking on the work of Knud Ejler Løgstrup and writes that trust is a fundamental feeling within all human beings, and it is up to each and one of us to be worthy of another person's trust (Martinsen, 2006). Especially healthcare professionals have a unique role in taking care of the life they are entrusted with, or as Martinsen puts it “caring for the life trust puts in our hand” (Martinsen, 2006, p. 71). The parents are in a dependency relationship with the staff members who can help their child, so how the parents are met by staff members is crucial for their relationship and further collaboration. For some parents, meeting staff members at the burn centre was a relief because they knew that their child were in the best hands (McGarry et al., 2015); for others, for instance in India, it was a more traumatic experience because they were told that their child would not survive (Ravindran et al., 2013a). Trust was established during the first meeting with the burn staff members (Study II and III). Trust is about recognising the other, being interested in the other and understanding the other (Martinsen, 2006). In Study III, the parents told how they were met by staff members who had everything ready to start treatment on their child. This can be seen as a trust-establishing act; the parents could feel that staff members took the situation seriously. Staff members should meet parents with a ‘person-oriented professionalism’, which means to be both professional and be open to sense the other’s suffering, and able to protect the other’s integrity (Martinsen, 2006). Martinsen points to a particular ability which is to see the other person “with the heart’s eye” (Martinsen, 2006, p. 82); that sensing the other instead of seeing with the eye that only records and registers (Martinsen, 2006). When parents remember the hospitalisation using words such as frightening and hell, being distrusted, feeling alone and not knowing what was going on, as reported in Study I and III, what they mean is maybe that they encountered the recording eye; that parent-staff member relations were not founded on trust, and that no person-oriented professional approach using the heart’s eye was in place.

The importance of support from staff members was also underlined by parents even after they had been discharged and were at home. This was seen in Study II and IV where parents expressed that they wanted to get in contact with the primary nurse or other key staff members who had treated them. Parents who had been contacted at home by a staff member whom they knew experienced this as comforting, significant and as a piece of outstanding support (Heath et al., 2018). The importance of contact with the hospital after discharge has also been reported in another study (Oster et al., 2014). The essence of the meeting with staff members, whether during hospitalisation or after discharge, is that staff members should met the parents with trust.

6.5 Personal needs being fulfilled

Parents hospitalised together with their child mentioned that getting some time alone while hospitalised was important. In Study I, the parents told that they put on a brave face and stayed strong when they were with their child, but as soon as they were alone, they let go of their feelings and broke down. This shows the importance of having some time alone to process everything that is happening. The need for getting time to see to personal needs and be alone was also voiced in Study III. Staff members in Study II explained that they believed that a good parent should attend "to one's own fundamental needs" (Lernevall et al., 2019, p. 216) to be able to care for their child in a positive way, e.g. get some breaks, eat, sleep and see to their basic needs. Therefore, they gave the parents some breaks, to relieve them. In another study, parents neglected their own needs and put them last because their main focus was on supporting their child (Heath et al., 2018). At home, as reported in Study IV, some parents felt exhausted from the hospital stay, which is not good because they need to have energy to take care of the child at home and to live their normal life. This parental need for having your personal needs fulfilled is, to my knowledge, quite unique. Little attention has been paid to this, probably because the parents forget about themselves, being absorbed in caring for the child. Seeing to one's fundamental needs such as eating, drinking, sleeping, maintaining personal hygiene, processing emotional events, etc. can be so basic that it is easily forgotten in the traumatic time following a child's burn injury.

Since the beginning of nursing, there has been a focus on the patients' fundamental needs. The nursing pioneer Florence Nightingale (1820-1910) wrote about the basics of nursing, mentioning some fundamental needs essential for the patient to recover from sickness (Nightingale, 2004). Among the important things she advised was to take in food and maintaining personal hygiene such as washing the skin (Nightingale, 2004). Even though the parents in the four studies are not patients, they are hospitalised together with their child and the fundamental needs apply for them as well. Parents in Study III asked specifically for time to see to their personal needs such as taking a shower. Fundamental needs are a basic theme with which many nurses have been working, referring to the American nursing theorist Virginia Henderson (1897-1996) who wrote about the fundamental needs of the human being (Henderson, 1964). We may argue that when parents of burn-injured children focus on their child's needs and forget or suppress their own needs, it is important that staff members remember the parents' needs and help parents organise their daily activities so that their fundamental needs are being fulfilled.

6.6 Acquiring the necessary skills needed after discharge

In all studies, being prepared for rehabilitation and the caring tasks at home was mentioned as really important to the parents. Thoughts about discharge or being discharged (too early) made parents unsure, worried and concerned as they felt that they were responsible for carrying out the medical treatment at home (Study I, III and IV). Parents of burn-injured children have to "acquire an array of skills needed to care for their child" (Horridge et al., 2010, p. 634). On top of parents having to return to work, returning home resulted in altered roles, changes in family life and routines in order to manage the child's psychological and physical recovery (Horridge et al., 2010). To some parents, responsibility for the aftercare was too big, as found in another study where a mother highlighted that she was "only a normal human being" (Oster et al., 2014, p. 610). To make transition to home easier, staff members in Study II told that they educated parents to become experts within wound care and scar treatment, and they talked about how parents should react to the scars. Even though it is of great importance that parents feel confident in performing the prescribed treatment at home, the findings from Study IV show that parents experienced a lack of education and training before being discharged, which made them feel greatly challenged at home. The evident lack of information related to the rehabilitation and follow-up was also reported by others (Oster et al., 2014).

The American phycologist David Kolb described learning styles using a circle containing four elements that a person goes through when learning something (Illeris, 2006). The first stage is a ‘concrete experience’ where the person carries out an action; the second stage is ‘reflective observation’ where the person reflects on the action; third stage is ‘abstract conceptualisation’ where the person learns from the experience; and, lastly, the fourth stage is about ‘active experimentation’ where the person tries out what has been learned before it all start again from the first stage (Illeris, 2006). In the four studies of this dissertation, only few parents had carried out the wound treatment themselves before discharge. According to the learning theory of Kolb, the most beneficial thing would be for the parents to actively do the wound treatment themselves in order to get concrete experience, which is more easily remembered when carried out bodily, so to speak. The more times parents carry out the wound treatment, the more secure they will be.

As a result of less organised hospital preparation of discharge chores, the parents struggled as clearly shown in Study IV, even though the best intentions were to prepare them, as reported in Study II. The parents felt alone, especially in relation to pressure garments and wound treatments, and some had to use force and to go to war with their child in order to complete the treatment (Study IV). The Finnish-Swedish nursing theorist Katie Eriksson (1943-2019) described three different ways of suffering within nursing; suffering associated with illness, care and life (Eriksson, 1995). Within the term ‘suffering in care’, Eriksson writes that caregivers must take care of the patient’s dignity and prevent any sort of transgression; even so, both patient and caregiver can feel that their boundaries are transgressed in the absence of natural care (Eriksson, 1995). When a parent is given the role of a caregiver carrying out prescribed treatment at home, such as burn wound treatment, the natural parent-child relationship is altered. The parents want to do the best they can for their child, but they are challenged because this means to give the child the right treatment even when it is painful. The child does not want to participate and resists, which makes it hard for the parent. Referring to Eriksson’s theory of suffering, one may argue that some parents experience suffering in care when having to enforce treatment on their child. The natural care is challenged and both child and parent have a negative experience. For these parents, it might be better if the medical procedures could be managed by the healthcare professionals at their local hospital or by their general practitioner. The essential thing for the parents is that they get help from staff members so that they acquire the necessary skills needed after discharge.

6.7 Methodological considerations

The methodological approach in all studies was phenomenological hermeneutics as part of the development phase of the MRC framework for complex interventions. The MRC framework guided the research process. To obtain enough knowledge about the field, different research methods were used; integrative review, focus group interviews and individual semi-structured interviews. In this thesis, the only phase explored of the MRC framework was the development phase, leaving out the remaining three phases of the framework: feasibility, evaluation and implementation. Thus, being unable to complete all phases and present an intervention. On 30 September 2021 an update version of the framework was published, stressing that “A research programme might begin at any phase, depending on the key uncertainties about the intervention in question. “Repeating phases is preferable to automatic progression if uncertainties remain unresolved” (Skivington et al., 2021, pp. 3-4). As found in Study I, knowledge about the support needs of these parents is sparse and uncertainties pertain to parents’ needs for support. The statement of the 2021 version (Skivington et al., 2021) supports the earlier version of the framework (Bleijenberg et al., 2018) which emphasized taking a more comprehensive development approach and thereby using more time on the development phase. This was done “to enhance the intervention design, increase value and minimize the risk of subjects being exposed to ineffective interventions” (Bleijenberg et al., 2018, p. 87). Therefore, the goal is not to complete the four phases of the framework, but instead to execute one phase thoroughly before continuing to the next, as it has been done in this thesis. This thesis unveils some parental needs for support when having a burn-injured child. It remains to be explored how the support for these parents can be implemented and evaluated.

For each study, it was discussed which analysis method would be most suitable to answer the research question. For an integrative review, the least developed part within the process is the data analysis, which is also the most difficult part filled with potential errors (Whittemore & Knafl, 2005). In order to prevent the analysis from being unstructured with the potential of many errors, which would weaken the integrative review, we used a qualitative design with a systematic analytical method, as recommended (Whittemore & Knafl, 2005). Where human experiences are explored, qualitative methods such as interviews "are the most adequate means of knowledge production" (Brinkmann & Kvale, 2005, p. 162). An inductive approach was therefore used, meaning that the object of research determines in this case the lived experiences of staff members and parents, and guided which research method to choose and use, in casu focus group interviews and individual semi-structured interviews.

The Danish professor of psychiatry Svend Brinkmann argues that a manuscript for a qualitative journal or a thesis based on qualitative research should be judged based on three virtues: epistemic (the true), ethical (the good) and aesthetic (the beautiful) (Brinkmann, 2014). Therefore, the aspects of 'sampling', 'data collection', 'data analysis' and 'results' from all four studies of this thesis will be discussed in the light of these virtues.

6.7.1 Epistemic virtue – the true

Qualitative analysis "can be true in a pragmatic everyday sense when it is honest; displays the researcher's theoretical perspective; situates the participants, their statements and the episodes treated; give examples that support the conclusions made; gives a coherent review of what is connected; and is able to tell a story that resonates with the reader" (own translation) (Brinkmann, 2014, p. 197).

Regarding the sampling of the material and data collection, detailed descriptions were made in the four studies. This was done to achieve transparency in order for the reader to follow each step. For the literature review in Study I, the search was systematically conducted by three of the authors, using both PICO, multiple databases and a flow-diagram. In addition, the trustworthiness of the literature search was strengthened by being controlled by an experienced librarian from the medical faculty. The interview participants from Study II, III and IV had received written documentation informing that they could access which information was recorded about them (Appendix I and III); however, none asked to read the transcribed interviews, and they were not contacted and encouraged to read and comment on the transcripts. According to Brinkmann, it would have heightened the ethical and scientific objectivity to let "the objects object to what we as researchers do to them and say about them" (Brinkmann & Kvale, 2005, p. 170). A strength, however, was that I was present at all focus group interviews, conducted all individual semi-structured interviews and transcribed all material (except for two interviews). This prolonged contact with the data material gave me an in-depth knowledge about the material. A guiding principle when sampling qualitative research is to "establish an adequate and information-rich sample providing coherent stories […] the sample should be sufficiently large and varied to elucidate our aim" (Malterud, 2012b, pp. 801-802). In Study II, III and IV, a sufficient sample size was achieved as the participants provided rich and diverse descriptions of the phenomenon: support for parents of burn-injured children. In Study III and IV, there were also variations in the parents' perspectives (for instance mother/father experience, present/not present when the accident happened, short/longer stay at the burn centre, treatment leaving scars/not leaving scars). It is a strength that both mothers and fathers were included as they had different experiences, for instance of their parental role if they were hospitalised or at home. All participants' experiences contributed to a new understanding of the phenomenon, which is a goal within qualitative research (Malterud, 2012b). The expressed parental needs for support in Study II, III and IV are all collected from the same location, the same burn centre, which is a shortcoming as the participants might express needs linked to a special culture at that burn centre. However, during the analysis process, I focused on understanding what the participants said about support needs of parents rather than on statements about the burn centre itself. This was done to be able to explain the essence of the meaning of the material, parents' essential support needs. This is what Ricoeur calls "the dialectic of explanation and understanding" (Ricoeur, 1976, p. 71), "from what it says, to what it talks about" (Ricoeur, 1976, p. 88).

During the creation of this thesis, I also made use of user involvement mainly in the beginning (first two years). The four parents' views and comments were highly important when developing the interview guide and preparing me for the interviews. After the first two years, contact became more sporadic, and when in contact we mostly discussed the development of the project and how their burn-injured child was doing. All contact with the parents gave me invaluable insight into the life of a parent whose child had had a burn injury.

For the data analysis, the researchers' theoretical perspectives were clarified, and they essentially used the same phenomenological hermeneutic approach. By following each step of the analysis method in a systematic way, the researchers showed that they were true and honest to the data material. By providing a naïve reading in Study III and IV and by strengthening the results sections in all four studies with quotations, we have tried to present the research to 'tell a story' that was easy to follow for the reader, using the participants' words. Testifying to the authenticity of the findings, variations in the material were displayed, for example the differences between parental couples and divorced parents' needs, as reported in Study III. It strengthens the analytical process that many researchers were involved in reading the data material and conducting the analysis.

6.7.2 Ethical virtue – the good

Good ethical research in qualitative interview research is about sensitivity related to confidence and consent, respecting participants (not trying to push or transform them in any particular direction), being loyal to participants' life and experiences and being aware of the power imbedded in an interview (Brinkmann, 2014). The researcher also has to consider the cultural context of the research (Brinkmann & Kvale, 2005).

During each interview, referring to the data collection, I was well aware of the ethical challenges that are imbedded in conducting interviews, such as asymmetrical power dynamics (Haahr et al., 2014) where I as a researcher had an certain responsibility to take care of each parent. When ethically challenged in an interview, I used my nursing backgound to handle the situation. Immediately after the interview was done, I had post-councelling with one of my supervisors, in person or by telephone, to discuss the situation and be guided on what to do. According to Brinkmann who cites Løgstrup, there is an ethical demand for the researcher to take care of the participant's life that lies in his/her power, because there is an interdependency between them (Brinkmann, 2007). Each participant was respected. If a participant became emotional, he or she was asked if they wanted to stop the interview and if they had someone they could talk to after the interview ended. All participants wanted to continue and all said that they had someone, e.g. a family member, a psychologist or their general practitioner. My personal knowledge about the field of burn injures contributed to a better understanding of the parents' experiences and helped me ask follow-up questions at the right time.

The Ricoeur-inspired method (Dreyer & Pedersen, 2009) used in the data analysis helped me stay loyal to what the participants had said as their words were central and brought forward in each step of the analysis. All four studies in this thesis add to the knowledge about the needs of parents of burn-injured children to be used when developing a support intervention for these parents. The findings can also enlighten burn staff members and help them target their support. Brinkmann argued to think about macro-ethical questions such as whom the research is for and who will be the winners and losers when the results are published (Brinkmann, 2014; Brinkmann & Kvale, 2005). The goal is here to help the parents so that they can support their child in the best possible way, both during hospitalisation and after discharge. This thesis provides knowledge about parental needs for support throughout the burn trajectory; from arrival at a burn centre, during the acute phase of hospitalisation up to the time of discharge, but also during the time at home after being discharged.

6.7.3 Aesthetic virtue – the beautiful

The aesthetic virtue is an important tool within qualitative research because it makes the research more accurate, moving, objective and stimulates the fantasy without overshadowing the researcher's message (Brinkmann, 2014). It also helps to reproduce a person’s lived experience as accurate and with as many nuances as possible (Brinkmann, 2014). In other words, it is a virtue that helps to move the reader that little extra inch, or mile.

Using the Ricoeur-inspired method, I have tried to write in a way that should move the reader. In Study III and IV, I give an example of the naïve reading; a short narration representing the first encounter with the material as a whole. If a naïve reading had been published in all four studies, this could have given this thesis what Brinkmann calls ‘that little extra thing’.

In all studies, the analysis text is true and loyal to what the participants have said, and their words are brought forward, helped by the analysis method used. In the result sections of the four studies and in this thesis, I have used a more ordinary language instead of the scientific language mostly used in extant literature. This was done to communicate the meaning of the text to the reader and move him/her. Or in Ricoeur’s words, I wanted “to insure the identity of the meaning from the beginning to the end of an argumentation” (Ricoeur, 1973, p. 104).

For the name of the themes, I worked on making them phenomenological in a way so that the reader by reading the theme name got a sense and understanding of what was to come in the following text, thereby providing the reader with something extra and a reference to a new understanding. The process of developing the right theme name is displayed Table 6 in the section ‘A Ricoeur-inspired interpretation method by Dreyer and Pedersen’. By using ordinary language in the result sections, combined with a scientific language in the rest of the articles and in this thesis, I try to give that little extra thing to the reader. Or as Ricoeur puts it, by combining the two it “has the extraordinary power of redescribing reality” (Ricoeur, 1973, p. 110).

7. Conclusion

This thesis highlights that parental needs for support must be catered for to come through it all as a family; the accidental burn injury, the stay at the hospital and the period at home after discharge. The burn accident disturbs and affects the life of the parents and the family, and support is needed to restore the parental role and the entity of the family. The right positive support can strengthen the parents and the family, whereas wrong or missing support can aggravate the damage caused by the burn accident. Through four separate studies, this thesis has identified six essential parental needs for support that should be addressed to support parents of burn-injured children, illustrated in a heart figure (Figure 3, on page 45).

The parents have *a need to be treated as a whole family*; child, mother and father. Fathers in particular wish to be recognised as a parental figure who are just as important as are mothers. They need to be welcomed and approached as a family, e.g. to be offered to sleep at the burn facility together and to receive the same information.

Parents of accidental burn-injured children have *a need that feelings of guilt, shame and blame are addressed and dealt with*. This was a predominant finding, highlighting that this need is present and difficult to accommodate. Even though these feelings may decrease over time, some parents remain affected in the longer run. Guilt, shame and blame often co-occur, but they are experienced differently by the parents. This study contributes with a new understanding, namely that guilt, shame and blame are three different feelings and therefore must be approach differently for the parents to be able to support their child.

Parents have *a need to receive information to get a sense of control over the situation they are in*. This need for getting information was proportional to how upset they were and how calm they became. When receiving information, the parents' lived time should be considered, approaching them at the right time.

Being met with trust by staff members is also revealed as an important need of this parental group. Parents are dependent on staff members who through their professional role have the power to make a tustful relation, by being open and professional, sensing the parents' suffering while protecting their integrity.

A particularly important, however often overseen, parental need is the parents' *need for time to see to their own fundamental personal needs*, for instance to eat, drink, sleep, process emotions, maintain personal hygiene, etc. When hospitalised with a burn-injured child, parents focus on their child's needs, thus forgetting or putting their own needs aside. Getting some breaks during the daily routines while hospitalised is essential for them to cater for their own fundamental needs and prevent burnout upon being discharged when having to assume sole responsibility for their child's care.

The last of the six needs identified in this thesis is a parental *need to obtain the right training prior to discharge*. Parents need to obtain the right skills to perform their child's psychological and physical aftercare with success.

7.1 Implications for practice

In order to influence current practice, staff members in burn facilities should try to implement initiatives to meet parents' support needs.

Staff members should treat parents as a whole family throughout the burn trajectory. This implies, among others, arranging for both parents to stay together with their child when possible, especially in the acute phase immediately after arrival at a burn facility and considering implementing the theory of family-centred care in their way of caring. Being treated as a whole family is also necessary after discharge, where staff members should consider how the whole family handles life at home.

Staff members should aid parents in processing their post-burn emotions of guilt, shame and blame. The feeling(s) affecting the parent should be discovered, and the right approach should be adopted and proper support measures should be implemented. Guilt feelings related to accidental burn injuries should be addressed and spoken about, and staff members should help parents process these feelings and thereby ease or help eradicate parental feelings of guilt. Burn staff should start addressing feelings of guilt immediately upon parents' arrival at the burn facility. Blame and self-blame should be addressed directly, too. Feelings of shame are more difficult to treat as the staff members have to detect these often-hidden feeling.

Receiving information is crucial for the parents to obtain some control in the situation they are in, and when giving information, staff members should be aware of the parents' lived time and that they are in a crisis. Staff members should also have the time to deliver the information and check how much information parents understood, for instance by asking them to repeat what they have just heard. If staff members use a family-centred care approach, they should be aware of the need for 'information sharing', focusing on delivering information in a useful and affirming way. Another question that staff members should ask themselves is in which form the information should be given: orally only or in writing? In addition to giving oral information, burn facilities should consider whether other kinds of information would be appropriate, for instance a website with information or a pamphlet.

Parents are affected by the way they are met by staff members, for which reason staff members play a unique role in establishing a trustful relationship with the parents during hospitalisation and after discharge. Staff members should look at parents with the 'heart's eye'. This entails making parents feel recognised and valued for whom they are. Staff members should also use 'person-oriented professionalism'. After discharge, contact with key staff members who treated the family is crucial. Burn facilities should consider to arrange that a key staff member could call the family at home one to two weeks after discharge to hear how the family is doing and to answer questions that may have arisen after the family returned home. In this way, parents could feel seen with the 'heart's eye' also after they have left the burn facility.

During hospitalisation, parents need time to see to their own fundamental needs in order for them to provide support for their child. Staff members should help organise the daily activities by remembering and being aware of fundamental human needs and giving parents time to cater to these needs. This could be done for instance by having a fixed time for the parents to be alone or that staff members offer to look after the child for a short period of time.

Prior to discharge, the parents need to be educated and trained to execute the prescribed treatment with success. Before parents leave the hospital, staff members have to educate and train parents so that they obtain the necessary skills needed after discharge. Being aware of learnings styles and letting parents perform the tasks and actions themselves, to allow them to better remember the necessary procedures, could be a way to improve parental education and training.

Staff members in burn facilities could build a care programme inspired by the heart figure (Figure 3) and the family-centred care approach in order to meet parents' needs for support in daily practice. Included in such a care programme could be a checklist, information material, tutorial videos, a website, etc.

7.2 Future perspectives

The findings of this thesis lay the groundwork for some suggestions for how this work can strengthen practice within the field and inspire further research.

The six identified parental needs displayed in the heart figure (Figure 3) could be the foundation for further research of parental support. The key components in the figure are 'a whole family', 'guilt, shame and blame', 'information', 'staff members trust', 'personal fundamental needs' and 'skills'. These six needs could become core elements of a future care programme. Further research could also address other aspects of perceived needs for supports that could be important for a care programme or a 'heart' intervention but were not investigated in this thesis. These perspectives could include those of fathers, in particular, but also those of siblings or parents who deliberately burned their child (paediatric burn cases of child abuse), as none of these aspects were explored in this thesis.

As this thesis is part of the development phase (the first out of four phases) of the MRC framework for complex interventions, it is possible to continue the work where this thesis ends. A support intervention could be designed using the six identified parental needs for support as key components and test the intervention for feasibility (second phase of the MRC framework). Creating the support intervention ought to happen in close collaboration with stakeholders, i.e. parents, staff members, etc. It would benefit the process to identify barriers and facilitators among parents and staff members that might affect the proposed intervention. Before testing an intervention for feasibility, a pilot-tested could be done in an experimental study before testing on a bigger population. A suggestion could be to do a Q-sort study, which is an innovative research method that combines both qualitative and quantitative research techniques (Akhtar-Danesh et al., 2008) to “deliver evidence-based practice in response to patients’ needs” (Simons, 2013). In the further evaluation, both qualitative and quantitative methods are needed.

8. References

Abma, T., Banks, S., Cook, T., Dias, S., Madsen, W., Springett, J., & Wright, M. T. (2018). *Participatory Research for Health and Social Well-Being*. Cham: Springer International Publishing AG.

Abramson, M. (1975). Group treatment of families of burn-injured patients. *Social Casework*, *56*(4), 235-241.

Akhtar-Danesh, N., Baumann, A., & Cordingley, L. (2008). Q-Methodology in Nursing Research: A Promising Method for the Study of Subjectivity. *West J Nurs Res*, *30*(6), 759-773. https://doi.org/10.1177/0193945907312979

Alexander, S. J. (2010). 'As long as it helps somebody': why vulnerable people participate in research. *International journal of palliative nursing*, *16*(4), 173-178. https://doi.org/10.12968/ijpn.2010.16.4.47783

Alsop-Shields, L., & Mohay, H. (2001). John Bowlby and James Robertson: theorists, scientists and crusaders for improvements in the care of children in hospital. *J Adv Nurs*, *35*(1), 50-58. https://doi.org/10.1046/j.1365-2648.2001.01821.x

Andrews, N., Jones, L. L., Moiemen, N., Calvert, M., Kinghorn, P., Litchfield, I., Bishop, J., Deeks, J. J., & Mathers, J. (2018). Below the surface: Parents' views on the factors that influence treatment adherence in paediatric burn scar management — A qualitative study. *Burns*, *44*(3), 626-635. https://doi.org/10.1016/j.burns.2017.09.003

Arabiat, D., Whitehead, L., Foster, M., Shields, L., & Harris, L. (2018). Parents' experiences of Family Centred Care practices. *Journal of Pediatric Nursing*, *42*, 39-44. https://doi.org/10.1016/j.pedn.2018.06.012

Armstrong-James, L., Cadogan, J., Williamson, H., Rumsey, N., & Harcourt, D. (2019). Using Photo-Elicitation to Explore Families' Experiences of Burn Camp. *J Fam Nurs*, *25*(1), 81-108. https://doi.org/10.1177/1074840718817630

Bakker, A., Maertens, K. J., Van Son, M. J., & Van Loey, N. E. (2013a). Psychological consequences of pediatric burns from a child and family perspective: a review of the empirical literature. *Clin Psychol Rev*, *33*(3), 361-371. https://doi.org/10.1016/j.cpr.2012.12.006

Bakker, A., van der Heijden, P. G. M., van Son, M. J. M., van de Schoot, R., Vandermeulen, E., Helsen, A., & Van Loey, N. E. E. (2014). The relationship between behavioural problems in preschool children and parental distress after a paediatric burn event. *Eur Child Adolesc Psychiatry*, *23*(9), 813-822. https://doi.org/10.1007/s00787-014-0518-y

Bakker, A., Van Der Heijden, P. G. M., Van Son, M. J. M., & Van Loey, N. E. E. (2013b). Course of Traumatic Stress Reactions in Couples After a Burn Event to Their Young Child. *Health Psychology*, *32*(10), 1076-1083. https://doi.org/10.1037/a0033983

Bakker, A., Van Loey, N. E., Van der Heijden, P. G., & Van Son, M. J. (2012). Acute stress reactions in couples after a burn event to their young child. *J Pediatr Psychol*, *37*(10), 1127-1135. https://doi.org/10.1093/jpepsy/jss083

Bakker, A., Van Loey, N. E., Van Son, M. J., & Van der Heijden, P. G. (2010). Brief report: mothers' long-term posttraumatic stress symptoms following a burn event of their child. *J Pediatr Psychol*, *35*(6), 656-661. https://doi.org/10.1093/jpepsy/jsp090

Barnett, B. S., Mulenga, M., Kiser, M. M., & Charles, A. G. (2017). Qualitative analysis of a psychological supportive counseling group for burn survivors and families in Malawi. *Burns*, *43*(3), 602-607. https://doi.org/10.1016/j.burns.2016.09.027

Bayuo, J., & Wong, F. K. Y. (2021). Issues and concerns of family members of burn patients: A scoping review. *Burns*, *47*(3), 503-524. https://doi.org/10.1016/j.burns.2020.04.023

Bennett, C. V., Maguire, S., Nuttall, D., Lindberg, D. M., Moulton, S., Bajaj, L., Kemp, A. M., & Mullen, S. (2019). First aid for children's burns in the US and UK: An urgent call to establish and promote international standards. *Burns*, *45*(2), 440-449. https://doi.org/10.1016/j.burns.2018.09.003

Bleijenberg, N., de Man-van Ginkel, J. M., Trappenburg, J. C. A., Ettema, R. G. A., Sino, C. G., Heim, N., Hafsteindóttir, T. B., Richards, D. A., & Schuurmans, M. J. (2018). Increasing value and reducing waste by optimizing the development of complex interventions: Enriching the development phase of the Medical Research Council (MRC) Framework. *Int J Nurs Stud*, *79*, 86-93. https://doi.org/10.1016/j.ijnurstu.2017.12.001

Bowden, M. L., & Feller, I. (1973). Family reaction to a severe burn. *Am J Nurs Sci*, *73*(2), 317-319. https://doi.org/10.1097/00000446-197302000-00050

Brady, K. J. S., Grant, G. G., Stoddard, F. J., Meyer, W. J., Romanowski, K. S., Chang, P. H., Painting, L. E., Fowler, L. A., Nelson, J. K., Rivas, P., Epperson, K., Sheridan, R. L., Murphy, M., O'Donnell, E. H., Ceranoglu, T. A., Sheldrick, R. C., Ni, P., Slavin, M. D., Warner, P., Palmieri, T. L., Schneider, J. C., Kazis, L. E., & Ryan, C. M. (2020). Measuring the Impact of Burn Injury on the Parent-Reported Health Outcomes of Children 1 to 5 Years: A Conceptual Framework for Development of the Preschool Life Impact Burn Recovery Evaluation Profile CAT. *J Burn Care Res*, *41*(1), 84-94. https://doi.org/10.1093/jbcr/irz110

Brinkmann, S. (2007). The Good Qualitative Researcher. *Qualitative research in psychology*, *4*(1-2), 127-144. https://doi.org/10.1080/14780880701473516

Brinkmann, S. (2014). *Det kvalitative interview [The qualitative interview]* (1. udgave. ed.). Hans Reitzel.

Brinkmann, S., & Kvale, S. (2005). Confronting the ethics of qualitative research. *Journal of constructivist psychology*, *18*(2), 157-181. https://doi.org/10.1080/10720530590914789

Brodland, G. A., & Andreasen, N. J. C. (1974). Adjustment problems of the family of the burn patient. *Social Casework*, *55*, 13-18.

Brown, E. A., De Young, A., Kimble, R., & Kenardy, J. (2018). Review of a Parent's Influence on Pediatric Procedural Distress and Recovery. *Clinical Child and Family Psychology Review*, *21*, 224-245. https://doi.org/10.1007/s10567-017-0252-3

Brown, E. A., De Young, A., Kimble, R., & Kenardy, J. (2019a). Impact of Parental Acute Psychological Distress on Young Child Pain-Related Behavior Through Differences in Parenting Behavior During Pediatric Burn Wound Care. *J Clin Psychol Med Settings*, *26*(4), 516-529. https://doi.org/10.1007/s10880-018-9596-1

Brown, E. A., De Young, A., Kimble, R., & Kenardy, J. (2019b). The role of parental acute psychological distress in paediatric burn re-epithelialization. *Br J Health Psychol*, *24*(4), 876-895. https://doi.org/10.1111/bjhp.12384

Brown, E. A., Egberts, M., Wardhani, R., De Young, A., Kimble, R., Griffin, B., Storey, K., & Kenardy, J. (2020). Parent and Clinician Communication During Paediatric Burn Wound Care: A Qualitative Study. *J Pediatr Nurs*, *55*, 147-154. https://doi.org/10.1016/j.pedn.2020.08.003

Brudvik, C., Hoem, E., Luggenes, B., & Vindenes, H. (2011). Brannskader hos barn i Bergen [Burn injuries in children in Bergen]. *Tidsskrift for den Norske Lægeforening [The Journal of the Norwegian Medical Association]*, *131*(1), 20-23. https://doi.org/10.4045/tidsskr.09.0641

Brusselaers, N., Monstrey, S., Vogelaers, D., Hoste, E., & Blot, S. (2010). Severe burn injury in Europe: a systematic review of the incidence, etiology, morbidity, and mortality. *Critical Care*, *14*(5), R188. https://doi.org/10.1186/cc9300

Burr, G. (1996). Unfinished business: interviewing family members of critically ill patients. *Nurs Inq*, *3*(3), 172-177. https://doi.org/10.1111/j.1440-1800.1996.tb00033.x

Bäckström, J., Willebrand, P. M., & Öster, C. (2019). Identifying the Needs of Family Members in Burn Care-Nurses' Different Approaches. *J Burn Care Res*, *40*(3), 336-340. https://doi.org/10.1093/jbcr/irz018

Cahners, S. S. (1979). Group meetings benefit families of burned children. *Scand J Plast Reconstr Surg*, *13*(1), 169-171. https://doi.org/10.3109/02844317909013049

Cahners, S. S. (1988). Coping as the parent of a burned child. In N. R. Bernstein, A. J. Breslau, & J. A. Graham (Eds.), *Coping Strategies for Burn Survivors and Their Families* (pp. 123-125). Praeger.

Cederström, C. (2019). *State of Nordic fathers*. Nordic Council of Ministers. https://doi.org/10.6027/NO2019-044

Celis, M. M., Suman, O. E., Huang, T. T., Yen, P., & Herndon, D. N. (2003). Effect of a supervised exercise and physiotherapy program on surgical interventions in children with thermal injury. *J Burn Care Rehabil*, *24*(1), 57-61; discussion 56. https://doi.org/10.1097/01.BCR.0000045662.98101.6D

Cella, D. F., Perry, S. W., Poag, M. E., Amand, R., & Goodwin, C. (1988). Depression and stress responses in parents of burned children. *J Pediatr Psychol*, *13*(1), 87-99. https://doi.org/10.1093/jpepsy/13.1.87

Cook. (1982). Psychosocial Assessments of Families on a Pediatric Burn Center. *JBCR*, *3*(2), 105-108.

Coy, K., Brock, P., Pomeroy, S., Cadogan, J., & Beckett, K. (2019). A Road Less Travelled: using Experience Based Co-Design to map children’s and families’ emotional journey following burn injury and identify service improvements. *Burns*, *45*(8), 1848-1855. https://doi.org/10.1016/j.burns.2019.07.024

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*, *337*(7676), 979-983. https://doi.org/10.1136/bmj.a1655

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2019). *Developing and evaluating complex interventions: Following considerable development in the field since 2006, MRC and NIHR have jointly commissioned an update of this guidance to be published in 2019*. https://mrc.ukri.org/documents/pdf/complex-interventions-guidance/

De Sousa, A. (2010). Psychological aspects of paediatric burns (a clinical review). *Ann Burns Fire Disasters*, *23*(3), 155-159.

De Young, A. C., Hendrikz, J., Kenardy, J. A., Cobham, V. E., & Kimble, R. M. (2014). Prospective evaluation of parent distress following pediatric burns and identification of risk factors for young child and parent posttraumatic stress disorder. *J Child Adolesc Psychopharmacol*, *24*(1), 9-17. https://doi.org/10.1089/cap.2013.0066

Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2008). Risk to Researchers in Qualitative Research on Sensitive Topics: Issues and Strategies. *Qualitative Health Research*, *18*(1), 133-144. https://doi.org/10.1177/1049732307309007

Doctor, M. E. (1994). Parent participation during painful wound care procedures. *Journal of burn care & rehabilitation*, *15*(3), 288-292. https://doi.org/10.1097/00004630-199405000-00016

Dorn, T., Yzermans, J. C., Spreeuwenberg, P. M., & van der Zee, J. (2007). Physical and mental health problems in parents of adolescents with burns — a controlled, longitudinal study. *J Psychosom Res*, *63*(4), 381-389. https://doi.org/10.1016/j.jpsychores.2007.02.005

Dreyer, P. (2019). Den kritiske fortolkning og diskussion med afsæt i Paul Ricoeurs filosofi [The critical interpretation and discussion based on Paul Ricoeur's philosophy]. In S. Rosberg, H. Dahlberg, S. Ellingsen, & B. Martinsen (Eds.), *Fenomenologi i praktiken : fenomenologisk forskning i ett skandinaviskt perspektiv [Phenomenology in practice: phenomenological research in a Scandinavian perspective]* (Första upplagan ed., pp. 88-114). Liber.

Dreyer, P. S., & Pedersen, B. D. (2009). Distanciation in Ricoeur's theory of interpretation: narrations in a study of life experiences of living with chronic illness and home mechanical ventilation. *Nurs Inq*, *16*(1), 64-73. https://doi.org/10.1111/j.1440-1800.2009.00433.x

Egberts, M., van de Schoot, R., Geenen, R., & Van Loey, N. (2017). Parents' Posttraumatic Stress After Burns in Their School-Aged Child: A Prospective Study. *Health Psychol.*, *36*(5), 419-428. https://doi.org/10.1037/hea0000448

Egberts, M. R., de Jong, A. E. E., Hofland, H. W. C., Geenen, R., & Van Loey, N. E. E. (2018a). Parental presence or absence during paediatric burn wound care procedures. *Burns*, *44*(4), 850-860. https://doi.org/10.1016/j.burns.2017.11.016

Egberts, M. R., Engelhard, I. M., de Jong, A. E. E., Hofland, H. W. C., Geenen, R., & Van Loey, N. E. E. (2019). Parents' memories and appraisals after paediatric burn injury: a qualitative study. *Eur J Psychotraumatol*, *10*(1), 1615346-1615346. https://doi.org/10.1080/20008198.2019.1615346

Egberts, M. R., Engelhard, I. M., Schoot, R. v. d., Bakker, A., Geenen, R., van der Heijden, P. G. M., & Van Loey, N. E. E. (2020). Mothers' emotions after pediatric burn injury: Longitudinal associations with posttraumatic stress and depressive symptoms 18 months postburn. *J Affect Disord*, *263*, 463-471. https://doi.org/10.1016/j.jad.2019.11.140

Egberts, M. R., van de Schoot, R., Geenen, R., & Van Loey, N. E. E. (2018b). Mother, father and child traumatic stress reactions after paediatric burn: Within-family co-occurrence and parent-child discrepancies in appraisals of child stress. *Burns*, *44*(4), 861-869. https://doi.org/10.1016/j.burns.2018.01.003

El Hamaoui, Y., Yaalaoui, S., Chihabeddine, K., Boukind, E., & Moussaoui, D. (2006). Depression in mothers of burned children. *Archives of Women's Mental Health*, *9*(3), 117-119. https://doi.org/10.1007/s00737-006-0124-1

Enns, J., Gawaziuk, J. P., Khan, S., Chateau, D., Bolton, J. M., Sareen, J., Stone, J., Doupe, M., & Logsetty, S. (2016). Mental and Physical Health Outcomes in Parents of Children with Burn Injuries as Compared with Matched Controls. *J Burn Care Res*, *37*(1), e18-e26. https://doi.org/10.1097/BCR.0000000000000309

Eriksson, K. (1995). Lidelsen i sygeplejen [The suffering within nursing]. In K. Eriksson (Ed.), *Det lidende menneske [The suffering human being]* (1. udgave, 1. oplag. ed., pp. 76-93). Munksgaard Danmark.

European Burns Association. (2017). *European practice guidelines for burn care – Minimum level of burn care provision in europe* (EBA - Guidelines, Version 4). https://www.euroburn.org/wp-content/uploads/EBA-Guidelines-Version-4-2017.pdf

Feiring, M., Heiaas, I., & Solvang, P. K. (2017). Fra deltakelse til brukermedvirkning i helseforskningen [From participation to user involvement in health research]. In M. Feiring, T. I. Juritzen, I. R. Knutsen, & K. Larsen (Eds.), *Kritiske perspektiver i helsefagene: Utdanning, yrkespraksis og forskning [Critical perspectives in the health sciences: Education, professional practice and research]* (pp. 281-308). Cappelen Damm Akademisk.

Foster, M., Whitehead, L., & Maybee, P. (2016). The Parents', Hospitalized Child's, and Health Care Providers' Perceptions and Experiences of Family-Centered Care Within a Pediatric Critical Care Setting: A Synthesis of Quantitative Research. *Journal of Family Nursing*, *22*(1), 6-73. https://doi.org/10.1177/1074840715618193

Fowler, J. (1978). The role of parent groups in the rehabilitation of the burned child. *Burns*, *5*, 86-88. https://doi.org/10.1016/0305-4179(78)90047-5

Francis, A. L. (1990). Symposium on burns. Support for parents of burned children. *Nursing (Lond)*, *4*(7), 7-12.

Frenkel, L. (2008). A support group for parents of burned children: a South African children's hospital burns unit. *Burns*, *34*(4), 565-569. https://doi.org/10.1016/j.burns.2007.09.016

Geanellos, R. (2000). Exploring Ricoeur's hermeneutic theory of interpretation as a method of analysing research texts. *Nursing Inquiry*, *7*(2), 112-119. https://doi.org/10.1046/j.1440-1800.2000.00062.x

Greenhalgh, D. G. (2019). Management of Burns. *N Engl J Med*, *380*(24), 2349-2359. https://doi.org/10.1056/nejmra1807442

Griffiths, C. (2017). How are parents affected when their child has an appearance-altering injury? *Journal of Aesthetic Nursing*, *5*(2), 79-81. https://doi.org/https://doi.org/10.12968/joan.2016.5.2.79

Guest, E., Griffiths, C., & Harcourt, D. (2018). A qualitative exploration of psychosocial specialists' experiences of providing support in UK burn care services. *Scars Burn Heal*, *4*, 2059513118764881-2059513118764881. https://doi.org/10.1177/2059513118764881

Guttormsen, A. B., & Brekke, R. L. (2021). Akuttbehandling av brannskader [Acute treatment of burns]. Retrieved November 2021, from https://nkt-traume.no/2021/09/akuttbehandling-av-brannskader/

Halkier, B. (2012). *Fokus grupper [Focus groups]* (2 ed.). Forlaget Samfundslitteratur.

Harrison, T. M. (2010). Family-Centered Pediatric Nursing Care: State of the Science. *Journal of Pediatric Nursing*, *25*(5), 335-343. https://doi.org/10.1016/j.pedn.2009.01.006

Haugen, T. B. (2013). User participation in research--real influence? *Tidsskrift for den Norske Laegeforening: tidsskrift for praktisk medicin [The Journal of the Norwegian Medical Association]*, *133*(17), 1791. https://doi.org/10.4045/tidsskr.13.0802

Hawkins, L., Centifanti, L. C. M., Holman, N., & Taylor, P. (2019). Parental Adjustment following Pediatric Burn Injury: The Role of Guilt, Shame, and Self-Compassion. *Journal of Pediatric Psychology*, *44*(2), 229. https://doi.org/10.1093/jpepsy/jsy079

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2018). Parent-perceived isolation and barriers to psychosocial support: a qualitative study to investigate how peer support might help parents of burn-injured children. *Scars Burn Heal*, *4*, 1-12. https://doi.org/10.1177/2059513118763801

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2019). Supporting children with burns: Developing a UK parent-focused peer-informed website to support families of burn-injured children. *Patient Educ Couns*, *102*(9), 1730-1735. https://doi.org/10.1016/j.pec.2019.04.003

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2020). www.SupportingChildrenWithBurns.co.uk: A website developed with parents and professionals for the psychosocial support of parents of burn-injured children. *Burns*, *46*(5), 1232-1233. https://doi.org/10.1016/j.burns.2020.01.013

Helse Bergen - Haukeland universitetssjukehus. (2021, 28.09.2021). *Nasjonal behandlingsteneste for avansert brannskadebehandling [National treatment service for advanced burn treatment]*. Retrieved November 2021 from https://helse-bergen.no/avdelinger/kirurgisk-klinikk/plastikkirurgi-og-brannskade/nasjonal-behandlingsteneste-for-avansert-brannskadebehandling

Helse- og omsorgsdepartementet. Forskrift om barns opphold i helseinstitusjon av 1. desember 2000 nr. 1217 [Regulations on children's stay in a health institution by 1. december 2000, no. 1217], (2000). https://lovdata.no/dokument/SF/forskrift/2000-12-01-1217

Henderson, V. (1964). The nature of nursing. *The American journal of nursing*, *64*(8), 62-68. https://doi.org/10.1097/00000446-196408000-00029

Holden, M. R., Watson, M. C., & Clifford, M. J. (2020). Parents' perceptions of unintentional paediatric burn injuries — A qualitative study. *Burns*, *46*(5), 1179-1192. https://doi.org/10.1016/j.burns.2019.12.009

Horridge, G., Cohen, K., & Gaskell, S. (2010). BurnEd: Parental, psychological and social factors influencing a burn-injured child's return to education. *Burns*, *36*(5), 630-638. https://doi.org/10.1016/j.burns.2009.08.013

Haahr, A., Norlyk, A., & Hall, E. O. C. (2014). Ethical challenges embedded in qualitative research interviews with close relatives. *Nurs Ethics*, *21*(1), 6-15. https://doi.org/10.1177/0969733013486370

Illeris, K. (2006). David Kolbs teori om læringsstile [David Kolb's theory of learning styles]. In P. Andersen (Ed.), *Læringens og tænkningens stil : en antologi om stilteorier* (1. udg.. 1. opl. ed., pp. 88-102). Billesø & Baltzer.

Institute for patient- and family-centred care. (2021). *Core Concepts of Patient- and Family-Centered Care*. Retrieved November 2021 from https://www.ipfcc.org/about/pfcc.html

Jeschke, M. G., van Baar, M. E., Choudhry, M. A., Chung, K. K., Gibran, N. S., & Logsetty, S. (2020). Burn injury. *Nat Rev Dis Primers*, *6*(1), 11-11. https://doi.org/10.1038/s41572-020-0145-5

Kitzinger, J. (1995). Introducing Focus Groups. *British Medical Journal*, *311*(7000), 299-302. https://doi.org/10.1136/bmj.311.7000.299

Kornhaber, R., Childs, C., & Cleary, M. (2018). Experiences of guilt, shame and blame in those affected by burns: A qualitative systematic review. *Burns*, *44*(5), 1026-1039. https://doi.org/10.1016/j.burns.2017.11.012

Krueger, R. A., & Casey, M. A. (2015). *Focus groups : a practical guide for applied research* (5th ed. ed.). Sage.

Landolt, A. M., Grubenmann, A. S., & Meuli, A. M. (2002). Family Impact Greatest: Predictors of Quality of Life and Psychological Adjustment in Pediatric Burn Survivors. *The Journal of Trauma: Injury, Infection, and Critical Care*, *53*(6), 1146-1151. https://doi.org/10.1097/00005373-200212000-00019

Leeder, C. J. (1979). Families of burn victims receive help through regular group meetings. *Burns*, *5*, 89-91. https://doi.org/10.1016/0305-4179(78)90048-7

Lernevall, L. S. D., Fogh, K., Nielsen, C. B., Dam, W., & Dreyer, P. S. (2017). Lived experiences of life with a leg ulcer - a life in hell. *EWMA Journal*, *17*(1), 15-21.

Lernevall, L. S. T., Moi, A. L., Gjengedal, E., & Dreyer, P. (2019). Staff members' experience of providing parental support in a national burn centre. *Open Nursing Journal*, *13*, 211-219. https://doi.org/10.2174/1874434601913010211

Lieberman, A. F. (2004). Traumatic stress and quality of attachment: Reality and internalization in disorders of infant mental health. *Infant Mental Health Journal*, *25*(4), 336-351. https://doi.org/10.1002/imhj.20009

Lindholm, C. (2005). *Sår [Wounds]*. Gad.

Lindholm, C. (2012). *Sår [Wounds]* (3. utg. Ny og rev. tekst oversatt av Kari Marie Thorbjørnsen. ed.). Akribe.

Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, *18*(2), 145-153. https://doi.org/10.1111/j.1471-6712.2004.00258.x

Luce, J. C., Mix, J., Mathews, K., Goldstein, R., Niewczyk, P., DiVita, M. A., Gerrard, P., Sheridan, R. L., Ryan, C. M., Kowalske, K., Zafonte, R., & Schneider, J. C. (2015). Inpatient rehabilitation experience of children with burn injuries: a 10-yr review of the uniform data system for medical rehabilitation. *Am J Phys Med Rehabil*, *94*(6), 436-443. https://doi.org/10.1097/PHM.0000000000000195

Løgstrup, K. E. (2010). *Den etiske fordring [The Ethical Demand]* (4. udg. ed.). Klim.

Malle, B. F., Guglielmo, S., & Monroe, A. E. (2014). A Theory of Blame. *Psychological inquiry*, *25*(2), 147-186. https://doi.org/10.1080/1047840X.2014.877340

Malterud, K. (2012a). *Fokusgrupper som forskningsmetode for medisin og helsefag [Focus groups as a research method for medicine and health sciences]*. Universitetsforl.

Malterud, K. (2012b). Systematic text condensation: A strategy for qualitative analysis. *Scand J Public Health*, *40*(8), 795-805. https://doi.org/10.1177/1403494812465030

Mani, R. (2003). *Chronic Wound Management - The evidence for change*. The Parthenon Publishing Group.

Martinsen, K. (2006). Seeing with the heart's eye (L. E. Kjerland, Trans.). In K. Martinsen (Ed.), *Care and vulnerability* (pp. 71-121). Akribe.

Martinsen, K. (2012). *Løgstrup & sygeplejen [Løgstrup & nursing]*. Klim.

Mason, S. A. (1993). Young, scarred children and their mothers—a short-term investigation into the practical, psychological and social implications of thermal injury to the preschool child. Part I: implications for the mother. *Burns*, *19*(6), 495-500. https://doi.org/10.1016/0305-4179(93)90006-T

McGarry, S., Elliott, C., McDonald, A., Valentine, J., Wood, F., & Girdler, S. (2015). "This is not just a little accident": a qualitative understanding of paediatric burns from the perspective of parents. *Disabil Rehabil*, *37*(1), 41-50. https://doi.org/10.3109/09638288.2014.892640

McGarry, S., Girdler, S., McDonald, A., Valentine, J., Wood, F., & Elliott, C. (2013). Paediatric medical trauma: The impact on parents of burn survivors. *Burns*, *39*(6), 1114-1121. https://doi.org/10.1016/j.burns.2013.01.009

McHugh, M. L., Dimitroff, K., & Davis, N. D. (1979). Family support group in a burn unit. *Am J Nurs*, *79*(12), 2148-2150. https://doi.org/10.1097/00000446-197912000-00031

Medical Research Council. (2000). *A Framework for the Development and Evaluation of RCTs for Complex Interventions to Improve Health*. MRC London.

Mirastschijski, U., Sander, J. T., Weyand, B., & Rennekampff, H. O. (2013). Rehabilitation of burn patients: an underestimated socio-economic burden. *Burns*, *39*(2), 262-268. https://doi.org/10.1016/j.burns.2012.06.009

Moher D, Liberati A, Tetzlaff J, Altman DG, & The PRISMA Group. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med*, *6*(7), e1000097. https://doi.org/10.1371/journal.pmed1000097

Morley, J., Holman, N., & Murray, C. D. (2016). Dressing changes in a burns unit for children under the age of five: A qualitative study of mothers' experiences. *Burns*, *43*(4), 757-765. https://doi.org/10.1016/j.burns.2016.11.015

Morse, J. M. (1994). *Critical issues in qualitative research methods*. Sage.

National Health Service (NHS). (2021, 24 September 2021). *Treatment - Burns and scalds*. NHS, the UK National Health Service,. Retrieved November 2021 from https://www.nhs.uk/conditions/burns-and-scalds/treatment/

NFFB - Norsk Forening For Brannskadde [The Norwegian Society for Burn Victims]. (2021a). *Burn Camp Norway*. https://nffb.no/. Retrieved November 2021 from https://nffb.no/burn-camp/

NFFB - Norsk Forening For Brannskadde [The Norwegian Society for Burn Victims]. (2021b). *NFFB - Norsk Forening For Brannskadde [The Norwegian Society for Burn Victims], .* https://nffb.no/. Retrieved November 2021 from https://nffb.no/

Nightingale, F. (2004). Notes on nursing - Bemærkninger om sygepleje [Notes on Nursing: What it is and What it is Not]. In F. Nightingale (Ed.), *Notes on nursing - Bemærkninger om sygepleje - Hvad det er, og hvad det ikke er [Notes on Nursing: What it is and What it is Not]* (1. udgave, 4. oplag. ed., pp. 115-227). Munksgaard Danmark.

Nolan, M., Hanson, E., & Magnusson, L. (2011). User involvement in research and development in health and social welfare: Some key concepts and their application using a relational approach. In L. Rönnmark (Ed.), *Vetenskap för profession 18:2011 - Brukarens roll i välfärdsforskning och utvecklingsarbete* (Vol. 18). Högskolan i Borås - Vetenskap før profession.

Norsk Brannvernforening [The Norwegian Fire Protection Association]. (2021). *Førstehjelp ved brannskader [First aid for burns]*. Norsk Brannvernforening [The Norwegian Fire Protection Association]. Retrieved November 2021 from https://brannvernforeningen.no/gode-rad/forstehjelp-ved-brannskader/

Odar, C., Kirschman, K. J. B., Pelley, T. J., Butz, C., Besner, G. E., & Fabia, R. B. (2013). Prevalence and correlates of posttraumatic stress in parents of young children postburn. *Journal of burn care & research : official publication of the American Burn Association*, *34*(3), 299-306. https://doi.org/10.1097/BCR.0b013e31825ae15d

Ohm, E., Madsen, C., & Kari, A. (2019). *Skadebildet i Norge - Fordeling etter utvalgte temaområder. [Injuries in Norway – Distribution according to selected areas]*. Folkehelseinstituttet [Norwegian Institute of Public Health].

https://www.fhi.no/globalassets/dokumenterfiler/rapporter/2019/skadebildet-i-norge_rapport_2019.pdf

Onarheim, H., Brekke, R. L., & Guttormsen, A. B. (2016). Patients with burn injuries admitted to Norwegian hospitals - a population-based study. *Tidsskr Nor Laegeforen*, *136*(21), 1799-1802. https://doi.org/10.4045/tidsskr.16.0047 (Original publication: Brannskadede innlagt i norske sykehus - en populasjonsbasert studie.)

Oster, C., Hensing, I., Lojdstrom, T., Sjoberg, F., & Willebrand, M. (2014). Parents' perceptions of adaptation and family life after burn injuries in children. *J Pediatr Nurs*, *29*(6), 606-613. https://doi.org/10.1016/j.pedn.2014.06.010

Pan, R., Egberts, M. R., Nascimento, L. C., Rossi, L. A., Vandermeulen, E., Geenen, R., & Van Loey, N. E. (2014). Health-Related Quality of Life in adolescent survivors of burns: Agreement on self-reported and mothers' and fathers' perspectives. *Burns*, *41*(5), 1107-1113. https://doi.org/10.1016/j.burns.2014.12.011

Pardo, G. D., García, I. M., Marrero, F. D. R. M., & Cía, T. G. (2008). Psychological impact of burns on children treated in a severe burns unit. *Burns*, *34*(7), 986-993. https://doi.org/10.1016/j.burns.2008.01.016

Paterson, B. L. (2001). The Shifting Perspectives Model of Chronic Illness. *J Nurs Scholarsh*, *33*(1), 21-26. https://doi.org/10.1111/j.1547-5069.2001.00021.x

Phillips, C., Fussell, A., & Rumsey, N. (2007). Considerations for psychosocial support following burn injury—A family perspective. *Burns*, *33*(8), 986-994. https://doi.org/10.1016/j.burns.2007.01.010

Phillips, C., & Rumsey, N. (2008). Considerations for the provision of psychosocial services for families following paediatric burn injury--a quantitative study. *Burns*, *34*(1), 56-62. https://doi.org/10.1016/j.burns.2006.12.003

Polit, D. F., & Beck, C. T. (2017). *Nursing Research : generating and assessing evidence for nursing practice* (10th ed. ed.). Wolters Kluwer.

Ravindran, V., Rempel, G. R., & Ogilvie, L. (2013a). Embracing survival: a grounded theory study of parenting children who have sustained burns. *Burns*, *39*(4), 589-598. https://doi.org/10.1016/j.burns.2012.12.016

Ravindran, V., Rempel, G. R., & Ogilvie, L. (2013b). Parenting burn-injured children in India: A grounded theory study. *International Journal of Nursing Studies*, *50*(6), 786–796. https://doi.org/10.1016/j.ijnurstu.2012.06.011

Reagan, C. E. (1996). *Paul Ricoeur : his life and his work*. The University of Chicago Press.

REC. (2021). *REC Regional Committees for Medical and Health Research Ethics* Retrieved November 2021 from https://rekportalen.no/

Richards, D. A., Hallbergn, I. R., Borglin, G., Meyer, G., Köpke, S., Cullum, N. A., Dumville, J., Noyes, J., Chandler, J., Rycroft-Malone, J., Butron, C. R., Hannes, K., Buhse, S., Mühlhauser, I., & Etc. (2015). *Complex Interventions in Health: An Overview of Research Methods* (Vol. 2). Ringgold Inc.

Ricoeur, P. (1973). Creativity in Language. *Philosophy Today*, *17*(2), 97-111. https://doi.org/10.5840/philtoday197317231

Ricoeur, P. (1976). *Interpretation theory : discourse and the surplus of meaning*. Texas Christian University Press.

Rimmer, R. B., Bay, R. C., Alam, N. B., Sadler, I. J., Richey, K. J., Foster, K. N., Caruso, D. M., & Rosenberg, D. (2015). Measuring the burden of pediatric burn injury for parents and caregivers: informed burn center staff can help to lighten the load. *J Burn Care Res*, *36*(3), 421-427. https://doi.org/10.1097/BCR.0000000000000095

Rivlin, E., & Faragher, E. B. (2007). The psychological sequelae on mothers of thermally injured children and adolescents: Future directions: Part 3. *Developmental Neurorehabilitation*, *10*(2), 183-190. https://doi.org/10.1080/17518420701309758

Rivlin, E., Forshaw, A., Polowyj, G., & Woodruff, B. (1986). A multidisciplinary group approach to counselling the parents of burned children. *Burns Incl Therm Inj*, *12*(7), 479-483. https://doi.org/10.1016/0305-4179(86)90073-2

Rizzone, L. P., Stoddard, F. J., Murphy, J. M., & Kruger, L. J. (1994). Posttraumatic stress disorder in mothers of children and adolescents with burns. *J Burn Care Rehabi*, *15*(2), 158-163. https://doi.org/10.1097/00004630-199403000-00010

Seivert, N. P., Sommerhalder, M., Stewart, D., Ziegfeld, S., Ostrander, R., Reynolds, E. K., & Parrish, C. (2019). Routine Psychological Screening for Parent Depressive Symptoms in an Outpatient Pediatric Specialty Burn Clinic. *J Burn Care Res*, *40*(6), 947-952. https://doi.org/10.1093/jbcr/irz130

Sheridan, R. L., Hinson, M. I., Liang, M. H., Nackel, A. F., Schoenfeld, D. A., Ryan, C. M., Mulligan, J. L., & Tompkins, R. G. (2000). Long-term outcome of children surviving massive burns. *JAMA*, *283*(1), 69-73. https://doi.org/10.1001/jama.283.1.69

Sheridan, R. L., Lee, A. F., Kazis, L. E., Liang, M. H., Li, N.-C., Hinson, M. I., Bauk, H., Meyer, r. W. J., Stubbs, T. K., Palmieri, T. L., & Tompkins, R. G. (2012). The effect of family characteristics on the recovery of burn injuries in children. *J Trauma Acute Care Surg*, *73*(3 Suppl 2), S205-S212. https://doi.org/10.1097/TA.0b013e318265c81f

Shields, L., Pratt, J., Davis, L. M., & Hunter, J. (2007). Family-centred care for children in hospital. *Cochrane Database Syst Rev*(1), CD004811-CD004811.

Simons, J. (2013). An introduction to Q methodology. *Nurse Res*, *20*(3), 28-32. https://doi.org/10.7748/nr2013.01.20.3.28.c9494

Simons, M. A., Ziviani, J., & Copley, J. (2010). Predicting functional outcome for children on admission after burn injury: do parents hold the key? *Journal of burn care & research : official publication of the American Burn Association*, *31*(5), 750-765. https://doi.org/10.1097/BCR.0b013e3181eebe88

Singsuriya, P. (2015). Nursing researchers' modifications of Ricoeur's hermeneutic phenomenology. *Nursing Inquiry*, *22*(4), 348-358. https://doi.org/10.1111/nin.12098

Skivington, K., Matthews, L., Simpson, S. A., Craig, P., Baird, J., Blazeby, J. M., Boyd, K. A., Craig, N., French, D. P., McIntosh, E., Petticrew, M., Rycroft-Malone, J., White, M., & Moore, L. (2021). A new framework for developing and evaluating complex interventions: Update of Medical Research Council guidance. *BMJ*, *374*, n2061. https://doi.org/10.1136/bmj.n2061

Smith, A. L., Murray, D. A., McBride, C. J., & McBride-Henry, K. (2011). A Comparison of Nurses' and Parents' or Caregivers' Perceptions During

Pediatric Burn Dressing Changes: An Exploratory Study. *J Burn Care Res*, *32*(2), 185-199. https://doi.org/10.1097/BCR.0b013e31820aadbf

Stokkebæk, A. (2007). Spædbarnsalderens fire perioder [The four periods of infancy]. In A. Stokkebæk & S. Dansk (Eds.), *Psykologi. Bind 1. Udviklingspsykologi. Lærebog for sygeplejestuderende [Psychology. Volume 1. Developmental Psychology. Textbook for nursing students]* (2 ed., pp. 85-102). Nyt Nordisk Forlag.

Sundal, H. (2014). *Inklusjon og eksklusjon av foreldre i pleie av barn innlagt på sykehus. Analysene er historiske og nåtidige og har utgangspunkt i norske lærebøker i sykepleie, bilder, litteratur og andre dokumenter fra perioden 1877-2013, og intervju og observasjoner med foreldre og sykepleiere ved en barneavdeling i 2007 [Inclusion and exclusion of parents in the care of children admitted to hospital. The analyses are historical and contemporary and are based on Norwegian textbooks in nursing, pictures, literature and other documents from the period 1877-2013, and interviews and observations with parents and nurses at a paediatric ward in 2007]* [Philosophiae Doctor (Ph.D.), The University of Bergen].

Sundal, H., Petersen, K. A., & Boge, J. (2019). Exclusion and inclusion of parents of hospitalized children in Norway in the period 1877-2017. *BMC Nurs*, *18*(1), 6-6. https://doi.org/10.1186/s12912-019-0330-6

Suurmond, J., Bakker, A., & Van Loey, N. E. (2020). Psychological distress in ethnic minority parents of preschool children with burns. *Burns*, *46*(2), 407-415. https://doi.org/10.1016/j.burns.2019.07.036

Sveen, J., Andersson, G., Buhrman, B., Sjoberg, F., & Willebrand, M. (2017). Internet-based information and support program for parents of children with burns: A randomized controlled trial. *Burns*, *43*(3), 583-591. https://doi.org/10.1016/j.burns.2016.08.039

Sveen, J., & Willebrand, M. (2018). Feelings of guilt and embitterment in parents of children with burns and its associations with depression. *Burns*, *44*(5), 1135-1140. https://doi.org/10.1016/j.burns.2018.02.005

Sørensen, L. J. (2013). *Skam - medfødt og tillært : når skam fører til sjælemord. [Shame - innate and learned: when shame leads to soul-murder]* (1. bogklubudgave. 1. oplag. ed.). Gyldendals Bogklubber.

United Nations. (1989). *Convention on the Rights of the Child* (vol. 1577). https://treaties.un.org/doc/Treaties/1990/09/19900902%2003-14%20AM/Ch_IV_11p.pdf

Van Niekerk, A., Seedat, M., Menckel, E., & Laflamme, L. (2007). Caregiver experiences, contextualizations and understandings of the burn injury to their child. Accounts from low-income settings in South Africa. *Child Care Health Dev*, *33*(3), 236-245. https://doi.org/10.1111/j.1365-2214.2006.00724.x

Verity, P. A. (1995). Burn injuries in children. The emotional and psychological effects on child and family. *Aust Fam Physician*, *24*(2), 176-178, 180-171.

Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *J Adv Nurs*, *52*(5), 546-553. https://doi.org/10.1111/j.1365-2648.2005.03621.x

Wiklund, L., Lindholm, L., & Lindström, U. Å. (2002). Hermeneutics and narration: a way to deal with qualitative data. *Nursing Inquiry*, *9*(2), 114-125. https://doi.org/10.1046/j.1440-1800.2002.00132.x

Willebrand, M., Sjoberg, F., Huss, F., & Sveen, J. (2018). Parents' perceived quality of pediatric burn care. *J Crit Care*, *43*, 256-259. https://doi.org/10.1016/j.jcrc.2017.08.037

Willebrand, M., & Sveen, J. (2016a). Injury-related fear-avoidance and symptoms of posttraumatic stress in parents of children with burns. *Burns*, *42*(2), 414-420. https://doi.org/10.1016/j.burns.2015.08.004

Willebrand, M., & Sveen, J. (2016b). Perceived support in parents of children with burns. *Gen Hosp Psychiatry*, *38*, 105-108. https://doi.org/10.1016/j.genhosppsych.2015.10.004

World Health Organization. (2018, 6. March 2018). *Burns*. Retrieved November 2021 from https://www.who.int/news-room/fact-sheets/detail/burns

World Medical Association. (1964/2013, 9th of July 2018). *WMA Declaration of Helsinki – Ethical principles for medical research involving human subjects*. World Medical Association. Retrieved November 2021 from https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

Papers I–IV

Paper I

Support needs of parents of hospitalised children with a burn injury: An integrative review

Paper II

Staff members' experience of providing parental support in a national burn centre

Paper III

Parents' lived experiences of parental needs for support at a burn centre

Paper IV

Parents' lived experience of caring for their burn-injured child after discharge from hospital

BURNS 46 (2020) 771–781

Available online at www.sciencedirect.com

ScienceDirect

journal homepage: www.elsevier.com/locate/burns

Review

Support needs of parents of hospitalised children with a burn injury: An integrative review

Lina S.T. Lernevall [a,b,*], Asgjerd L. Moi [a,c], Michelle Cleary [d], Rachel Kornhaber [d,e], Pia Dreyer [f]

[a] Department of Plastic, Hand and Reconstructive Surgery, National Burn Centre, Haukeland University Hospital, Bergen, Norway
[b] Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway
[c] Department of Health and Caring Sciences, Western Norway University of Applied Sciences, Bergen, Norway
[d] College of Health and Medicine, University of Tasmania, Sydney, NSW, Australia
[e] National Burns Center, Sheba Medical Center, Israel
[f] Department of Public Health, Section of Nursing, Aarhus University, Aarhus, Denmark

ARTICLE INFO

Article history:
Accepted 17 April 2019

Keywords:
Burns
Integrative review
Parents
Support
Pediatrics
Psychosocial

ABSTRACT

Background: Good family functioning is important to improve outcomes for children who have sustained a burn injury. While knowledge regarding parental distress is increasing, less is known about parents' need for support during their child's hospitalisation.
Aim: To systematically synthesise existing research focussing on the support needs of parents of children hospitalised with a burn injury.
Methods: An integrative review was conducted using a literature search from multiple health-related databases. Original studies reporting on support for parents during their child's hospitalisation at a burn facility were included. A Ricoeur-inspired method was the framework used for the analysis.
Results: Of the 468 identified papers, only seven studies met the inclusion criteria. In total, 521 parents and caregivers from six different countries were represented. Key findings related to the support needs of parents, including the need for information through all stages of treatment, support needs during emotional distress, feelings of guilt and blame relating to the injury and having someone to lean on or being alone.
Conclusion: Findings from this review describe parental feelings of distress, guilt and blame and parental needs of information and support. Further research is needed to facilitate the development of evidence-based support programmes for parents of burn injured children that address these parental needs.

---

* *Corresponding author at*: Department of Plastic, Hand and Reconstructive Surgery, National Burn Centre, Haukeland University Hospital, Postboks 1400, 5021 Bergen, Norway.
E-mail address: lina.lernevall@helse-bergen.no (L.S.T. Lernevall).

https://doi.org/10.1016/j.burns.2019.04.021
0305-4179/

Contents

1. Introduction

Worldwide, children under five years are over-represented among paediatric burns [1–5]. In Europe, children under five account for 50–80% of all childhood burns [6], while in the Eastern Mediterranean Region they account for up to 78% [7]. These young children in particular are dependent on their parents for the best possible outcome after their injury.

Most burn injuries in children (80–90%) occur at home [2,3,6,7], and many parents witness the accident, being nearby but not close enough to prevent it from happening. Severe burn injuries require hospitalisation at a burn intensive care unit. Professional healthcare from a multidisciplinary burn team is needed in the time after the accident [8]. The parents see their child undergo painful medical procedures and need to deal with their own feelings while supporting their child, making parenting challenging [9,10]. One to four weeks post-burn, 18–50% of parents show symptoms of post-traumatic stress disorder (PTSD) [11,12], a rate that declines over time to 17% seven years post-burn [13]. Parents also report higher levels of anxiety (69%) and depression (44%) than the general population [14]. Moreover, parents can struggle with feelings of guilt [15,16], and fear of losing their child [17]. Treating parental depression can have a positive effect not only on the mental health of the parent but also on the mental health of their children [18,19]. Moreover, supporting parents and family functioning can improve the child's well-being and functional outcomes [8,20]. Supporting parents in providing care for their burn-injured child and understanding the right support needs of these parents are therefore crucial to the recovery of the child. This support can be multi-faceted and include emotional, psychological, and spiritual support, all of which are overviewed in this review.

Clinical experts have contributed to the literature sharing their experiences of how staff can better support parents of burn-injured children [21–23]. Different recommendations have been suggested: providing parents with written information on arrival [21], therapeutic intervention [22], instructions on how to touch the child and handle the bandages [23], education and emotional support [21,23], weekly group meetings [21,22] and access to financial assistance [23].

Different group treatments for parents and caregivers of burn-injured children have been described [9,10,17,24–26]. In some instances, weekly group meetings have been held at a burn facility, led by a nurse and a social worker. The aim of the group meetings is for parents and caregivers to share feelings, questions and concerns with others in the same situation. The majority of participating parents have found it beneficial to attend group meetings [9,17,24,25].

It is recommended that healthcare professionals working with burn injuries facilitate the building of relationships with patients and families and look at much-needed social services such as support, crisis intervention and referral to appropriate community agencies [27,28]. Furthermore, it is crucial to detect if the burn injury is due to neglect or child abuse and to provide the burn facility with a psychosocial assessment of family functioning [28]. Information about how to deal with a family's financial situation as a consequence of the burn injury is also a part of the social worker's role [21].

In summary, what this literature shows is wide-ranging. Parents of burn-injured children have multiple needs and concerns during the process of treatment and recovery, and support is essential for both parental well-being and the child's outcome. An understanding of parental feelings post-injury, the importance of treating parental depression and the input clinicians have had on suggesting effective support measures for parents are established. What the literature does not cover, however, is parental perspectives on support needs and what they consider to be of value during the process of injury, treatment and rehabilitation. By adding parental perspectives into the overall understanding, researchers might better target support services and measures. Therefore, this integrative review aims to systematically synthesise the literature focussing on support needs of parents of burn-injured, hospitalised children. How is support for parents of these children perceived by these parents, and what is the content and context of the given support? While needs other than support are equally as important and warrant research and review, this paper focusses specifically on support needs.

2 Methods

2.1. *Review process*

An integrative review is a method that enables researchers to synthesise literature on an area of interest in an integrative manner that generates new understanding and perspectives [29]. An integrative review methodology was chosen given the dearth of literature in the area of burn care and because it is the broadest research review method, allowing for the inclusion of heterogeneous studies [30]. Whittemore and Knafl's [30] framework for integrative reviews was used to guide the review process. It consists of five stages: problem identification, literature search, data evaluation, data analysis, and presentation.

2.2. *Inclusion and exclusion criteria*

The inclusion criteria were studies describing support for parents of burn-injured, hospitalised children 18 years old or younger where support was limited to initiatives provided while the children were hospitalised. To obtain a broad overview, there was no limit on the year of publication. Only publications written in English were included.

2.3. *Search strategy*

A systematic search was conducted in February 2017 by the authors (LSTL, RK, MC) with experience in the development of search strategies and in conducting reviews. The search was updated in May 2018. Five electronic databases were targeted: Cumulative Index of Nursing and Allied Health Literature (CINAHL), Excerpta Medica dataBASE (EMBASE), PsycINFO, PubMed and Scopus. Medical subheadings (MeSH) and keywords were combined with Boolean operators AND, OR and NOT using the following MeSH/index and keywords: burn*, caregiver*, parent*, child*, paediatric*, adolescen*, support, adaption and coping. The use of MeSH terms to construct search strategies has been shown to enhance the precision and the retrieval of information, resulting in more-efficient and better-informed search strategies [31,32]. The search was initially constructed in PubMed and adapted for subsequent databases. MeSH-indexed terms differed across the databases. The search strategies were therefore adapted to reflect the syntax between different databases (Table 1).

The initial search identified 468 papers. A total of 317 articles remained after removal of duplicates and review of reference lists. Titles and abstracts not relevant to the aim of the review were then removed. Inclusion was based on title and abstract (by LSTL, PD) with full consensus. Thirty-two full-text articles were assessed, and 25 were excluded. Articles excluded were discussion papers (n = 4), papers focussing on parental feelings (n = 16) or on the child, other relatives, or on prevention or discharge (n = 5). The full texts were read by LSTL (reviewed by PD). Seven studies [33–39] met the inclusion criteria (Fig. 1). Details of the seven included studies are given in Table 2. Eighteen articles were identified in the updated search, but no further studies met the inclusion criteria.

2.4. *Quality appraisal*

To evaluate the quality of the studies, two checklists were used: The *Critical Appraisal Skills Programme* (CASP) [40] and the *Newcastle–Ottawa Quality Assessment Scale* (adapted for cross sectional studies) [41]. The CASP checklist for Qualitative Research, with 10 questions, was chosen based on the methods used in the articles. The Newcastle–Ottawa Quality Assessment Scale consists of seven questions. A double-blind review was undertaken (by LSTL, ALM, MC, RK) with 100% agreement on the score (Supplementary file 1).

Table 1 – Example of search strategy.

Example of search strategy: PubMed
burns [mh] OR burn* [tiab] AND Caregivers [mh] OR Caregiver* [tiab] OR parents [mh] OR parenting [mh] OR parent* [tiab] AND child [mh] OR child* [tiab] OR Pediatrics [mh] OR Pediatric* [tiab] OR Paediatric* [tiab] OR Adolescent [mh] OR adolescen* [tiab] AND Social support [mh] OR social [tiab] OR Adaptation, Psychological [mh] OR coping [tiab] NOT Burnout NOT burn* [author]

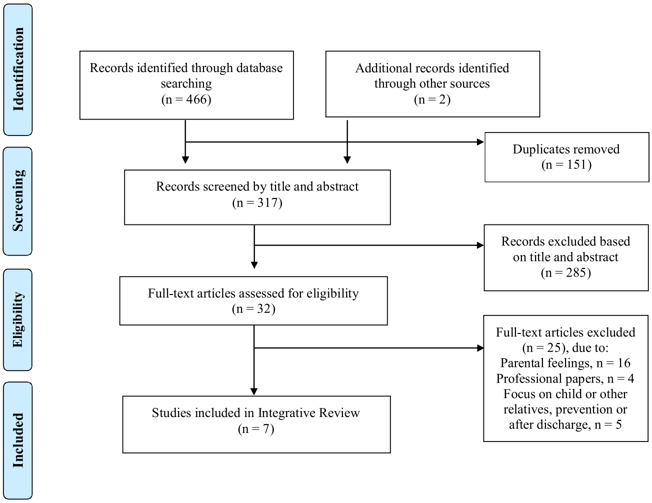


Fig. 1 – Flow diagram.

2.5. *Data abstraction and synthesis*

Data were abstracted and synthesised (by LSTL, PD) using Whittemore and Knafl's five stages [30]. Whittemore and Knafl recommend analysis methods that have been developed for mixed-methods and qualitative designs for integrative reviews [30]. In our case, a Ricoeur-inspired method, described by Dreyer and Pedersen, was the framework used for text analysis [42] in an attempt to carry out "a more systematic and rigorous approach to the process," as requested [30, p. 552]. Dreyer and Pedersen's Ricoeur-inspired method consist of three steps: (1) a naïve reading, (2) a structural analysis and (3) a critical analysis and discussion [42]. First, the naïve reading was conducted, where all seven articles were read as a whole, to get an overview. The structural analysis of the text consisted of three steps: *What is said?*, *What does it speak about?*, and *Emerging themes*. All qualitative articles were read and coded before the review of the quantitative articles because of their more detailed descriptions. Sections in each text were searched for "*What is said?*" This was comparable to Whittemore and Knafl's [30] 'data reduction', an overall classification system dividing sections into subgroups. Then, the paragraphs from all texts were united in a describing text, "*What does it speak about?*" This was comparable to Whittemore and Knafl's [30] 'data display', where data from individual sources are compiled to display data from multiple sources. Finally, themes emerged, consistent with Whittemore and Knafl's [30] approach to 'data comparison', where patterns, themes or relationships are identified. These themes gave meaning to the patterns and consistencies found in the results and eventually became the core categories that arranged the information in a comprehensive way that allowed for discussion and understanding.

The last step in Dreyer and Pedersen's [42] Ricoeur-inspired method is critical analysis and discussion, similar to Whittemore and Knafl's [30] conclusion drawing, and verification. The analyses are brought from a descriptive level to "higher levels of abstraction, subsuming the particulars into the general" [30, p. 551]. The results are critically deliberated with relevant literature and research. The data were analysed using QSR International's NVivo 11 Software [43].

3 Findings

From the data analysis, four themes emerged: emotional distress, guilt and blame, information is central, and having someone to lean on or being alone. These themes "unfold" the parents need for support and are presented in the following section.

3.1. *Study characteristics*

In total, 521 parents/caregivers to burn-injured children were represented in the seven studies: 390 females and 118 males. Two studies [37,39] did not specify the gender of all the family members who participated. The hospitalised children were three months to 18 years old. The studies were conducted in six countries, representing different cultures: Australia [34], India [35], Malawi [33], Sweden [38,39], the United Kingdom [36] and the United States of America [37].

Four qualitative studies [33–35,37] and three surveys [36,38,39] were included. Two studies looked at support interventions provided by the burn facilities [33,36], and the others explored parental experience and needs for support [34,35,37–39] (Table 2).

3.2. *Emotional distress*

All seven articles discussed parents' emotional distress [33–39]. This distress was expressed by the parents in terms of fear of

Table 2 – Summary of included articles.

Authors, year and country	Design	Purpose	Sample and study population (F/M = Female/Male)	Data collection method	Method of analysis	Findings
Barnett, Mulengad, Kisere, Charles, (2017, Malawi).	Qualitative exploratory	To provide an account of a support group for burn survivors and to determine themes discussed by the group participants.	48 caregivers (F/M 35/13, age 19–63 years). 18 patients (F/M 6/12, age 12–45 years).	12 weekly group sessions. Both patients and caregivers attended the same group.	Quantitative: Ficher's exact test, Student's T-test. Qualitative: Thematic analysis.	The support group provided a setting for patients and their caregivers to discuss their subjective experience, emotions and struggles, finding mutual support from other group members and receiving coping strategies.
McGarry, Elliott, McDonald, Valentine, Wood, Girdler (2015, Australia)	Qualitative descriptive study	To investigate and describe the experiences of parents of children admitted to hospital for a burn.	Purposive sample of 21 parents (F/M 14/7). 17 children (F/M 7/10, age 6–15 years).	Face to face in-depth unstructured interviews 6 months' post-burn.	Thematic analysis using Colaizzi's phenomenological method.	The parents go through a three-step journey: experiencing the accident; the in-patient phase; and, the return to community. Subthemes: stressors; behavioural and emotional responses; and, coping factors.
Ravindran, Rempel, Ogilvie, (2013, India).	Qualitative descriptive study	To explore and discover processes of parenting children in India who had sustained burns and to develop a conceptual model to inform interventions.	18 parents and 4 family members from 12 families (F/M 13/9). 12 children (F/M 4/8 age 8 months-9 years).	25 face to face semi-structured interviews. Field notes.	Constructivist grounded theory methodology using open and focused coding.	The process of embracing the survival included three stages: (1) suffering the trauma; (2) sustaining life; and, (3) shielding from stigma. Parents perceived minimal support from health professionals and family members.
Rivlin, Forshaw, Plowyj, Woodruff, (1986, UK).	Survey	To measure the efficacy of a multidisciplinary group approach to counselling the parents of burned children.	266 parents/caregivers (F/M 217/49). 238 staff members.	Questionnaire. 50 weekly meetings, (mean parents per session = 5.28 (2–12 parents)). 238 ratings over 50 sessions were made, mean = 4.76 ratings.	Summary statistics, i.e., means, standard deviations or frequency counts. Unpaired *t*-test.	Scarring and skin grafts was what the parents were most worried about. Present state anxiety and anxiety concerning particular worries decreased after attending the support group.
Thompson, Boyle, Teel, Wambach, Cramer, (1999, USA).	Qualitative, descriptive study	To identify support needs and concerns of family members of adult and paediatric patients currently in a burn centre and explore the relationship between family needs and the patient's severity of injury.	97 family members (27 were family members to paediatric patients, 70 to adult patients). Age 19–76 years. 38% were parents, 33% spouses, 11% siblings, 7% children, 5% grandparents and 6% others. 59 patients (age 1–83 years).	Face to face semi-structured interviews.	Observational design. Content analysis.	Parents of paediatric patients worried about pain, skin graft surgery, scarring and infection. Seeing their child improve and retaining optimism and hope about their situation helped. Parents were generally satisfied with the support provided.

(continued on next page)

Table 2 (continued)

Authors, year and country	Design	Purpose	Sample and study population (F/M = Female/Male)	Data collection method	Method of analysis	Findings
Willebrand, Sjöberg, Huss, Sveen (2018, Sweden).	Survey	To describe parents' perceived quality of paediatric burn care and evaluate factors associated with differences in perceived quality among parents.	Purposive sample of 62 parents (F/M 42/20) (13 were parents to same child), 49 children (F/M 22/27, mean age 6).	Questionnaires.	Cronbach's alpha. Spearman's rho. Linear regression model.	Most parents reported high satisfaction (Quality to Care Indices). Reasons for low satisfaction included information routines (adequate information about routines at the burn center), accessibility (contacting the Burn Center by phone) and participation (opportunities to ask questions and discuss treatment).
Willebrand, Sveen, (2016, Sweden).	Cross-sectional study	To investigate parents' perception of support after paediatric burn and associations with parent, child and injury characteristics.	Purposive sampling of 106 parents (F/M 69/20, and 17 parents unspecified) 106 children (F/M 40/66, age 3 months-15 years and 7 months).	Questionnaires.	Chi-square test, Fisher's Exact Test, Student's t test and logistic regression.	21% of the parents reported inadequate medical, psychological or social support after their child was burned.

the child's prognosis, shock from witnessing their child's treatments and pain, trying to stay strong, and accepting the current situation [33–35,37].

3.2.1. *Fear of losing child and fear of medical treatments*

When their child was admitted to the burn unit, the parents realised how severe and serious the injury was [33,34,35]. Some parents tried to accept that "there's no quick fix for this, you're in for a long haul" [34, p. 47]. Even so, the parents recognised that only very ill people went to hospital [33]. Many parents had a profound fear of losing their child [33,35]: "Will our child leave us?" [35, p. 592]. The fear and shock affected some parents to such a degree that it affected their eating patterns. A father lost 13 kg in two months, and a pregnant mother stopped eating: "I could not eat food. If I go near the food I will think of the child only. I will remember only how he cries (with wobbling voice, tears). I won't even be able to eat" [35, p. 592]. Parents had disturbing and negative thoughts, and a father was so affected by his son's suffering due to a below-the-elbow amputation that he "wanted to commit suicide" [35, p. 592]. Some described the time at the hospital as "hell" and as "frightening" [35, p. 592]. Pain and skin-graft surgery were something that paediatric family members were worried about [34,36,37]. The parents feared that the treatment caused their child great pain: "I looked at how much pain she was tolerating and would feel like crying . . . I cried" [35, p. 592]. The worst part was surgery with skin grafts and anaesthetics, which scared the "hell out of" the parents [34, p.44]. To witness a dressing change was experienced as very traumatic. Parents felt physically sick and nauseated, finding it distressing and horrific, for instance, to see when the nurses were "popping blisters, cutting skin and pulling it off" [34, p. 44]. It was hard to participate in the dressing changes and to hold the child still [34]. Some parents relived the dressing changes mentally when closing their eyes: "Like, as soon as I closed my eyes, all I could see was that [the child's dressing changes], and that would be the dream straightaway" [34, p. 47]. For some, this continued up to six months post-injury [34]. It came as a shock to some parents when their child needed a skin graft, and many felt they had not received the appropriate information: "We weren't prepared for that, and it was a shock" [34, p. 44].

3.2.2. *Staying strong and accepting the situation*

Parents tried to stay strong for the sake of their child, putting on a brave face, even though the extra pressure started to weigh on them [34]. When alone, some parents broke down and gave in to their true feelings: "There was times where I got home and I screamed and yelled and cried and whatever, but I tried to do a brave face in front of her" [34, p. 46]. Some felt that they neglected their other children and their partner at home due to their stress, leading to partner conflicts [34].

The parents wished for the injury not to have happened: "an incident that should not even be thought of in life" [35, p. 592]. The first three months were particularly tough and emotional due to dealing with the burn and the healing process [34]. While some parents were relieved when their child was discharged [35], others were concerned and worried [34]. Getting a sense of distance from the injury was seen as a natural progression. The burn injury happened and could not be undone.

In addition to coping with the injured child, the parents had to cope with their own emotions, some parents demonstrating low symptom levels of post-traumatic stress, depression, general anxiety and low fear avoidance [38,39]. One study reported exceeded cut-off scores on symptoms of PTSD (20%), the HADS Anxiety subscale (25%) and the HADS Depression subscale (10%) indicating the prevalence of the conditions [39]. The parents tried to accept and learn from what they were going through: "I mean, the initial part of its bad when you've got the trauma, the accident, the grief and the loss and all that . . . but it's all a natural progression once you've kind of accepted it" [34, p. 47]. They learned to live with it, adjust to it and see it as a lifelong journey [34].

The experience of a lack of support among parents was "associated with parents' combined symptoms of general anxiety and depression (HADS), injury-related fear avoidance, parent ratings of their child's general health and heat sensitivity" [39, p. 107]. There was no significant association between lack of support and symptoms of post-traumatic stress among parents [39].

3.3. *Guilt and blame*

Experiences of guilt and blame were mentioned in five of the seven articles [33–36,39]. The parents had to deal with their own feeling of guilt [33–36,39] and blame from others [34,35].

3.3.1. *Blaming oneself or blaming the partner*

Many parents blamed themselves for their child's injury, thinking that it was their fault that their child got burned and that they should have been able to prevent it: "It is my fault my child is here. I feel as though I was not caring for him properly" [33, p. 605]. Some parents found it hard to forgive themselves: "I'll never completely forgive myself for it, because it's something that shouldn't have happened" [34, p. 46]. Parental guilt was a frequently discussed topic during 50 group sessions with parents [36]. Other parents thought about the source of the accident, and many subsequently altered their behaviour. In one case, the treadmill that caused the accident would never be used again, while another said "I will not cook her noodles that way" or "We never went back to the farm . . . so we sold it" [34, p. 47].

Some parents blamed their partner for the accident that caused the burn. They wanted to talk to their partner about what had happened, but felt worried they might say, "It was your fault" [34, p. 45]. "I can honestly say I've never been so angry in my life. I was so angry, I couldn't even look at his Dad. It took me weeks" [34, p. 45].

3.3.2. *Blame from family members and hospital staff*

Some parents felt blamed by family members and healthcare professionals [34,35]. "How did you allow this?" [35, p. 592]. If they did not follow treatment instructions properly, they were scolded by the nurses [35]. The parents felt terrible for what had happened and found it hard to talk about this with others. They were unsure what people thought of them: " . . . and as much as you know people are trying to be honest, saying, 'It's not your fault', you think to yourself, 'Do they really think that?', especially when my own mother-in-law said it was my fault" [34, p. 46]. Living with this blame from others and from themselves made the parents uncertain about their abilities as a parent: "Will I harm my own child?" [35, p. 592]. "What else am I doing wrong, or not right? What else am I doing that's then going to affect her?" [34, p. 46].

3.4. *Information is central*

Information was central across all studies [33–39], especially timely and complete information.

3.4.1. *Information from the healthcare professionals*

Having the necessary information and "knowing what was happening next" [34, p. 45] was important for the parents and alleviated anxiety about their child: "things were really confusing at first, there was a lot to deal with, but with the support of the staff things are becoming a lot more clear" [37, p. 490]. It gave them a sense of being in control and made them cope better [34]. Too much information, however, could lead to panicked parents [34]. Some parents were told that their child might die: "this case will not survive" [35, p. 592]. Even so, most parents preferred to be informed rather than uninformed. Having information was important and helpful to sort out the logistics in the family at home and "keep other family members posted" [34, p. 45].

3.4.2. *Missing information*

When parents felt that they were not given all the information needed, they panicked, stressed, and became worried and anxious [33,34]: "So, for me, it came down to the amount of information I had about what was going on, which was directly related to how calm or how upset I became" [34, p. 45]. Information was crucial for the parents to feel prepared:

> If I'd had the information [he was undergoing surgery], I could have dealt with it. I could have been on the phone to a friend and said, 'Could you sit with me?' Just so that I've got somebody to talk to and take my mind off it. But, I didn't have the opportunity to do that, because I wasn't told [34, p. 45].

An absence of information led to worry not only in the acute phase but also prior to the discharge phase: "I am worried though that we have not been told of any counselling for after discharge" [33, p. 606]. Parents of burn-injured children expressed concern about the physical (scarring, mobility) and psychological challenges [36]. Parents needed information about progress, rehabilitation and how to protect their child [34,35,37], "I need to know everything there is to make sure that that doesn't affect her growing up" [34, p. 46]. Some of the parents also felt they were missing information on how family members could talk about their emotions [34]. Many parents sought and received information or guidance from health professionals [35,39]. However, not having access to relevant information resulted in negativity about the quality of care [38]. Information could also be overwhelming, especially for those parents who were on their own: "it was a lot to take in, because I was by myself with him" [34, p. 45].

3.5. *Having someone to lean on or being alone*

Six of the seven articles mentioned the importance of being supported by others [33–35,37–39]. Many parents found support in the healthcare system [33–35,37,38]. Some parents talked with friends or with family members [33–35,37], and some attended support groups while their children were hospitalised [33]. Nevertheless, for some parents, family was everything: "As long as I have family, I have everything" [37, p. 490].

3.5.1. *The healthcare system*

When the parents saw that their child was getting the appropriate medical attention, they felt more at ease and let go of their own feelings: " . . . until I was in the hospital and [my child] had sort of calmed down a bit, then I broke down" [34, p. 44]. Parents experienced an enormous sense of relief from being with professionals at a burn unit [34]. In one study the parents had confidence in the hospital system and felt that they received the "very, very best treatment on an international level" [34, p. 44]. The burn team gave support, which was crucial for the family members [37]. Staff attitudes reportedly resulted in a high parent satisfaction in relation to the quality of care provided [38].

3.5.2. *Support from others*

Social support was important, as the parents felt they could not have managed on their own [33,34]. Being in close contact with the family at home was important, especially for families in rural areas [34]. In the acute period, some were supported with soothing words: "Don't be frightened. Our child will return to us . . . We did not sin against anyone" [35, p. 592]. Support from their spouse was, for some, the most important form of support [34,35]: "So, it was good that I had [my husband] and I think if I didn't have him, I would have fallen apart" [34, p. 45]. They formed a dyad, helping, providing, relieving, taking things off each other's minds and making the other brave: "When I saw my husband, I used to feel a little brave" [35, p. 593].

Furthermore, group sessions were experienced as very beneficial and comforting [33]. Through support initiatives arranged by the burn unit, the parents met others in the same situation and shared their feelings: "This is the first time since coming to this ward that I have seen patients and guardians from different families come together to share experiences and learn from one another. I think this has value" [33, p. 606]. They learned relaxation techniques such as breathing exercises and positive thinking [33]. These techniques were appreciated and helpful.

3.5.3. *Being alone*

Some parents found that they or their child had lacked support [34,39]: "didn't have anybody to talk to throughout the day" [34, p. 45]. Some parents lacked support from the medical profession, from several professions, from the family or psychosocial support [39]. Hospital visiting hours were identified as making it difficult for other family members to help [35]. Some parents travelled alone and were the only ones looking after their child [34,35], and many felt alone [34,35,39], scared [34,35] and found it difficult to leave the child [34]. Some parents found support in prayer or spiritual practices [33,35,37].

4 Discussion

Information was central in all seven studies, as it has been in other studies [24–26,28]. This demonstrated that the key needs of parents with burn-injured children did not differ according to cultural context or socioeconomic circumstances, as it was consistent across the countries represented in the studies. This points to the universality of parental responses to child burn injuries and their subsequent needs. Several findings related to whether the parents felt that they had been given enough information. Parents found it easier to deal with the situation when they thought that they had received all appropriate information. Having information had a calming effect and was seen as important and helpful. Not getting information typically led parents to feel worried, anxious and stressed. The studies included in this review do not identify the kind of information the parents sought. Parents of children with a burn injury need information when their child is hospitalised. Therefore, more intervention studies are needed to investigate what kind of information, in what form and when in the patient trajectory the information should be given.

Our review found that some parents were emotionally distressed, and similar to other studies [17,21], these parents also had a profound fear that their child would die. Witnessing and/or participating in the medical treatments of their child was also traumatic, and this was further compounded by being overwhelmed with their other responsibilities, such as caretaking of other children and other family members. Moreover, a child's burn injury will often affect the relationship between the parents [17,28]. Some come through it more "together" than before, while others get divorced [9]. This in part may be explained by the fact that a common reaction to a burn injury is intensification of pre-existing problems in the relationship [44].

Guilt was a common feeling among parents, with some parents blaming themselves for their child's injury. Guilt is one of the most common reactions to a burn injury among family members [9,17,22,23,27,28,44] and may lead parents to attributing blame to others [27]. Similar to another study [17], our review found that parents, particularly mothers, were often blamed by others, such as family members and staff.

Parents who were or felt alone had a harder time dealing with the situation. Feelings of isolation are also mentioned in earlier studies [9,17,22]. Prayer or spiritual practices helped some parents, as reported in other studies [17,22]. More knowledge is needed on how to support religious or spiritual practices amongst parents in the acute phase of a child's burn injury. Further studies should discuss the need for spiritual and religious support.

The studies included in this review move beyond outlining problems and concerns and are instead rich with information on how interventions might be developed to support parents during hospitalisation. The understanding that information gives a sense of control and confidence by parents, even where that information might be 'bad', was perhaps the most paramount finding. This can be incorporated into clinical settings to ensure that timely, complete and accurate information is imparted to parents throughout the process.

The use of formal support groups was another strong source of intervention. Arranged group sessions at the burn facility helped many parents, as they could talk to others in the same situation. Clinical experts have written about support groups and how they can serve as a surrogate family [24], a place where the parents can show and let go of their true emotions [10,24,25] and support one another [9,17,21,24,26,27]. Some said that it was “a place to share problems with others who understood” [24, p. 239], both with other parents and with staff members [10,24]. Burn facilities that arrange group meetings/sessions/treatment for parents of burn-injured children should therefore be encouraged to publish new studies, so others can learn from the outcomes of these groups. However, support clearly moved beyond formal groups and was needed by parents from social networks as well. This proved particularly challenging for single parents or those attending hospital on their own, and interventions focussed on helping these people connect with support networks could also aid parents.

Attitudes among healthcare staff were another area highlighted in the findings. Parents gained a strong sense of reassurance once their child was in the hospital setting, yet this was quickly undermined when parents experienced blame being directed towards them. Designing support interventions that use neutral language to avoid blame and promote that sense of reassurance might well equip parents to interact confidently with their child and to relieve both parental and child anxiety, while also improving perceptions of quality of care and trust in the health system.

This integrative review highlights the need for support for parents of children hospitalised with a burn injury. What it does not encompass, however, is what support currently exists that aligns with these needs and what types are effective for parents. Further research could investigate parents’ experiences to get a better understanding of the best way to deliver appropriate support needs and what support is required after discharge, to develop an evidence-based support programme for parents of burn-injured hospitalised children.

In addition, family, friends and neighbours were important in supporting parents while at the hospital. A parent’s “next of kin” (a person’s closest relatives, not necessarily blood relatives) should therefore be mapped, and the burn facilities ought to look at ways to ensure these relatives can act as helpers and assets. For example, hospitals’ visiting hours could be made more flexible for those family and friends supporting parents of burn-injured children.

4.1. *Limitations*

The inclusion of both qualitative and quantitative studies is a strength of the study as is the use of the Ricoeur-inspired method for text analysis [42]. However, only seven articles were included in this review, all of which were assessed for quality and deemed suitable for inclusion. The small number of included articles highlights the sparse knowledge on this field. All articles attained high quality scores. Two articles [36,37] were older than the others, and they were not as extensive in the presentation of their data as the newer articles. Nevertheless, they provided knowledge about this topic. One study [34] was cited many times in this review with direct quotations, due to the richness of parental statements.

Included studies provided limited key information, such as mortality rates and TBSA ranges for participants. This limited comparison between studies including whether cultural and socioeconomic contexts impacted the findings. The studies focussed on parental needs for support during the period when their child was hospitalised, including in-hospital preparations for the time post-discharge. Thus, the review focussed on inpatient care and the support measures that could be offered within this setting. This excluded the perspectives of parent’s support needs they might have post-hospitalisation. However, a further area of research could be parental support needs and how these might change after discharge from hospital. In the seven studies, the number of female participants (mothers) was higher than the number of male participants (fathers). However, in many cultures the primary caregiver is the mother, as explained in the study from India [35], thus potentially explaining this high ratio of females to males. This distribution can affect the whole picture of perceived support, as fathers might have a different perception of their experience than mothers. Further research should look at the needs of both mothers and fathers, whether these needs differ by gender and whether these needs change according to whether the parent is the main carer present during hospitalisation or at home. Further research could also confirm whether the majority of burn-injured children are boys, as indicated in the studies included, and the explanations for this.

5 Conclusion

Findings from this integrative review describe a mix of both parental feelings (distress, guilt and blame) and parental needs (information and support). The knowledge about the parents’ need for more information, as well as support to address feelings of guilt and blame, support for couples and single parents, and support for spiritual and religious needs, is sparse. Therefore, further research is needed to facilitate the development of an evidence-based support programme for parents of burn-injured hospitalised children. Further studies could also look further at the effect of support group meetings to maximise the benefit of this resource for parents.

Funding

Western Norway Regional Health Authority, project number: 912138.

Declaration of interest

None.

Author contributions

All authors have made substantial contributions to the conception and design of the study. Systematic literature search: LSTL, MC, RK. Inclusion based on title and abstract: LSTL, PD. Scoring full text papers: ALM, LSTL, MC, RK. Manuscript preparation, revisions and final approval of the article: All authors.

Acknowledgements

Professor Emerita Eva Gjengedal, Department of Global Public Health and Primary Care, University of Bergen, Norway, is thanked for valuable discussions and review of final manuscript.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.burns.2019.04.021.

REFERENCES

[1] Chien WC, Pai L, Lin CC, Chen HC. Epidemiology of hospitalized burns patients in Taiwan. Burns 2003;29:582–8.

[2] Golshan A, Patel C, Hyder AA. A systematic review of the epidemiology of unintentional burn injuries in South Asia. J Public Health 2013;35:384–96.

[3] Han TH, Kim JH, Yang MS, Han KW, Han SH, Jung JA, et al. A retrospective analysis of 19,157 burns patients: 18-year experience from Hallym Burn Center in Seoul, Korea. Burns 2005;31:465–70.

[4] Rybarczyk MM, Schafer JM, Elm CM, Sarvepalli S, Vaswani PA, Balhara KS, et al. A systematic review of burn injuries in low- and middle-income countries: epidemiology in the WHO-defined African region. Afr J Emerg Med 2017;7:30–7.

[5] Wasiak J, Spinks A, Ashby K, Clapperton A, Cleland H, Gabbe B. The epidemiology of burn injuries in an Australian setting, 2000–2006. Burns 2009;35:1124–32.

[6] Brusselaers N, Monstrey S, Vogelaers D, Hoste E, Blot S. Severe burn injury in Europe: a systematic review of the incidence, etiology, morbidity, and mortality. Crit Care 2010;14:R188.

[7] Othman N, Kendrick D. Epidemiology of burn injuries in the East Mediterranean Region: a systematic review. BMC Public Health 2010;10:83.

[8] Bakker A, Maertens KJ, Van Son MJ, Van Loey NE. Psychological consequences of pediatric burns from a child and family perspective: a review of the empirical literature. Clin Psychol Rev 2013;33:361–71.

[9] Cahners SS. Group meetings benefit families of burned children. Scand J Plast Reconstr Surg 1979;13:169–71.

[10] Fowler J. The role of parent groups in the rehabilitation of the burned child. Burns 1978;5:86–8.

[11] Bakker A, Van Loey NE, Van der Heijden PG, Van Son MJ. Acute stress reactions in couples after a burn event to their young child. J Pediatr Psychol 2012;37:1127–35.

[12] Fukunishi I. Posttraumatic stress symptoms and depression in mothers of children with severe burn injuries. Psychol Rep. 1998;83:331–5.

[13] Rizzone LP, Stoddard FJ, Murphy JM, Kruger LJ. Posttraumatic stress disorder in mothers of children and adolescents with burns. J Burn Care Rehabil 1994;15:158–63.

[14] Phillips C, Rumsey N. Considerations for the provision of psychosocial services for families following paediatric burn injury—a quantitative study. Burns 2008;34:56–62.

[15] Kornhaber R, Childs C, Cleary M. Experiences of guilt, shame and blame in those affected by burns: a qualitative systematic review. Burns 2018;44:1026–39.

[16] Sveen J, Willebrand M. Feelings of guilt and embitterment in parents of children with burns and its associations with depression. Burns 2018;44:1135–40.

[17] Frenkel L. A support group for parents of burned children: a South African children's hospital burns unit. Burns 2008;34:565–9.

[18] Cuijpers P, Weitz E, Karyotaki E, Garber J, Andersson G. The effects of psychological treatment of maternal depression on children and parental functioning: a meta-analysis. Eur Child Adolesc Psychiatry 2015;24:237–45.

[19] Gunlicks ML, Weissman MM. Change in child psychopathology with improvement in parental depression: a systematic review. J Am Acad Child Adolesc Psychiatry 2008;47:379–89.

[20] Sheridan RL, Hinson MI, Liang MH, Nackel AF, Schoenfeld DA, Ryan CM, et al. Long-term outcome of children surviving massive burns. JAMA 2000;283:69–73.

[21] Brodland GA, Andreasen NJC. Adjustment problems of the family of the burn patient. Soc Casework 1974;55:13–8.

[22] Cahners SS. Coping as the parent of a burned child. In: Bernstein NR, Breslau AJ, Graham JA, editors. Coping strategies for burn survivors and their families. New York: Praeger; 1988. p. 123–5.

[23] Francis AL. Symposium on burns. Support for parents of burned children. Nursing (Lond) 1990;4:7–12.

[24] Abramson M. Group treatment of families of burn-injured patients. Soc Casework 1975;56:235–41.

[25] Leeder CJ. Families of burn victims receive help through regular group meetings. Burns 1979;5:89–91.

[26] McHugh ML, Dimitroff K, Davis ND. Family support group in a burn unit. Am J Nurs 1979;79:2148–50.

[27] Cahners SS, Bernstein NR. Rehabilitating families with burned children. Scand J Plast Reconstr Surg 1979;13:173–5.

[28] Cook T. Psychosocial assessments of families on a pediatric burn center. 1982.

[29] Torraco RJ. Writing integrative literature reviews: guidelines and examples. Hum Resource Dev Rev 2005;4:356–67.

[30] Whittemore R, Knafl K. The integrative review: updated methodology. J Adv Nurs 2005;52:546–53.

[31] Yu Z, Bernstam E, Cohen T, Wallace BC, Johnson TR. Improving the utility of MeSH® terms using the topicalMeSH representation. J Biomed Inform 2016;61:77–86.

[32] Richter RR, Austin TM. Using MeSH (medical subject headings) to enhance PubMed search strategies for evidence-based practice in physical therapy. Phys Ther 2012;92:124–32.

[33] Barnett BS, Mulenga M, Kiser MM, Charles AG. Qualitative analysis of a psychological supportive counseling group for burn survivors and families in Malawi. Burns 2017;43:602–7.

[34] McGarry S, Elliott C, McDonald A, Valentine J, Wood F, Girdler S. "This is not just a little accident": a qualitative understanding of paediatric burns from the perspective of parents. Disabil Rehabil 2015;37:41–50.

[35] Ravindran V, Rempel GR, Ogilvie L. Embracing survival: a grounded theory study of parenting children who have sustained burns. Burns 2013;39:589–98.

[36] Rivlin E, Forshaw A, Polowyj G, Woodruff B. A multidisciplinary group approach to counselling the parents of burned children. Burns Incl Therm Inj 1986;12:479–83.

[37] 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.

[38] Willebrand M, Sjoberg F, Huss F, Sveen J. Parents' perceived quality of pediatric burn care. J Crit Care 2018;43:256–9.

[39] Willebrand M, Sveen J. Perceived support in parents of children with burns. Gen Hosp Psychiatry 2016;38:105–8.

[40] CASP-cheklists, (Critical Appraisal Skills Programme). Critical Appraisal Skills Programme (CASP). In: Ltd BVH, editor. http://www.casp-uk.net2017.

[41] Modesti PA, Reboldi G, Cappuccio FP, Agyemang C, Remuzzi G, Rapi S, et al. S1 Text: NEWCASTLE - OTTAWA QUALITY ASSESSMENT SCALE (adapted for cross sectional studies). Panethnic differences in blood pressure in europe: a systematic review and meta-analysis. http://journals.plos.org/plosone/article/file?type=supplementary&id=info:doi/10.1371/journal.pone.0147601.s0012016.

[42] Dreyer PS, Pedersen BD. Distanciation in Ricoeur's theory of interpretation: narrations in a study of life experiences of living with chronic illness and home mechanical ventilation. Nurs Inq 2009;16:64–73.

[43] QSR International Pty Ltd. NVivo qualitative data analysis Software, Version 11. 2018.

[44] Bowden ML, Feller I. Family reaction to a severe burn. Am J Nurs Sci 1973;73:317–9.

II

1874-4346/19 *Send Orders for Reprints to reprints@benthamscience.net*

The Open Nursing Journal

Content list available at: https://opennursingjournal.com

RESEARCH ARTICLE

Staff Members' Experience of Providing Parental Support in a National Burn Centre

L.S.T. Lernevall[1,2,*], A.L. Moi[1,3], E. Gjengedal[2] and P. Dreyer[2,4]

[1] *Department of Plastic, Hand and Reconstructive Surgery, National Burn Centre, Haukeland University Hospital, Bergen, Norway.*
[2] *Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway.*
[3] *Department of Health and Caring Sciences, Western Norway University of Applied Sciences, Bergen, Norway.*
[4] *Department of Public Health, Section of Nursing, Aarhus University, Aarhus, Denmark.*

Abstract:

Background

Paediatric burn injuries affect not only the child but the whole family, especially the parents. Knowledge of how parents are affected psychologically has increased, but there is an ongoing dearth of literature on parental support while hospitalised. There is also very little documentation of the ways in which burn staff members support parents.

Objectives

To explore staff members' lived experiences of supporting parents with children hospitalised at a burn centre due to a burn injury.

Methods

Four focus group interviews were conducted in 2017 with a total of 21 staff members at the National Burn Centre in Norway. Seven different burn staff professions participated. Data were analysed using a Ricoeur-inspired method for text analysis and managed using NVivo 12Plus.

Results

Four themes were identified in the treatment trajectory: creating a safe, secure and trusting environment from the moment parents enter the burn centre; helping parents deal with feelings of guilt; helping parents navigate in their daily routines while continuing to be a mother or father; and gradually involving parents in wound treatment as preparation for discharge.

Conclusion

Staff must carefully consider their verbal and non-verbal (body) language and how to approach parents from the very moment they enter the burn ward. Most parents are affected by feelings of guilt and these feelings must be addressed and processed. During the treatment trajectory, parents are guided to participate in the daily care of their child and are gradually assisted in taking over the wound treatment prior to discharge.

Keywords: Burns, Care, Child, Focus groups, Multidisciplinary care team, Parents, Phenomenological hermeneutical approach, Ricoeur.

Article History	Received: October 19, 2019	Revised: November 17, 2019	Accepted: November 19, 2019

1. INTRODUCTION

A major burn injury is among the most traumatic experiences due to severe pain related to the burn injury itself and subsequent reconstructive surgery, skin grafting and physical therapy [1]. A burn injury on a child affects the whole family [2]. The family's reaction is important because it also affects the wellbeing not only of the child but also of the parents [3]. The way a parent responds to a traumatic event and to the child's response affects the child's psychological recovery from the traumatic event [4, 5]. For instance, acute parental psychological distress and parental behaviour are shown to affect the child's behaviour during paediatric burn wound care [6].

In Europe, children represent 40-50% of all severe burn injuries; and among all childhood burns, children under five

---

[*] Address correspondence to this author at the Department of Plastic, Hand and Reconstructive Surgery, National Burn Centre, Haukeland University Hospital, Jonas Lies vei 65, 5021 Bergen, Norway; E-mail: lina.lernevall@helse-bergen.no

DOI: 10.2174/1874434601913010211, 2019, *13*, 211-219

years account for 50-80% of burn injuries [7]. In Norway, children aged 0-3 years have a twelve times higher risk of being hospitalised due to burn injuries than all other age groups [8, 9]. All children, especially the youngest, need their parents while hospitalised. Norwegian law therefore states that a child has the right to have one of its parents present during hospitalisation, and both parents if the injury is highly critical or life-threatening [10]. Most burn injuries are unintentional, and the majority of burn injuries in children occur at home (80-90%) [7]. Most children are with a relative when the burn injury happens: in 12% both parents are present, in 26% mothers are present and in 18% other relatives are present [11]. Many parents therefore witness the burn accident without being able to prevent it.

How parents are affected by their child's burn injury is well-documented. Many parents of burn-injured children struggle with feelings of guilt [12 - 16], anger [16, 17], depression [18 - 20] and anxiety [18, 20]. Many parents also experience that they blame themselves or that they are blamed by their partner [17], family members, the burn-injured child, health professionals or others [21, 22]. Studies show that parents of burn-injured children can be affected by symptoms of posttraumatic stress disorder (PTSD) [5, 16, 18, 23 - 30], but that the PTSD symptoms decrease over time [5, 16, 24 - 26, 29]. In a review, it was found that 43-69% of parents reported general anxiety during the acute phase, and 47% reported clinically significant posttraumatic stress symptoms (PTSS) during the first months after the burn accident [3]. Another study found similar numbers, reporting that 69% of parents had clinically significant anxiety and 44% of parents had clinically significant depression at the inpatient stage. These percentages decreased to 33% and 22%, respectively, 6 to 24 months after the burn [20]. Additionally, parents can struggle with low self-confidence and self-doubt [31], feel isolated or lonely [17, 32], be overprotective [17, 31] or try to avoid fear [30]. Studies also report that parents encounter difficulties in returning home after being hospitalised [17, 22, 33, 34] and experience conflict with their partner [17] or financial problems [22].

If parents are affected by guilt, PTSS, anxiety or depression, their ability to support their child positively is weakened, for instance, during burn wound care [6]. It is therefore extremely important that these parents receive the support and help they need. In an integrative review [35], it was concluded that staff members should address parental feelings (such as guilt, blame and distress) and parental needs (such as for support and information). To improve the experience of wound treatment, it was recommended in a new study to support parents with psychological and behavioural instruction prior to burn wound treatment [6].

If a parent has high parental anxiety combined with ineffective coping strategies, the child is at great risk of having a non-adaptive outcome after the burn injury [36]. Clearly, there should be more focus on parental support as it profoundly affects the burn-injured child's coping and outcomes. To generate more knowledge on parental support in relation to paediatric burn injuries, we explored staff members' lived experiences of supporting parents.

2. MATERIALS AND METHODS

2.1. Study Design

This particular study is one part of a multi-phase study examining parental needs for support when their child is hospitalised at a burn centre due to a burn injury. We adopted a phenomenological-hermeneutic approach based on the philosophy of the French philosopher Paul Ricoeur [37]. According to Ricoeur, experiences captured in a text hold "the others mind's experiences" [38]. To grasp the meaning of the text, interpretation is therefore a necessity. By approaching a text with interpretation, understanding is crucial, which is a cornerstone in hermeneutics. To grasp the burn team members' experiences of parental support, focus group interviews were used. In focus group interviews, participants are encouraged to talk with each other rather than with the interviewer, which often leads to discussion or clarifications of opinions [39, 40]. Using focus groups interviews as a data collection technique is particularly useful when examining work place cultures as it highlights group norms and cultural values [39]. The combination of focus groups and phenomenology is beneficial as it supports collaboration and dialogue, stimulates discussion, brackets prejudices among participants as their opinions are being challenged by others and opens up new perspectives [41]. Using focus groups in a phenomenological study enhances the quality as "the phenomenon being researched comes alive within the group" [41]. The transcribed interviews constitute the data to be analysed. A text analysis method inspired by Ricoeur [37] was used to gain deeper understanding of staff members' lived experiences.

2.2. Setting

At the end of 2018, Norway had 5.3 million citizens [42]. The most severe burn casualties in Norway are transferred to the National Burn Centre (NBC) where patients of all ages are treated (50 children annually, which is one third of all admitted burn patients at the NBC) [43]. The NBC has five burn intensive care unit beds and can treat eight hospitalised burn patients simultaneously. The length of stay at the NBC is calculated to be 1-1 ½ days per percentage of total body surface area (TBSA) burned skin [44]. Burn treatment is undertaken by a multidisciplinary team consisting of nurses (only registered nurses work at the NBC) including intensive care nurses and nurse anaesthetists, plastic surgeons, anaesthesiologists and physiotherapists. In addition, there are cleaning assistants and office personnel. When needed, assistance is also provided by other professions employed elsewhere at the university hospital, such as hospital clowns, social workers, psychologists, psychiatrists, priests and kitchen workers.

2.3. Participants and Recruitment

Staff members from eight professions at the NBC who regularly care and treat burn-injured children and their parents were invited using purposive sampling. This included critical care nurses, hospital clowns, hospital priests, nurse anaesthetists, physiotherapists, plastic surgeons, psychologists and social workers. For professions of two to five employees, all staff members were invited to participate. The head nurse at the

NBC made a list of the nurses chosen to care for children and their families, including nearly half of the nurses. All leaders of the different professions were invited to participate in a focus group consisting of leaders only.

Written information was sent by mail to all leaders who forwarded the invitation to staff members. Those interested in participating contacted the main author (LSTL) to arrange the interview date. To ensure variation in experiences of parental support, more than one health care professional within each professional group participated. Small-numbered professions were asked to participate on different days in order to increase variation in the perspectives in the group discussions.

2.4. Data Collection

Three focus group interviews with a total of 16 staff members (n=3, 5 and 8), representing seven professions, were conducted in May and June 2017. In October 2017, the focus group interview with the leaders (n=5) was conducted. All leaders had working experience of parental support, and all were still working with patients at the NBC (Table **1**).

EG, a professor and intensive care nurse experienced in conducting focus group interviews and having no earlier collaboration with the participants facilitated all of the focus group interviews. Also present was an observer (LSTL), who summed up the interview at the end. LSTL had worked at the NBC in the year prior to the interview and knew the participants. Staff members were asked about how they support parents of children who had sustained an accidental burn, excluding those in whom the burn was a result of child abuse.

All four focus group interviews lasted for two hours and were recorded using three digital voice recorders. The interviews took place in a remote meeting room outside the NBC during working hours. The interviews were transcribed verbatim by LSTL directly after the interviews took place.

2.5. Data Analysis

When conducting focus group interviews to better understand people's lived experience, spoken language becomes the research data, and transcribed interviews are the texts to be analysed. To understand a text is to look at the whole text to recognise its parts. Ricoeur writes that one should follow the movements of the text "from sense to reference: from what it says, to what it talks about" [38]. It is a circular process: when construing the details, we construe the whole [38]. In this circular process, a text's depth is opened up to allow us to discover "the sense of the text" [38]. This model implies that during analysis, the researcher moves back and forth between the different parts and in a circular move between explanation and comprehension. By following the text, looking for what it says and what it speaks about, the researcher tries to understand its meaning.

The interpretation of the four focus group interviews was divided into three stages: a naïve reading, a structural analysis, and critical analysis and discussion [37]. With the naïve reading, the researcher gets acquainted with the text and writes a short narration about this first impression. The researcher tries to get an "immediate understanding of the meaning content" [37]. In our study, the transcripts of all four focus group interviews were read to give a sense of the whole material, the text as a whole. Then a short text (about one A-4 page) was written, describing this first spontaneous impression used for further analysis.

The next stage is a structural analysis which consists of the following three steps: first, meaning-bearing units are identified, "What is said in the text?"; second, significance-bearing units are found, "What does the text talk about?"; and, third, themes are created [37]. In our study, we interpreted the text, exploring sections or paragraphs across the data to understand "What is said in the text". Sections with quotations were highlighted and grouped. Then we examined each created group to see "What the text talks about?". To distance ourselves from the text and the interpretation, an interpretation text was created (Table **2**).

After this, the interpretation texts are given a name, a theme, which distances the researcher even more from the text. During this process, we thematised and named each interpretation text, looking at the two previous steps to check that the themes given related to it all.

During all three steps, the researcher moves between explanation and comprehension, from understanding the whole, to the parts, to the whole again, in a hermeneutic circle [37].

The third stage involves critical analysis and discussion. To 'grasp' an in-depth understanding of the interpreted themes in the structural analysis, a critical discussion is performed. To reach an in-depth interpretation, the findings from the structural analysis are critically discussed in relation to relevant literature, such as research studies, philosophical texts and clinical experiences.

Data were managed using QSR International's NVivo 12 Plus qualitative data analysis software [38 - 45].

Table 1. Participant characteristics (n=21).

Sex of Participants	Females (n=18) and males (n=3)
Number of professions	7
Distribution among the professions	Anaesthesiology and intensive care nurses (n = 11) Doctors, hospital clowns, physiotherapists, psychologists and social workers (n = 10)
Working experience Mean (min-max)	14 years (10 months to 35 years)

Table 2. An example of the structural analysis.

Meaning-bearing Units (What is said in the text?)	Significance-bearing Units (What does the text talk about?)	Theme
"It's tremendously important to see to this at once: That the parents feel secure, that they can trust us and assure them that their child will get the very best treatment". "I think a lot about how we meet them. You know, the very first meeting when they come in, it means so much for the contact". "Yes, we think a lot about how we meet them, and that they should feel safe with us. Feeling safe about themselves and their child. It's tremendously important to establish that right from the start. That we, through what we say and how we behave verbally, make them feel safe and well looked after". "Body language says a lot. How we walk around and not least what we say to each other. How we behave. They (the parents) see straightaway who's comfortable in their job". "I think that body posture and the way you are and the way you meet them. Showing respect is important as well". "They are in a crisis situation when they arrive". "And they need information in a crisis situation like that. What is going to happen now?" "We try to take care of them as soon as they come in the door". "If they are very anxious about what has happened, we try to calm them down. In the beginning, it is a good idea to give them something to drink or something like that". "That someone can look after the parents, while others take care of the child". "But it can be very different how they (the parents) react. Some get more confused and can't manage to organise themselves and need help. "Okay, you can sit here". "You can do this and this". ""Now you can do this, and then we will come and inform you afterwards." Yes. A lot of concrete information about what they can do". "It's very important to care for the parents also in the beginning, because they are very, very distressed, in a way. To show them that we care for them". …	From the moment the parents enter the door of the burn centre, staff members try to create a good connection and form a good relationship with them. They highlight that the very first meeting is particularly important for establishing contact with the parents and making them feel secure. Staff members immediately introduce themselves and their role while they think about what they communicate verbally and through their body language. Staff members analyse the situation: how the parents are doing and feeling. To reduce chaos and crisis, and to make them less confused and disorganised, the parents are given specific information. …	Creating a safe, secure and trusting environment from the moment parents enter the burn centre

3. RESULTS

The four themes will be presented in chronological order following the trajectory of hospitalisation. Even so, if parental needs revert to earlier needs staff members will address these. As an overall comprehensive understanding, staff members support the parents in maintain their parental role. This will be illuminated in the four themes to follow.

3.1. Creating a Safe, Secure and Trusting Environment from the Moment Parents Enter the Burn Centre

From the moment parents enter the door of the NBC, staff members try to establish a good connection and relationship. "*It's tremendously important to see to this at once: That the parents feel secure, that they can trust us and assure them that their child will get the very best treatment* (No. 9)". Staff members explain that they immediately introduce themselves and their role while thinking about what they communicate verbally and through their body language. They also analyse the situation: how the parents are doing and feeling. "*If they are very anxious about what has happened, we try to calm them down. In the beginning, it is a good idea to give them something to drink or something like that* (No. 2)".

To reduce chaos and crisis, and make the parents less confused and disorganised, they are given specific information such as "*Okay, you can sit here* (No. 16)" and "*You can do this and this* (No. 16)". Staff members state that they try to meet the parents with "*kindness and respect* (No. 11)". They acknowledge the parents as "*super-users* (No. 3 and 7, from two different focus groups)" and "*specialists* (No. 4)" on their child. During the first meeting, they need to exchange information with the parents and ask questions about the accident and the child in a gentle way. The parents' answers are important for staff members to be acquainted with the child but also to start treatment straightaway. They ask questions in ways that avoid condemning parents for the accident. To create an atmosphere where parents feel comfortable to talk about the accident, they withdraw from the hallway to an empty patients' room or a meeting room at the NBC. With the door closed, they sit down and talk. No matter how much work they have to do at the department, staff members say that they take the time needed to talk to the parents, and they are aware of not using too much time. "*They get tired very quickly and in a situation like that, we need to take care of them* (No. 16)". To make parents feel secure and familiar with the routines at the NBC, they are told who to contact if they need something, that staff members are nearby at all times, when food is served and the plan for the next day. They are also told that the surgeon will come and inform them about the burn injury: its size and depth, the treatment plan and how many in-hospital days to expect. "*We also update them continually about the status of their child, if there are changes and the reason why we do what we do* (No. 10)".

To reduce child and parental stress, the staff organise things so that few people treat the family, with primary or contact nurses appointed to ensure continuity. "*...we try to be the same individuals that deal with the family* (No. 12)". Usually, all parents also meet with the same child psychologist and social worker. To make parents feel safe, it is important that they meet the same people. "*Something the parents say all the time is that they want the same hospital clowns. They want the same ones to come repeatedly. I understand them very well* (No. 13)". To reassure parents, the staff tell them that they have reached the final hospital department for treatment and that their child will be treated until it is healthy again. "*They have often been at the local hospital and regional hospital and then they end up here with us. There has been a lot of insecurity, clamouring and shrieks before they end up here. We signal that they have reached the end station when they come to us* (No.19)".

3.2. Helping Parents Deal with Feelings of Guilt

In order to try to help parents with their feelings of guilt, staff members report taking the initiative to talk about the guilt openly and on many occasions. They explain that accidents can happen to everyone. "*One of the first things I say to them is "That an accident can occur to all of us", that it has happened to other parents before and will happen to other parents in the future* (No. 6)". Some staff members explain in general terms what they have seen before and how it turned out for those families. "*That it turned out very well and that they are back to their normal lives. That life continues, also after all of this* (No. 6)". By sharing this information, they try to help parents deal with their guilt and live with it. Sometimes, they have to tell parents to focus on their child instead of the guilt. "*Okay, what you might have to say to yourself is that it actually was your mistake, for what you did. But a mistake is something everyone can make. This has had a consequence, but it won't help your child or yourself if you go around criticising yourself in the future. There comes a time where you have to say "Okay, this happened" and move on"* (No. 1)". All professions except the hospital clowns report approaching the issue of guilt. The hospital clowns avoid the issue of guilt and instead move the focus from guilt to the child. The other professions listen to the parents and inform them about normal reactions for parents and children.

Staff members explain that they always try to acknowledge the parents' feelings and meet and care for each parent equally and that they try to be open-minded and unprejudiced towards the parents despite the course of the accident and what they might think themselves. "*No matter which nationality or how the accident happened, everyone will get the same care* (No. 15)".

One way of strengthening parents is to praise them for what they did right and thereby reduce their guilt. This may be done, for instance, by emphasising their good decisions when the accident happened, like quickly calling for help and putting the child in the shower, cooling the burned area and minimising the depth of the burn. "*It was really remarkable that you reacted so quickly and removed the clothes, because, although the accident happened, in doing that, you may have reduced the injury* (No. 12)".

If others were responsible for the accident, staff members also help parents let go of their anger toward them. If one parent is to blame for the accident, staff members have seen some couples getting into a conflict. Usually, parents are left to handle the conflict on their own. If they cannot stand being together, an arrangement is made so that only one parent is with the child at any time. If couples blame each other, psychologists have to "*handle the situation* (No. 16)" and help them focus on what is best for their child. "*They can't manage being normal or supporting the normal development of their child, which will make it even more difficult for the child. Not only did they cause the injury but they drop out of their normal parental role, and things get very insecure* (No. 21)".

To help parents optimally, staff members describe supporting each other by talking and discussing among themselves. Previously, staff members were taught and trained in how to handle crisis reactions. That knowledge has since been passed on to new staff members. Even though most staff members have two or three decades of experience of working with burn injuries, they can still be challenged to find the right words. "*But to really say something complementary rather than just saying "I understand that it's painful for you", that's difficult! And it's not always easy in the moment* (No. 15)".

3.3. Helping Parents Navigate in their Daily Routines while Continuing to be a Mother or Father

Despite what happened, it is important for staff members that parents continue being the parents of their child and act accordingly. Therefore, they explain that they encourage parents to carry out as many of their normal routines as possible while hospitalised, because this is beneficial for the child. "*Parents can brush the children's teeth and sit in the bed and read a book, that the parents carry out all the normal things* (No. 17)". In order to include parents in the care, they are asked to pay attention to what the child is eating; for instance, if he/she receives enough protein. Parents are thereby given some responsibility for the care of their child.

Even though parents are encouraged to be active and participate in the daily care of their child, it is important for staff members that certain rules are clarified. Redirecting parents later if they make their own rules and routines will not help the child, but instead make things more difficult. "*Because, if we don't do it, they will make their own routines and solve tasks their way, and it's not advantageous for how we want it to be. They postpone training with the physiotherapist, what time they have to eat, what time they have to be active and stuff like that. And if they continue doing things their own way, things will be delayed and they..., the treatment won't be adequately executed, and then there will be* *more operations, and the wounds won't heal* (No. 3)". Parents are, for instance, informed about the strict hygienic rules at the department. These rules have been implemented to minimise potential infections that would prolong the hospital stay. Expectations of parental presence and participation are clarified immediately on arrival. Some parents, both foreigners and Norwegians, think that they can leave the child at the NBC, letting staff members care for the child while they only come to visit. In these cases, staff members have to explain the laws that apply in Norway: a child has the right to have one parent by its side at any time. "*Except when there is wound treatment in anaesthesia or operations. Except for that, we expect parents to be with the child all the time* (No. 4)".

Being a good parent also includes attending to one's own fundamental needs while being there for the child. "*To take care of their child in a good way, they also need to take care of themselves; basic needs, that they eat, sleep and get some breaks* (No. 16)". If a parent needs some hours at the hospital hotel, some staff members will help to give them breaks and relieve them of their care duty. Some staff members "*accept that they stay a little at the hospital hotel, sleep a little, that they take a shower. Get some air, let go of their thoughts. Just exist* (No. 2)". And some staff members say that they occasionally perform caring acts like changing a diaper and taking the temperature. Doing too much, nannying or getting too service-minded can complicate matters for the next staff member working with the parents, and may result in divisions among staff members. Therefore, they strive to approach the parents equally and try to resist the temptation to perform ordinary parental caring activities. "*It is tempting sometimes, when you see that they are a little clumsy and that. But I think one gains a lot by letting them do at least some things with the child. So they feel a little bit that they have control. Like changing diapers, for instance; they always dread it, if a child has a lot of wounds by the genitals. In that case, they don't want to do it, but then I force them a little bit to change the diaper. Simply making it harmless. Because then they feel that "this wasn't dangerous"* (No. 3)".

3.4. Gradually Involving Parents in Wound Treatment as Preparation for Discharge

During medical procedures, staff members need parents to participate actively and support their child, such as holding the child close. "*I am here with you, even though it hurts. I will not leave you when something happens to you* (No. 4)". In relation to operations or wound treatments in anaesthesia, the child is given anaesthetic drugs. To make it less traumatic for the child, parents are guided in how to hold their child in their arms until it fades away or falls asleep due to the anaesthesia. When the child is unconscious, parents are told to leave the room to protect them from seeing unpleasant things such as staff members scratching and scouring the wounds. "*The first time they come in for the anaesthesia and see their child fall asleep, looking unconscious, and they have to leave him while we treat the wounds. Right. It's very traumatic for them and it's an art to take care of them, to take them outside and explain what is happening, and make sure that they are taken care of the first time. Then, it might be better the next time, because there are often several wound treatments like the first one* (No. 4)". Staff members explain how they make sure to have enough time before and after wound treatment to take care of the parents. They give thorough information prior to these treatments and feedback afterwards explaining what has been done, why, and how it looks. They answer questions, correct the parents if necessary, and add more information as parents get more comfortable and secure. The information is repeated again and again, because most parents forget the oral information they have been given.

When parents see the wounds for the first time (wound treatment without anaesthesia), staff members protect them by preparing them since they have not seen the burn wounds since admission. "*We want parents to attend wound care sessions as quickly as we think it's good for the parents and the child. It's important not to create another traumatic experience by letting them participate too early* (No. 2)". During wound treatments with a child that is awake and with parents present, hospital clowns or iPads are used as "*a distraction* (No. 16)". Some staff members also try to divert the child themselves. However, in diverting not only the child but also its parents, the hospital clowns play a unique role. "*It's magical to watch how both the children and their parents respond when hospital clowns enter the room* (No. 1)". Hospital clowns are present during procedures, react in a normal way and feel more equal to the parents since they are not associated with any procedures, and they are the only profession not obliged to give any information to the parents. "*That's our advantage, because we have no information to give to them. In a way, we are their free minute, their break, the breathing space that they... yeah, everyone needs* (No. 5)".

Staff members want parents to participate in wound treatment prior to discharge to make transitioning home easier. By educating parents, they want them to become experts on the burn care of their child with respect to how to manage the wounds at home and treat the scars. They tell parents that their approach towards the scar will affect the child. "*If you stress and bother about this little scar, that's how it will be. The child does not remember, so tell the story and let the child own the scar, so it becomes a natural part of the child itself* (No. 6)".

Before leaving the NBC, staff members encourage parents to call the department if they have questions after discharge. Some parents do call and most often, they want to talk to the physiotherapists regarding pressure garments and aftercare. Sometimes they want to talk to the primary nurse, but if that person is off duty, it is difficult for other staff members to provide adequate help.

4. DISCUSSION

In this study, support was described as an act of caring not only for the patient (the child) but also for its parents. Right from the first meeting at the NBC, staff members meet parents in a way furthering the development of a trusting relationship. Both in care and in treatment, the whole family (child and parents) was included in the daily burn care. This is in line with family-centred care (FCC), a model where the unlimited presence, negotiation and involvement of the family is vital to the child's world [46]. In FCC, there are three core principles: partnership, participation and protection [46]. *Partnership* means relationship and collaboration in an honest, equal, respectful and trusting way [46]. This is accomplished right from the moment parents enter the NBC by focusing on creating a trusting relationship. *Participation* is when the type and level of involvement are decided by the family [46]. Our study shows that parents are voluntarily involved in the care but also sometimes persuaded based on the law, which stipulates that a child needs its parents, and parents are encouraged to take an active part in caring for their child. *Protection* refers to the family's or child's right to receive the best physical, emotional, psychosocial and spiritual care [46]. This core principle of FCC is also fulfilled, as staff offer the parents space and time for emotional expression, and the care provided is adjusted to their needs. All of these aspects are in keeping with the European Burns Associations practice guidelines for burn care [47]. Staff also inform parents as a means of creating a trusting atmosphere and relationship with the parent. In another study within burn care, it was highlighted that FCC implemented in burn units increased collaboration between families and staff members [33].

We show that staff members find it important to talk with parents about their feelings of guilt; not necessarily to make these feelings go away but instead to help them deal with or accept what has happened. The Norwegian nursing philosopher Kari Martinsen has asserted that giving comfort is not about removing grief, pain and suffering [48]. That would be to "comfort it away" as she calls it [48]. Instead, one should help the other to be in the grief, the pain and the hopelessness [48]. We show that staff members helped parents to stay in their feeling of guilt by talking openly about the guilt with the parents, with staff listening to parents and acknowledging their feelings. As such, one could argue that staff members helped parents to embrace their emotions instead of running away from them. At the same time, some parents need help to avoid being stuck in guilt rumination. This can be seen as a balance between, on the one side, accepting what has happened with the feelings attached and, on the other side, focusing on the child and how to overcome this traumatic event. This is similar to the dialectic movement in the Dual Process Model of Coping with Bereavement model by professors Margaret Stroebe and Henk Schut from Utrecht University [49]. They have argued that a grieving process is a dialectic movement between the two poles of loss-oriented and restoration-oriented coping. Staff members caring for these parents should therefore be attentive to how parents handle guilt and help them when needed.

In our study, a challenge about daily routines is described regarding staff members' expectation that parents are there for the child at all times while also seeing to their own fundamental needs. Should staff members demand that parents are present or facilitate breaks during the day? This is a difficult dilemma. In our study, staff members tried to solve the problem by considering individual needs.

To protect parents from being more traumatised by seeing wound care in the acute stage, parents were not allowed to be present during wound treatment in anaesthesia. As the wounds healed and the child could be awake, parents could participate by slowly taking over the responsibility. At this stage of treatment, hospital clowns had the unique ability to care for the child and its parents. Thus, in a systematic review and meta-analysis on therapeutic clowns in paediatrics, it was concluded "that hospital clowns play a significant role in reducing stress and anxiety levels" [50] of both hospitalised children and their parents. In a study from 2017, 84.8% of the participating parents considered clowns to be beneficial for their child, themselves and the caregivers [51]. Burn units should discuss the advantage of having hospital clowns as part of the burn team when providing parental support.

4.1. Limitations and Strengths of the Study

An important point to be made that we here assess staff members' perceptions of parental support, not the parents' actual experience and needs. It is important to understand the staff's perceptions of how they provide support, but their perceptions may not correspond with what parents really need.

When conducting focus group interviews, it is an advantage that the group is homogeneous [52]. One could argue that the inclusion of different professions from the same department does not meet that criterion as there often are hierarchical relations. The danger of such group dynamics is that some individuals might be silenced [39]. Despite the presence of such hierarchical relations, staff members were in much in agreement in their answers regarding how to support parents. This can be seen as a cultural behaviour at the NBC and as a glimpse of the existing supporting culture. A decade ago, the combination of focus groups and phenomenology might have been seen as a methodological 'oxymoron', but since the debate about this within nursing research started in 2009 [41], it has become more common to combine the two. The combination of focus groups and phenomenology is beneficial as it stimulates discussion about the phenomenon under study [41], which we have demonstrated with our study.

Two guidelines for qualitative research [53, 54] were used to ensure that all essential elements were reported. This contributes to transparency and trustworthiness. Because of the verbatim transcriptions and the detailed step-by-step analysis, the decisions and procedures may be said to strengthened the transparency and trustworthiness of the study. Another strength of the present study is that facilitation and moderation of the interview were undertaken by a person familiar with the field and a person who was not familiar with the field, but who was experienced with the method.

The Ricoeur-inspired method [37] was chosen as it offers an easy-to-follow step-by-step method where the second step in the structural analysis can be copy-pasted into an article manuscript. PD, who developed the method used in the present study, used her expertise to validate that the analytical process was correctly executed. This method aims to generate comprehensive understanding of the lived experience as reflected in a text. It is a model for in-depth analysis that brings the researcher closer to "being in the world" [37] with a view to understanding what the text says.

CONCLUSION

We show that healthcare professionals resort to different strategies to assist parents' coping strategies. The first strategies aim at making parents feel safe and secure from the moment they enter the ward. Then, parents are helped to process their feelings of guilt. After this, they are supported while participating in the daily care of their child at the ward, and, lastly, they are assisted in gradually taking over wound treatment prior to discharge.

AUTHOR'S CONTRIBUTIONS

Study design: All authors. Focus group interviews: EG (interviewer), LSTL (moderator). Transcription: LSTL. Analysis: LSTL discussed with all authors. Manuscript preparation: LSTL. Revisions and final approval of the article: all authors.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Ethical approval was obtained from the Norwegian Regional Committees for Medical and Health Research Ethics (REC) project number: 2017/54/REK, Norway.

HUMAN AND ANIMAL RIGHTS

Not applicable.

CONSENT FOR PUBLICATION

Inform consent has been obtained from all the participants.

AVAILABILITY OF DATA AND MATERIALS

Not applicable.

FUNDING

The Western Norway Regional Health Authority (Helse Vest). Funder ID: https://orcid.org/members/0010f00002IM4UGAA1-western-norway-regional-health-authority.
Awards/Grant number: 912138.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

ACKNOWLEDGEMENTS

A profound “thank you” to all staff members at the National Burn Centre in Norway, who during a busy workday took the time to participate and share their knowledge.

Also, a big acknowledgement to the four parents with personal experience, who throughout LSTL’s PhD were sparring partners as part of user involvement in the research.

REFERENCES

[1] Wiechman SA, Patterson DR. ABC of burns. Psychosocial aspects of burn injuries. BMJ 2004; 329(7462): 391-3. [http://dx.doi.org/10.1136/bmj.329.7462.391] [PMID: 15310609]

[2] Phillips C, Fussell A, Rumsey N. Considerations for psychosocial support following burn injury--A family perspective. Burns 2007; 33(8): 986-94. [http://dx.doi.org/10.1016/j.burns.2007.01.010] [PMID: 17624678]

[3] Bakker A, Maertens KJ, Van Son MJ, Van Loey NE. Psychological consequences of pediatric burns from a child and family perspective: A review of the empirical literature. Clin Psychol Rev 2013; 33(3): 361-71. [http://dx.doi.org/10.1016/j.cpr.2012.12.006] [PMID: 23410718]

[4] Lieberman AF. Traumatic stress and quality of attachment: Reality and internalization in disorders of infant mental health. Infant Ment Health J 2004; 25(4): 336-51. [http://dx.doi.org/10.1002/imhj.20009]

[5] De Young AC, Hendrikz J, Kenardy JA, Cobham VE, Kimble RM. Prospective evaluation of parent distress following pediatric burns and identification of risk factors for young child and parent posttraumatic stress disorder. J Child Adolesc Psychopharmacol 2014; 24(1): 9-17. [http://dx.doi.org/10.1089/cap.2013.0066] [PMID: 24494782]

[6] Brown EA, De Young A, Kimble R, Kenardy J. Impact of parental acute psychological distress on young child pain-related behavior through differences in parenting behavior during pediatric burn wound care. J Clin Psychol Med Settings 2019; 26(4): 516-29. [http://dx.doi.org/10.1007/s10880-018-9596-1] [PMID: 30610521]

[7] Brusselaers N, Monstrey S, Vogelaers D, Hoste E, Blot S. Severe burn injury in Europe: A systematic review of the incidence, etiology, morbidity, and mortality. Crit Care 2010; 14(5): R188. [http://dx.doi.org/10.1186/cc9300] [PMID: 20958968]

[8] Onarheim H, Brekke R, Heisterkamp H, Guttormsen AB. Burns admitted to Norwegian hospitals in 2012 - A national survey. The 17th Congress of the International Society for Burn Injuries (ISBI). Sydney, Australia. 2014.

[9] Brekke RJ, Heisterkamp H, Guttormsen AB, Onarheim H. Høy forekomst av brannskade hos småbarn i innvandrerfamilier. Vitenskapelige forhandlinger, 90 Høstmøtet i Norsk Kirurgisk Forening; Holmenkollen Park Hotell, Oslo, Norway 2014.

[10] Forskrift om barns opphold i helseinstitusjon av 1. desember 2000 nr 1217, 2000.

[11] Delgado Pardo G, Moreno García I, Marrero FR, Gómez Cía T. Psychological impact of burns on children treated in a severe burns unit. Burns 2008; 34(7): 986-93. [http://dx.doi.org/10.1016/j.burns.2008.01.016] [PMID: 18511201]

[12] Kornhaber R, Childs C, Cleary M. Experiences of guilt, shame and blame in those affected by burns: A qualitative systematic review. Burns 2018; 44(5): 1026-39. [http://dx.doi.org/10.1016/j.burns.2017.11.012] [PMID: 29454710]

[13] Sveen J, Willebrand M. Feelings of guilt and embitterment in parents of children with burns and its associations with depression. Burns 2018; 44(5): 1135-40. [http://dx.doi.org/10.1016/j.burns.2018.02.005] [PMID: 29929898]

[14] Barnett BS, Mulenga M, Kiser MM, Charles AG. Qualitative analysis of a psychological supportive counseling group for burn survivors and families in Malawi. Burns 2017; 43(3): 602-7. [http://dx.doi.org/10.1016/j.burns.2016.09.027] [PMID: 27743733]

[15] Rivlin E, Faragher EB. The psychological sequelae on mothers of thermally injured children and adolescents: future directions: Part 3. Dev Neurorehabil 2007; 10(2): 183-90. [http://dx.doi.org/10.1080/17518420701309758] [PMID: 17687991]

[16] Egberts MR, van de Schoot R, Geenen R, Van Loey NEE. Parents’ posttraumatic stress after burns in their school-aged child: A prospective study. Health Psychol 2017; 36(5): 419-28. [http://dx.doi.org/10.1037/hea0000448] [PMID: 27929329]

[17] McGarry S, Elliott C, McDonald A, Valentine J, Wood F, Girdler S. “This is not just a little accident”: A qualitative understanding of paediatric burns from the perspective of parents. Disabil Rehabil 2015; 37(1): 41-50. [http://dx.doi.org/10.3109/09638288.2014.892640] [PMID: 24576308]

[18] Willebrand M, Sveen J. Perceived support in parents of children with burns. Gen Hosp Psychiatry 2016; 38: 105-8. [http://dx.doi.org/10.1016/j.genhosppsych.2015.10.004]

[19] El Hamaoui Y, Yaalaoui S, Chihabeddine K, Boukind E, Moussaoui D. Depression in mothers of burned children. Arch Women Ment Health 2006; 9(3): 117-9. [http://dx.doi.org/10.1007/s00737-006-0124-1] [PMID: 16583152]

[20] Phillips C, Rumsey N. Considerations for the provision of psychosocial services for families following paediatric burn injury--A quantitative study. Burns 2008; 34(1): 56-62. [http://dx.doi.org/10.1016/j.burns.2006.12.003] [PMID: 17618055]

[21] Ravindran V, Rempel GR, Ogilvie L. Parenting burn-injured children in India: A grounded theory study. Int J Nurs Stud 2013; 50(6): 786-96. [http://dx.doi.org/10.1016/j.ijnurstu.2012.06.011] [PMID: 22795907]

[22] Ravindran V, Rempel GR, Ogilvie L. Embracing survival: A grounded theory study of parenting children who have sustained burns. Burns 2013; 39(4): 589-98. [http://dx.doi.org/10.1016/j.burns.2012.12.016] [PMID: 23375535]

[23] Hall E, Saxe G, Stoddard F, *et al.* Posttraumatic stress symptoms in parents of children with acute burns. J Pediatr Psychol 2006; 31(4): 403-12. [http://dx.doi.org/10.1093/jpepsy/jsj016] [PMID: 15788717]

[24] Bakker A, Van Loey NE, Van Son MJ, Van der Heijden PG. Brief report: mothers’ long-term posttraumatic stress symptoms following a burn event of their child. J Pediatr Psychol 2010; 35(6): 656-61. [http://dx.doi.org/10.1093/jpepsy/jsp090] [PMID: 19846581]

[25] Fukunishi I. Posttraumatic stress symptoms and depression in mothers of children with severe burn injuries. Psychol Rep 1998; 83(1): 331-5.

[http://dx.doi.org/10.2466/pr0.1998.83.1.331] [PMID: 9775690]

[26] Bakker A, Van der Heijden PGM, Van Son MJM, Van Loey NEE. Course of traumatic stress reactions in couples after a burn event to their young child. Health Psychol 2013; 32(10): 1076-83. [http://dx.doi.org/10.1037/a0033983] [PMID: 23957899]

[27] Odar C, Kirschman KJB, Pelley TJ, Butz C, Besner GE, Fabia RB. Prevalence and correlates of posttraumatic stress in parents of young children postburn. J Burn Care Res 2013; 34(3): 299-306. [http://dx.doi.org/10.1097/BCR.0b013e31825ae15d] [PMID: 23128125]

[28] McGarry S, Girdler S, McDonald A, Valentine J, Wood F, Elliott C. Paediatric medical trauma: The impact on parents of burn survivors. Burns 2013; 39(6): 1114-21. [http://dx.doi.org/10.1016/j.burns.2013.01.009] [PMID: 23465789]

[29] Egberts MR, van de Schoot R, Geenen R, Van Loey NEE. Mother, father and child traumatic stress reactions after paediatric burn: Within-family co-occurrence and parent-child discrepancies in appraisals of child stress. Burns 2018; 44(4): 861-9. [http://dx.doi.org/10.1016/j.burns.2018.01.003] [PMID: 29657096]

[30] Willebrand M, Sveen J. Injury-related fear-avoidance and symptoms of posttraumatic stress in parents of children with burns. Burns 2016; 42(2): 414-20. [http://dx.doi.org/10.1016/j.burns.2015.08.004] [PMID: 26775217]

[31] Horridge G, Cohen K, Gaskell S. BurnEd: parental, psychological and social factors influencing a burn-injured child's return to education. Burns 2010; 36(5): 630-8. [http://dx.doi.org/10.1016/j.burns.2009.08.013] [PMID: 19875239]

[32] Heath J, Williamson H, Williams L, Harcourt D. Parent-perceived isolation and barriers to psychosocial support: A qualitative study to investigate how peer support might help parents of burn-injured children. Scars, Burns & Healing 2018; p. 4. [http://dx.doi.org/10.1177/2059513118763801]

[33] Öster C, Hensing I, Löjdström T, Sjöberg F, Willebrand M. Parents' perceptions of adaptation and family life after burn injuries in children. J Pediatr Nurs 2014; 29(6): 606-13. [http://dx.doi.org/10.1016/j.pedn.2014.06.010] [PMID: 25046370]

[34] Rivlin E, Forshaw A, Polowyj G, Woodruff B. A multidisciplinary group approach to counselling the parents of burned children. Burns 1986; 12(7): 479-83. [http://dx.doi.org/10.1016/0305-4179(86)90073-2] [PMID: 3779470]

[35] Lernevall LST, Moi AL, Cleary M, Kornhaber R, Dreyer P. Support needs of parents of hospitalised children with a burn injury: An integrative review. Burns 2019. S0305-4179(18)30581-3 [http://dx.doi.org/10.1016/j.burns.2019.04.021] [PMID: 31126776]

[36] Simons MA, Ziviani J, Copley J. Predicting functional outcome for children on admission after burn injury: do parents hold the key? J Burn Care Res 2010; 31(5): 750-65. [http://dx.doi.org/10.1097/BCR.0b013e3181eebe88] [PMID: 20683197]

[37] Dreyer PS, Pedersen BD. Distanciation in Ricoeur's theory of interpretation: narrations in a study of life experiences of living with chronic illness and home mechanical ventilation. Nurs Inq 2009; 16(1): 64-73. [http://dx.doi.org/10.1111/j.1440-1800.2009.00433.x] [PMID: 19228305]

[38] Ricoeur P. Interpretation theory: discourse and the surplus of meaning. Fort Worth, Tex: Texas Christian University Press 1976.

[39] Kitzinger J. Qualitative research. Introducing focus groups. BMJ 1995; 311(7000): 299-302. [http://dx.doi.org/10.1136/bmj.311.7000.299] [PMID: 7633241]

[40] Krueger RA, Casey MA. Focus groups: A practical guide for applied research. 5th ed. Los Angeles: Sage 2015.

[41] Bradbury-Jones C, Sambrook S, Irvine F. The phenomenological focus group: An oxymoron? J Adv Nurs 2009; 65(3): 663-71. [http://dx.doi.org/10.1111/j.1365-2648.2008.04922.x] [PMID: 19222664]

[42] Statistics Norway. Folketallet - Inbyggere i Norge ssb.no, 2019. Available from:. 2019.https://www.ssb.no/befolkning/faktaside/befolkningen.

[43] Onarheim H, Brekke RL, Guttormsen AB. Patients with burn injuries admitted to Norwegian hospitals - A population-based study. Tidsskr Nor Laegeforen 2016; 136(21): 1799-802. [http://dx.doi.org/10.4045/tidsskr.16.0047] [PMID: 27883102]

[44] Helse Bergen - Haukeland universitessjukehus. Brannskadar: Helse Bergen 2019. Available from: https://helse-bergen.no/behandlinger/brannskadar

[45] QSR International Pty Ltd. inventorNVivo qualitative data analysis software, Version 12 Plus 2019.

[46] Foster M, Whitehead L, Maybee P. The parents', hospitalized child's, and health care providers' perceptions and experiences of family-centered care within a pediatric critical care setting: A synthesis of quantitative research. J Fam Nurs 2016; 22(1): 6-73. [http://dx.doi.org/10.1177/1074840715618193] [PMID: 26706128]

[47] European Burns Association. European practice guidelines for burn care - minimum level of burn care provision in europe. 2017.

[48] Martinsen K. Løgstrup & sygeplejen. Aarhus: Klim 2012.

[49] Stroebe M, Schut H. The dual process model of coping with bereavement: Rationale and description. Death Stud 1999; 23(3): 197-224. [http://dx.doi.org/10.1080/074811899201046] [PMID: 10848151]

[50] Sridharan K, Sivaramakrishnan G. Therapeutic clowns in pediatrics: A systematic review and meta-analysis of randomized controlled trials. Eur J Pediatr 2016; 175(10): 1353-60. [http://dx.doi.org/10.1007/s00431-016-2764-0] [PMID: 27605131]

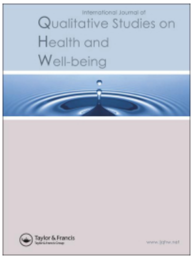
[51] Mortamet G, Merckx A, Roumeliotis N, Simonds C, Renolleau S, Hubert P. Parental perceptions of clown care in paediatric intensive care units. J Paediatr Child Health 2017; 53(5): 485-7. [http://dx.doi.org/10.1111/jpc.13448] [PMID: 28073176]

[52] Polit DF, Beck CT. Nursing Research: generating and assessing evidence for nursing practice. 10th ed.. Philadelphia: Wolters Kluwer 2017.

[53] O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: A synthesis of recommendations. Acad Med 2014; 89(9): 1245-51. [http://dx.doi.org/10.1097/ACM.0000000000000388] [PMID: 24979285]

[54] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007; 19(6): 349-57. [http://dx.doi.org/10.1093/intqhc/mzm042] [PMID: 17872937]

III



Taylor & Francis
Taylor & Francis Group

International Journal of Qualitative Studies on Health and Well-being

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/zqhw20

Parents’ lived experiences of parental needs for support at a burn centre

Lina S. T Lernevall, A. L. Moi, E. Gjengedal & P. Dreyer

To cite this article: Lina S. T Lernevall, A. L. Moi, E. Gjengedal & P. Dreyer (2021) Parents’ lived experiences of parental needs for support at a burn centre, International Journal of Qualitative Studies on Health and Well-being, 16:1, 1855749, DOI: 10.1080/17482631.2020.1855749

To link to this article: https://doi.org/10.1080/17482631.2020.1855749

INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH AND WELL-BEING
2020, VOL. 16, 1855749
https://doi.org/10.1080/17482631.2020.1855749

Taylor & Francis
Taylor & Francis Group

Parents' lived experiences of parental needs for support at a burn centre

Lina S. T Lernevall [a,b], A. L. Moi [a,c], E. Gjengedal [b] and P. Dreyer [b,d]

[a]Department of Plastic, Hand and Reconstructive Surgery, National Burn Centre, Haukeland University Hospital, Bergen, Norway; [b]Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway; [c]Department of Health and Caring Sciences, Western Norway University of Applied Sciences, Bergen, Norway; [d]Department of Public Health, Section of Nursing, Aarhus University, Aarhus C, Denmark

ABSTRACT

Purpose: A burn injury to a child is a traumatic event and the parent's emotional reactions and coping strategies affect the child's adaptive outcome. It is therefore important that parents get the right support. The aim was to explore parents' lived experiences of their need for support when having a child admitted to a burn centre.

Methods: Semi-structured face-to-face interviews were conducted with 22 parents of children age <12 years hospitalised with an accidental burn injury, 9 to 27 days after the burn accident, from April 2017 to July 2018. A Ricoeur-inspired textual analysis method was used.

Results: Four themes emerged from the analysis and describe the parents' needs for support. The parents wanted to be taken care of as a whole family and feel safe in the hands of professionals. This, in turn, depended on being informed about the child's condition and treatment, but also on getting help in dealing with feelings of guilt. Not least, parents wanted opportunities to take care of their own fundamental needs in terms of hygiene, food, adequate rest and activities.

Conclusion: As an overall understanding the healthcare providers should focus on the family as a whole in care and treatment.

ARTICLE HISTORY
Accepted 21 November 2020

KEYWORDS
Burns; child; interview; intensive care units; human needs; paediatric; parents; phenomenological hermeneutics; psychosocial; Ricoeur

1. Introduction

Childhood burns are among the most severe forms of injury, with high morbidity and mortality rates worldwide (Kim et al., 2012). In Europe, 50–80% of all burns in children affect children under the age of five (Brusselaers et al., 2010). In Norway, children between zero and three years of age are 12 times more prone to experience a burn injury than children >5 years and adults (Onarheim et al., 2014). Both the injury and the burn treatment are known to be painful. Treatment often includes reconstructive surgery and a long rehabilitation period (Greenhalgh, 2019; Wiechman & Patterson, 2004). Apart from the impact of the injury and its treatment, parents' reaction and responses to the traumatic event have been shown significantly to influence the child's functioning, wellbeing and phycological recovery (Bakker et al., 2013; De Young et al., 2014; Lieberman, 2004). Supporting parents of burn-injured children is therefore an important part of the regular care offered at burn centres.

Parents, mostly the mother (26%) or both parents (12%), are often present when a burn injury occurs, and the accident typically happens at home in the kitchen or dining room (47%) or the bathroom (12%) (Pardo et al., 2008). Parents can therefore easily be affected by negative feelings and emotions. A recent systematic review reported that many parents were affected by guilt, shame and blame (Kornhaber et al., 2018). Moreover, many parents developed anxiety reactions and traumatic stress due to their child's burn injury (Bakker et al., 2013; Hawkins et al., 2019). For most parents, traumatic stress symptoms decline after the first months; in some, though, symptoms may persist for years (Bakker et al., 2013; M. Egberts et al., 2017; M. R. Egberts et al., 2018b). It has also been reported that mothers of burn-injured children have a higher depression score than the general population (El Hamaoui et al., 2006). When parents are affected by accident-related psychological distress, they are more challenged when seeking to positively support their child through medical care (Brown et al., 2019). A high state of parental anxiety combined with ineffective parental coping strategies can also cause the child to have a non-adaptive outcome after the burn injury (Simons et al., 2010). Hence, having a healthy and supportive family seems to positively affect the child's health-related quality of life (Landolt et al., 2002).

A recent review of parental needs for support while hospitalised in a burn centre identified only seven articles, highlighting the sparsity of knowledge within the field

CONTACT Lina S. T Lernevall Lina_Lernevall@hotmail.com Department of Plastic, Hand and Reconstructive Surgery, National Burn Centre, Haukeland University Hospital, Bergen N-5021, Norway

(Lernevall et al., 2019a). The described support offered to parents included different kinds of group consultation (Barnett et al., 2017; Cahners, 1979; Frenkel, 2008; Rivlin et al., 1986), an internet-based information and support programme (Sveen et al., 2017) and parental presence during wound care procedures (M. R. Egberts et al., 2018a). Parents participating in group consultations found it beneficial to process and share their feelings and learn about coping strategies such as how to manage stress and how to maintain psychosocial wellbeing. The internet-based information and support programme was perceived as informative, comprehensive, meaningful and supportive, though some parents found it time-consuming. Regarding parental presence during wound care procedures, some parents were glad to have been present while others were happy they were not. A critical factor for parents' choice was their emotional state prior to the wound care. A new study investigated how staff members at a burn centre supported parents of burn-injured children; the staff created a safe, secure and trusting environment upon arrival, addressed parental guilt, supported parents in doing daily routines and involved them in wound treatment before discharge (Lernevall et al., 2019b). This study did not, however, investigate parents' actual experience and needs (Lernevall et al., 2019b). Assessing parents' emotional status and support needs during their child's hospitalisation may be difficult as they are so concerned about their child's wellbeing that they supress their own needs, which also makes it difficult for them to receive psychosocial support (Griffiths, 2017; Heath et al., 2018). Parent-perceived isolation and barriers to psychosocial support as well as the current lack of evidence-based parental support programmes testify to the need for further research in this field (Heath et al., 2018; Lernevall et al., 2019b). The review by Lernevall et al. presents different types of support offered to parents of burn-injured children, but does not mention which kinds of support they needed and requested. The aim of the present study was therefore to explore parents' lived experiences of their need for support when having a child admitted to a burn centre.

2. Materials and methods

2.1. Study design

This study is one stage of a multi-phase study investigating parents' needs for support while having a child hospitalised with a burn injury (Lernevall et al., 2019a, 2019b). It is an explorative study that uses a phenomenological-hermeneutic approach (Dreyer & Pedersen, 2009) to gain a deeper understanding of the parents' lived experiences. Phenomenology helps the researcher to look at how the world is experienced by the subject by studying different aspects of consciousness and experience (Zahavi, 2019). " To get a deeper understanding of the parents' lived experiences, a textual analysis method inspired by the French philosopher Paul Ricoeur was chosen (Dreyer & Pedersen, 2009). When recorded interviews with parents are transcribed, their lived experiences are transformed into a text. "The others mind's experiences" are captured and maintained in the text (Ricoeur, 1976, p. 73). The text can then be analysed to understand the parents' need for support during hospitalisation. To "grasp" the meaning of the text, one needs to use interpretation. Ricoeur argues that as soon as a text has left the author, its original addressee is released, and "A text is addressed to anyone who can read" (Ricoeur, 1976, p. 92). It is thereby possible for everyone to interpret the meaning in the text. This interpretation process is circular as it moves from looking at the parts in the text, then looking at the whole of the text, then returning to the parts again. In this way, one gets a deeper understanding of both parts and whole. During this process, one discovers "the sense of the text" (Ricoeur, 1976, p. 87) as the depth of the text is unfolded. To grasp the parents' experiences of their needs for support, face-to-face interviews were used for data collection.

2.2. Setting

The study took place at a Norwegian burn centre with eight beds, five of which are burn-intensive care unit beds. The burn centre treats about 150 inpatients per year, of whom one third are childr,en. Patients are treated by a multidisciplinary burn team consisting of surgeons, nurses, anaesthesiologists, physiotherapists, psychologists, social workers, hospital clowns, psychiatrists and priests.

2.3. Participants and recruitment

Participants were parents (n = 22) of children (4 girls and 9 boys, mean age 2 years and 2 months (2 months to 7 years)) hospitalised due to an accidental burn injury. The participants were 12 mothers, 9 fathers and 1 stepfather, their mean age was 33 years and 3 months (21 to 46 years). Eighteen parents were together/married, three were divorced living alone and the stepfather was a partner to one of the divorced mothers. Eight parents had one child, while 14 had more than one. All parents were employed. Sixteen parents were Norwegian, and six were from other European countries. Nearly all spoke Norwegian fluently, except for two parents who mixed Norwegian and English, and got help from their spouses for the interview. Nine children had been burned with hot coffee, tea, soup or water; one had been burned with fire, one with electricity; and two had come into contact with a hot surface. Two injuries resulted in amputation, three children got skin graft surgery, seven would get a scar and five had a life-threatening but non-fatal injury. Some days after admission, all parents were seen by a psychologist, who recruited parents for this study. If the inclusion criteria were fulfilled (Table I), parents were

Table I. Inclusion criteria.

- Parents who could speak and understand Norwegian, need not be ethnic Norwegians. During the inclusion period, this criterion was changed to include all parents (no restrictions on language) due to low participation. If parents could not speak Norwegian, an interpreter would be present at the interview.
- The child had to be under the age of 12 years. The Norwegian "Barnelova" (The children's law) § 31 states that a child who has turned 12 years must say its opinion about decisions regarding personal matters (Barnelova, 1981). If the child were to be 12 years or above, the child would also need to be interviewed which would change the aim of this study.
- The children and parents had to be hospitalised for a minimum 24 hours to have the experience of being at the ward.
- The burn injury had to be caused by an accident. Any burn injuries caused deliberately should not be included.

informed about the study and invited to participate. Thirty invitations were handed out (27 in Norwegian and 3 in English). The first author, who is a former burn care nurse, contacted all parents who consented to participate, and dates were set for an interview.

2.4. Data collection

The first author conducted all face-to-face interviews (Table II) from April 2017 to July 2018. Sixteen interviews were completed. There was no need for an interpreter as parents managed to express themselves. Parents decided themselves whether they wanted to be interviewed together (n = 12 parents) or separately (n = 10 parents) and where the interview should take place. All parents appreciated, and some were even thankful, for the opportunity to participate in this study and share their experiences. The semi-structured interview guide used had been tested on four parents who were part of user involvement in research (these interviews were not included in the analysis). The main topics in the interview guide were how the parent(s) experienced being at the burn centre, how they experienced the staff members, what was meaningful to them and if they had been or missed being supported. The interviews were digitally recorded and transcribed verbatim, 14 by the first author and 2 by a secretary.

2.5. Data analysis

Data were managed in NVivo 12 Plus (QSR International Pty Ltd., 2019). The transcripts were read and analysed by the first and last author, using a Ricoeur-inspired method (Dreyer & Pedersen, 2009). An in-depth analysis, which resulted in a comprehensive understanding of the lived experience, brought the researchers closer to the parents "being in the world" (Dreyer & Pedersen, 2009, p. 65). The method consists of three steps: a naïve reading, a structural analysis and, a critical analysis and discussion.

The first step is a naïve reading, where the whole text is read so the researcher gets an "immediate understanding of the meaning content" (Dreyer & Pedersen, 2009, p. 67). In our study, all interviews were read as one text and a short narration (an A-4 page) was created from this first impression of the text as a whole (Table III). This was done to show the first analytical process.

The second step is a structural analysis, consisting of three steps: 1) meaning-bearing units are found "What is said in the text?", 2) significance-bearing units are found/created "What does the text talk about" and 3) themes are created (Dreyer & Pedersen, 2009) (Table IV). In our study,

Table II. Characteristics regarding the interviews (n = 16).

Duration of interviews:	Total: 20 hours, 12 minutes and 15 seconds
Mean (min-max)	Mean: 1 hour, 15 minutes and 46 seconds. (33 minutes—2 hours and 55 minutes)
The number of days since burn injury when interviewed: Mean (min-max)	17 days (9 days—27 days)
Place of interview:	At the hospital near the burn centre (n = 8), at a hotel (n = 2), at a local hospital (n = 1) or in parents' homes (n = 5).
Hospitalized or discharges:	Hospitalised (n = 8) and discharged (n = 8).
Interviewed together or individually:	Interviewed together (n = 6 interviews) and interviewed individually (n = 10 interviews) by the choice of the parents and depending on the situation (were both parents at the hospital together, was one at home or were they divorced?)

Table III. Naïve reading (short version).

In the traumatic chaos following an acute accidental burn injury to a child, being transferred to a burn centre, the parents are somewhat calmed by knowing that they will be treated by the country's top specialists within burn care; but they are also frightened, realising the seriousness of the situation. Arriving at the burn centre, parents meet staff members who are waiting ready to start treatment immediately. This first meeting is particularly important for the parents as it creates a trustful and safe atmosphere. However, parents are frustrated when they cannot get specific information about how it will all turn out or how long they have to stay. When being transferred to the burn centre, both parents want to travel together; however, this is not always possible. Parents arriving alone long to hear news about their child, but are surprised to realise that the door to the department is locked. They have to ring a bel for someone to come and open up. Again, they are surprised to be questioned about who they are and to learn that they cannot sleep at the burn centre. Many fathers explain how important it is for them to be there for their wives and support them. Therefore, they find it difficult that they cannot stay together as a family. Many parents have feelings of guilt, and they feel that staff help them deal with this guilt. It added to parents' stress level and workload when they experienced miscommunication among staff members and lack of a contact person with an overview. The most important thing for parents was that their child was treated. However, expressed very modestly, parents also wished that some of their own fundamental needs would be met. They wished to have access to a shower so that they could clean themselves and to get a break so that they could think for themselves for just some minutes.

Table IV. An example of the structural analysis of “3.1. Being in it together—for their child”.

Meaning-bearing units (What is said in the text?)	Significance-bearing units (What does the text talk about?)	Theme
“It’s obvious that I would have had him here all the way. That’s obvious. But then they haven’t arranged it so that we can be the two of us. He didn’t get to stay with us. [. . .] but for my part, then it would have been a huge support if he had also been allowed to be there (M1)”. “The first day it was quite nice to be two, so we had a chance to talk about it together and things like that (F3)”. “I don’t know how other parents are, but we . . . we complement each other. [. . .] While I’m at 100, he stays at 50, and then we end up at 75 when there are the two of us (M12)” “He (red. husband) has been a wingman . . . (M14)”. “It costs us a lot to order tickets and everything, but now it’s important that we are together as a family (M16)”. “I think it would have done something if the family could have been two on the room some nights [. . .] a family would appreciate to be together (M17)”. “But then again, the ideal solution would be for me to sleep here (red. at the burn centre). That would have been normal in a perfect world (F18) ”. “I didn’t want to sleep because I wanted to be with my son . . . all the time. So, we changed like; he (red. husband) slept a few hours and after that we changed (M19)”. “And I think it’s much better for us, ehh, if we stay together the whole time. And then the doctor said ‘Okay today you can, you can stay and sleep here’, right. And both of us smiled and that was so nice, right (F20)”.	. . . The couples described themselves as a team complementing one another and therefore wanted to be together during the traumatic and chaotic situation they were in. The couples tried to help each other and stay positive during the difficult times. This was a way of taking care of each other and themselves. Being together was described as very comfortable, safe, helpful and nice, both during the day and during the night. When they experienced the same things, they could more easily share the burden; and, for example, at night being only the two of them, they went through what had happened. In that way, being together was described as extremely valuable to the processing of everything that had happened. Even physically separated couples called each other using video-calls, because having each other made it easier to cope, and some said that their relationship became stronger.	Being in it together—for their child
““I saw that she was in shock. She was so sad that she burned X (red. the child) and I knew that I had to be near her. [. . .] I wasn’t allowed to stay. I was only allowed to visit. Nothing more. But we wanted to be all of us together (F22)”. . . . (there are more citations).	For various organizational reasons, both parents were seldom allowed to spend the night at the burn centre. . . .	

we started to look across the data for sections or paragraphs to understand “What is said in the text”. Sections were highlighted and then grouped. Each group was then examined for “What does the text talk about”. A narration using poetic language was generated, creating a distance in the interpretation, where we as researchers became more distanced from the text. As the third step, the narrations were given names or themes, which allows the researcher to become even more distanced from the text. This process is not straightforward. Instead, it is a circular movement between the three steps to ensure that the meaning is not changed or the parents’ words are lost. Throughout the structural analysis, there is a constant movement between explanation and comprehension, where one understands the whole by understanding the parts and so on, forth and back (Dreyer & Pedersen, 2009, p. 68).

As a final and third stage, the findings from the structural analysis were critically analysed and discussed by all authors in light of other relevant literature, research studies and theory. Through the critical analysis and discussion, we got an in-depth understanding of the interpreted themes: the parents’ needs for support. This third step is integrated in the discussion.

2.6. Ethics

This study followed the Helsinki Declaration (World Medical Association, 1964/2013) and was ethically approved by REC—the Norwegian Regional Committees for Medical and Health Research Ethics (REC, 2019), project number: 2017/54/REK. Informed consent was obtained from all parents, and no one from the burn centre knew who participated. All audio records were digitally recorded and kept in a secured research server at the university hospital. All names of individuals and places were removed to anonymize the transcripts.

All parents were interviewed by the first author, who was familiar with the burn centre but not with the participants. She was particularly observant of parental reactions during the interviews to ensure that parents could be followed up if needed by a psychologist. Parents who got strong emotions during the interviews were asked if they wanted to stop the interview (all wanted to continue) and if they needed to talk to a psychologist (all declined).

Halfway through three of the interviews, the first author realized that five parents had been wrongfully included which represented an ethical problem. To respect the parents, their shared experiences and time used, the interviews were continued and data from these interviews were included for further analysis.

3. Results

Four themes showing the parents’ needs for support were found during the analysis. These themes will be presented in the following text.

3.1. Being in it together—for their child

An accidental burn injury in a child was experienced as a traumatic event by the parents. They dealt with the burn accident together, one way or another. In most cases, both travelled to the hospital together; some drove while others were transported by air ambulance or helicopter. Couples wanted to travel together; however, it was not always possible due to lack of space in the helicopter.

The couples described themselves as a team complementing one another and therefore wanted to be together during the traumatic and chaotic situation. "I don't know how other parents are, but we … we complement each other. […] While I'm at 100, he stays at 50, and then we end up at 75 when there are the two of us (M12)". The couples tried to help each other and stay positive during the difficult times. This was a way of taking care of each other and themselves. Being together was described as very comfortable, safe, helpful and nice, both during the day and during the night. When they experienced the same things, they could more easily share the burden; and, for example, at night being only the two of them, they went through what had happened. "The first day it was quite nice to be two, so we had a chance to talk about it together and things like that (F3)". In that way, being together was described as extremely valuable to the processing of everything that had happened. Even physically separated couples called each other using video-calls, because having each other made it easier to cope, and some said that their relationship became stronger.

For various organisational reasons, both parents were seldom allowed to spend the night at the burn centre. Many parents were surprised about this and found it stressful and a hassle to find other accommodation for one parent. For some families, this extra expense was too costly, and only one could stay. However, most families payed so that they could handle the situation as a family, coming through it together. One mother explained the scenario if they would have been forced to choose that only one of them stayed:

> " … for his sake (red. the child), then dad would have travelled. Because he is more mentally stable so that he can handle and process … […] I'm more … mother, 100% mother. And I don't think about anything else than X (red. the child). Ehh, I would have been sitting at home and probably been completely … crazy (M12)".

Most often it was the father who slept elsewhere, for instance, in a nearby hotel or with relatives. The fathers said it was unpleasant not being hospitalised with the mother and the child. "It was quite sad to feel a little unneeded (F8)". The fathers wanted to be support persons who were present and could help, also during the night. One father was described as a wingman; one who was there on the side, but present to step in when needed. Some fathers explained that it would be better for both of them to stay together because they were not so easily stressed as their wives. "I saw that she was in shock. She was so sad that X (red. the child) got burned and I knew that I had to be near her (F22)". Being together, they could also relieve each other by taking turns. One parent was so afraid to lose her child that she could only sleep with her husband present.

Sometimes, one parent had to leave to go home for various reasons such as tending to other children, work, getting extra clothes, etc. Being alone at the burn centre was experienced as stressful, energy-consuming, sad, tough and as putting extra pressure on the one parent who stayed, especially during the first days, the acute phase. They were longing for their partner and found it hard to deal with everything on their own.

Parents with more than one child felt divided between their need to care for the hospitalised child and for their child/children at home. In some families, the siblings visited the hospital. But for some it was too expensive, and they communicated using video-calls from home. It burdened the parents not to meet their other child/children during the hospitalisation.

The parents wanted to be there for their child; even parents who were divorced. They were also in it together as parents to the same child, but had no desire to be at the burn centre together with the other parent. Divorced parents with less good contact acknowledged that the other parent needed to be around the child, but were exhausted to be around the other parent the whole day, every day. For some, the situation was even more challenging when the staff mistakenly thought that they were still married and treated them as a couple. This made the parents irritated, frustrated and unsure if the staff knew about their situation.

3.2. Being taken care of by professionals makes you feel calm and safe

Upon arrival at the burn centre, many parents described themselves as terrified, alert, sleep-deprived, exhausted, stressed and filled with fear. However, as soon as they were finally there, they relaxed, knowing they were at last with burn specialists. The parents were really moved seeing so many people waiting for them and they felt prioritised and taken care of.

> " … we were greeted by a whole team up there who knew that we were coming. They had made everything ready to start treatment on her (red. the child) immediately. You felt in a way very safe at once you entered the department (F4)".

The way the parents were met upon arrival was highlighted as particularly important and described as "accommodating" or 'being cared for". They felt met and seen as staff greeted them in an open way, introduced themselves and told what they were going to do. Parents felt comfortable, relaxed and cared for when staff listened to them, answered their questions and were always patient with them. They experienced staff members as trustful, helpful, self-confident, skilled, calm and caring, all of which made them trust the staff to care for their child. "I've said to everyone that it's angels in hospital coats that work here (laughs) (M16)". What the parents experienced as particularly important was that staff were there for them no matter how busy the department was. "And you feel that they have enough time to answer, that it isn't just a production line (M1)". Having or taking the time to listen and answer questions was of importance to the parents.

Some parents were reassured by the staff that things would be fine even though they were not promised anything by the staff. Others calmed down as they saw how medical equipment was removed from their child such as a respirator, intravenous fluids, urine catheter and other cables. They were happy to hear that the child did not need it anymore and reassured that it might not be so bad after all. "And it was very nice when I came in: they had removed it all, catheter and surveillance and cables . . . except that they had given her a feeding tube. And when I came in, my wife was standing holding her in her arms without all the cables. That meant a lot (F8)".

When fathers did not arrive together with their child, they were very happy and emotional finally to arrive, longing to hear news about their child. When reaching the burn centre, they were astonished to realize that they had come to a locked door where they had to ring a bell for someone to lock them in and on top of that hear: "It's not possible for you to sleep here. There is only room for one relative (F18)". After all, they were happy to be reunited with their family; but at the same time, it was experienced as shocking and frightening to enter a room full of unfamiliar people without knowing what was happening or how the child was doing.

Nearly all parents had feelings of guilt upon arrival, including those who were not present when the accident happened. "No matter what, you feel guilty for not being able to protect your child, which is the most important task you have. And then it is the most vulnerable person, the youngest person in the family who gets to suffer the worst consequences (M16)". The way staff members reacted and approached their feelings of guilt meant much to the parents. Staff members told them that they should not blame themselves or ruminate about it; that it was not their fault; that they were not the only one who had experienced that their child got burned. "I really felt that I had done something terribly wrong. The doctor from the emergency department, he really placed all the guilt on me. And that was the first thing they said at the burn centre: 'These things happen. And it can happen to anybody' (M10)". Some parents, though, got puzzled and felt uneased if staff raised the topic suddenly and without context; but after a while, they accepted that doing so had had a helping effect. However, not all parents were open enough to share their feelings, and they suffered alone. Even though family members tried to address the topic, it made a difference hearing it from the staff. "Someone that really tells you: 'It's normal to have these feelings, and in time they will … disappear. It will not entirely disappear forever, but … it will get easier in time … and then it actually isn't your fault' (M12)". Furthermore, it helped to talk to other parents at the department.

3.3. Trying to have some control in an uncertain situation

The parents got really frustrated when they did not know what was going on or what to expect next. In their chaotic and uncertain situation, they wished to have concrete information to hold on to. Being informed made them understand what was happening, made them more optimistic and unworried and not so afraid of bad news. "But here we get to talk to the doctor straight away, and that's really great. It makes it much safer as a mother (M14)". When they experienced that staff were honest with them, whether they delivered positive or less positive information, they trusted them more and felt safe. Parents who had received a "Welcome to the burn centre"-pamphlet containing information about the department's routines when they arrived felt calmer and better prepared for what to expect. This made it easier to ask the doctor about things they wondered about or did not understand. Divorced parent with less good contact did not share all information, resulting in the fathers still being stressed and lacking information. A stepfather felt that his presence and existence went unrecognised, as he was not a legal parent of the child. Many parents felt that there was a lack of structure, and they felt alone and had to spend enormous amount of energy trying to get an overview of the situation. Many experienced that staff members gave contradicting information, which made them confused, irritated, despairing and hampered their ability to navigate the information given. They wished for some standard information about the department but also information about burn injuries, and some searched the Internet but were unsure which information to trust. Not getting any information after wound treatment or surgery made parents impatient, frustrated and scared that something was wrong.

> "There was very little information. Both before and after wound treatment and when they transplanted some skin and we were at the recovery and we were there to pick him up. I talked to the anaesthesiologist … he wouldn't

> say anything because he wanted the surgeon to say it. But the surgeon didn't come (F9)".

Upon arrival as well as during hospitalisation, they wanted to know when they were being discharged. Getting contradicting information about this, parents became scared that the situation might be worse than they had thought and unsure whether the staff were withholding information from them. One couple had mistakenly been told that they had to stay for another 12 days, just to find out that they got discharged the following day. This made them distrust the staff; and when staff could give them no specific departure date, parents got frustrated, disappointed, sad, unsure or angry. "And I asked 'Well how long do we have to stay here?'. 'Yes at least 10 days more, because 20 days is standard procedure'. [...] well I feel like I'm never coming home, because they say so many different things (M10)". When staff members told them about the process of wound healing, they could more easily relax and accept the uncertainty of departure even though they got irritated. "Even though it makes it difficult to plan, it would have been nice to know (red. when to go home), yes (M1)".

Some parents, though, were better at taking one day at a time, whereas not knowing really affected other parents. Being informed about the time of discharge and future caring tasks at home made them more relaxed, calm, safe and secure of their role, and gave them time to think everything through, prepare questions and focus on the tasks ahead. However, receiving this information on the day of discharged was experienced as extremely stressful. Even though they were happy to hear that they could finally go home, abruptness of discharge made them unsure what was going on or if they had been forgotten. Many also forgot to ask questions and to get all the papers they needed, even though they had both questions and worries.

> "Maybe they could have had some kind of end-conversation or recap. [...] Because my version might quite certainly be different from the staff members' version, just so that we, in a way are on the same page (M15)".

3.4. *Getting time to be yourself and see to personal needs*

Although parents were happy to be at the burn centre, they found that being hospitalised was a strenuous experience. The burn centre was not like other hospital departments; parents described it as being isolated and with very strict hygienic rules. "One door, two doors, a lot of disinfectants, on with clean cloaks, off with that and on with that (breathes heavily). Ahhh ... help (M12)". In the first acute phase, they appreciated all the care and the kindness when they were being brought things; but after a while, they became a little passive. The parents had to adapt to the rules and routines of the department, which some of them found really hard. "And THEY are the one who must get us some food [...]. And we're not ... helpless. We can manage OURSELVES. 'Well, then, we better follow their schedule'! I think it's very much, it's like being in a prison (M17)". They wished to do everyday chores while hospitalised, a way to gather energy. One couple changed weekly, as one stayed at the hospital and the other at home. "It has been so nice for me to be at home with our daughter and then come back with recharged batteries (M16)".

The parents longed to get just a small break, for instance, to get a cup of coffee and think about something else, but it was hard to ask for it themselves. "Not like they had to take the child for hours, but just 10 minutes here and there if one had to some small errand (M15)". They did not want to be a burden, to be perceived as too demanding when asking for time alone. However, only few parents experienced that staff could babysit the child to give them a small break. "She asked, 'Is there anything I can do for you'? And I felt like screaming (red. gets a wobbly voice and almost cries). But I didn't, I kept in within me. She was the first one in 16 days who had asked me (M17)". The parents highlighted how important it was for them to get out, and, for instance, exercise so that they could let go of their feelings.

When parents were offered personal time to eat, drink and maintain personal hygiene, they were really touched and felt treated with dignity and as a human being. Getting time to eat while the child was undergoing wound treatment in anaesthesia or taking a shower was also extremely important. Only few parents were offered to use the staff shower in the hallway, as there were none in the patient's rooms.

> "I REALLY missed to be offered a shower. I was CERTAINLY not clean all those days; [...] I didn't feel that I could, I couldn't leave him, [...]. But what I did was, while he was being operated, then I washed my hair in the sink (laughs). I was quite desperate (laughs) (M15)".

The parents were happy that staff offered to wash their clothes in the department's washing machine, especially when acute transferred to the burn centre.

The days at the burn centre were experienced as "very long (M1, F8, F13, M15, M16)", and the parents tackled this differently. Some had brought books, computer, mobile phones or kept a diary. Others relaxed in the patients' living room at the burn centre. Those who had a television on the room were happy to be entertained. Meeting the hospital clowns was also a possibility to get a pause from everything. "It's not something that takes a long long time, but all of a sudden, for 15 minutes, you forget that you're at the hospital (M12)". Parents talking about the clowns smiled and laughed as they were retelling what the clowns did. The hospital clowns gave them a positive experience.

When someone had time to sit down and drink a cup of coffee together with them, talking about everything and nothing, they felt that others took interested in their life and in them as a person. One way of getting a chance to talk things through was seeing the psychologist or a social worker. Many parents had also contacted a psychologist in their hometown. Some mothers staying alone at the burn centre got help from their own mother who came and stayed nearby the hospital. Having their mothers there was experienced as a kind of self-therapy.

3.5. Overall comprehensive understanding

All four themes create a comprehensive understanding showing the parents' fundamental needs to be seen and treated as a unique individual. Parents need to be together with their partner during a traumatic experience, they need to feel safe in the hands of professionals, and they try to cope in an uncertain situation and to see to their own fundamental needs.

4. Discussion

Our results show that parents' need for support was very much an existential need. In the face of the difficult situation following a paediatric burn injury, they wanted to be taken care of as a whole family and feel safe in the hands of professionals in order to be there for their child. This, in turn, was closely linked to being informed about the child's condition and treatment and about routines and future prospects. Not least, parents wanted the opportunity to take care of their own fundamental needs in terms of hygiene, food, adequate rest and activities.

We found that being together to support each other was a prime need for couples of burn-injured children. The traumatic situation of having a burn-injured child was handled as a team by couples; and they had a strong need for being together both during the transfer to the burn centre and during their stay, day and night. Being separated was therefore hard and challenging. The need to face challenges as a team has also been reported in two other Australian and Indian studies of parents of burn-injured children (McGarry et al., 2015; Ravindran et al., 2013b), implying that this is fundamental to parents rather than a culturally determined need. Our data also show that divorced parents had other needs than couples. They still needed to be together with the child but not with the other parent. This particular need and the challenges involved in treating divorced parents seem not to have been discussed in the burn literature. However, previous studies of critical care settings have described that staff should be aware of divorced couples if major differences or conflicts still exist when decisions are made regarding the patient (Leon & Knapp, 2008). Our results highlight that being treated as a family strengthens parents, which is in line with family-centred care (FCC). FCC means caring for both the child and its parents, using the four concepts: "respect, dignity, information sharing, and participation and collaboration" (Foster et al., 2016, p. 432). Staff should have time to listen to and answer parents' questions, as this study shows. Years ago, FCC was implemented as a philosophy within paediatric nursing (Harrison, 2010), and parents of hospitalised children have reported overall positive experience with FCC (Arabiat et al., 2018). This perspective should also be highly relevant for burn centres treating children. Parents should therefore be included in the care.

Parents with more than one child had a double responsibility as they had to care not only for their hospitalised child but also for the child/children at home. For some, this was difficult to balance in a good way, and not being able to be both places could add to their feelings of guilt. Staff members should be aware of the parents' worries and support them to maintain contact with their family at home.

Our data suggest that parents need to talk not only about feelings of guilt, but also about how to deal with these feelings. In the present study, parents' willingness to share their feelings and thoughts seemed to be linked to how safe they felt in the care of burn staff members. Parental feelings of guilt seem to be common in relation to paediatric burn injuries (Kornhaber et al., 2018; Sveen & Willebrand, 2018) and critically ill children (Engström et al., 2015). The present study shows that the way staff members approached the topic was pivotal. Hence, staff can either make parents feel worse by assigning guilt to them or make them feel better, helping them by telling them that accidents do happen. When parents are assigned guilt for their child's injury, their belief in themselves as good parents weakens, as also reported in another study (Ravindran et al., 2013b). Staff members should recognise their influence on parents' feelings of guilt.

Another main finding of the present study is that parents felt a strong need to gain some control by getting information. Getting information either from a written welcome pamphlet or by talking with the staff made parents feel calm, safe, less afraid, prepared and more trusting. Not being informed, getting contradicting information or not being answered, on the other hand, made them feel frustrated, angry, stressed, scared, impatient, irritated and despairing. Our findings here echo those of a study of parents to children in an intensive care unit in which parents felt calmer the more information they got; and more stressed, insecure and afraid when they received no information (Engström et al., 2015). A need for information shortly after wound treatment and operations, as well as being well prepared and informed about discharge, was an important finding in our study.

A study from 2008 investigating how to involve family systems in critical care nursing found that family stress lowered when information was provided continuously (Leon & Knapp, 2008). Information given in continuous, frequent and small portions was more easily absorbed by parents (Engström et al., 2015). The legal right to receive information differs if you are a parent or a stepparent. Knowing how modern family structures vary, we find that more emphasis should perhaps be devoted to stepparents' information needs.

In the present study, getting time to see to one's own fundamental needs such as having time to eat, drink, clean oneself, do some exercise, talk, laugh and have a break were essential for parental wellbeing. This can seem like a very natural thing, and maybe so natural and fundamental that it is easily forgotten or overlooked. It might be worth reminding ourselves of Maslow's hierarchy of human needs, according to which basic physiological needs have to be fulfilled before catering for higher ranked needs like safety, love and belonging, esteem, and self-actualisation (Jackson et al., 2014; Mohammadhossini et al., 2019). Henderson and Orem have also described fundamental human needs, and they added a number of important aspects such as keeping the body clean and well-groomed; communicating by expressing feelings, needs, fear, etc.; playing or participating in different kinds of entertainment; and balancing between being alone and having social contact (Henderson, 1964; Orem, 1971). Our data showed that parents needed to talk to both staff members and other parents, which has also been described elsewhere (Engström et al., 2015; Heath et al., 2018). However, our data also displayed a parental need for some time alone to see to personal needs, which seems not to have been addressed in prior burns research. Our analysis revealed that a burn centre can give parents a feeling of being isolated or in prison. Other studies also found that being in the strict hygienic environment of an intensive care unit, the parents felt isolated and focused only on their child, making them neglect some of their basic needs (Foster et al., 2016; Heath et al., 2018).

4.1. *Strengths and weaknesses*

To ensure complete reporting of all relevant matters and to enhance trustworthiness and transparency, we used two guidelines for qualitative research (O'Brien et al., 2014; Tong et al., 2007). Trustworthiness and transparency were strengthened by using verbatim transcription, a meticulously described step-by-step analysis and by justifying the findings using citations with the parents' own words.

Another important strength of the present study is that 45% (n = 10) of the parents were fathers or father figures. Even though the mother is considered the main caregiver in some cultures (Ravindran et al., 2013a), it is important to take the fathers' perspectives into account. Parents were included consecutively, and by pure chance they displayed much variety, for example, in terms of nationality, sex, parental role and length of stay. This diversity is seen as a further strength. Purposeful sampling was not possible and is a shortcoming of the present study. However, as we included patients hospitalised at a burn centre; there is little doubt that all burn injuries were severe and that the parents had rich experiences to share. The divorced parents added knowledge about the need for equal treatment of parents, especially when communicating about sensitive issues, that the parents may find difficult to discuss between them. The stepfather also highlighted an unnoticed problem of how stepparents are met and treated. Further studies should investigate if these experiences were just a single case or a more general problem. Even though this study targeted parents of burn-injured children, some of their experiences and the study findings in general may be comparable to those of parents of children suffering from critical illness.

Five parents were wrongfully included as their stay lasted less than 24 hours. This challenged our preunderstanding, yet turned out positive as the parents were included in the study and contributed with important experiences that would otherwise not have been reflected in the material.

5. Conclusion

In this study, we explored parents' lived experiences of their need for support when having a child admitted to a burn centre. In the context of facilitating their positive contribution to their child's treatment and recovery while hospitalised at a burn centre, they had different needs for support. However, they all shared a need to be cared for as one whole family, including siblings at home, facing the situation as a team while supporting each other. At the same time, they needed support from the multidisciplinary burn team; they needed help in dealing with their feelings of guilt and they needed information to gain some control over the situation and to be informed about their child's condition and treatment and about routines, discharge and future prospects. They also needed breaks during the day to see to their own fundamental needs in terms of hygiene, food, adequate rest and activities, and to recharge their batteries. Our study shows that it seems essential that healthcare providers focus on the family as a whole when a child is hospitalised and treated for a burn injury.

6. Implications

Based on this study, some advice can be given to burn centres treating children. A strategy on how to welcome, treat and discharge parents is needed. When possible, both parents should be transferred together and allowed to stay together both during the day and during the night. It should also be considered to assign a contact person to each family to ensure correct information; and to consider which kind of information to give and in which form. Further suggestions include ensuring some predictability and offering daily breaks where the staff look after the child to ensure that parents have time for personal hygiene and rest. Having hospital clowns at burn centres can offer relief, making parents momentarily laugh and forget about the situation. A multidisciplinary approach is needed to support parents after a burn accident in their child.

Acknowledgments

Our profound thanks go to all parents who participated and shared their experiences.

Thanks to the psychologists/psychiatrist who managed the inclusion for this study: Licenced Psychologist and Specialist in Clinical Children's and Youth's Psychology: Grethe Smelvær, Ingrid Lovise Nordfonn, Nadja Josefine Nyhammer Monsen and Psychiatrist and Psychotherapist Maire Wellner.

The first author also wishes to extend her gratitude to the four parents (who would like to stay anonymous) for partaking as sparring partners in research and for sharing their personal experience throughout her PhD studies.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by the Western Norway Regional Health Authority under [Grant 912138], as part of LSTL's Ph.D. study.

Notes on contributors

Lina S.T.Lernevall (RN, MScN, PhD Student) is a true Scandinavian speaking Swedish, Danish and Norwegian fluently. She was born in Sweden, moved to Denmark when she was nine and since 2016 she has lived in Norway. She has always had a special interest in patients with wounds, since the fourth week at the nursing education. How do people with wounds experience their life with a wound? At the moment she is a Ph.D. candidate at Haukeland University Hospital and Bergen University, in Norway. The working-title of her Ph.D. study is "Parent experience of burn injury in their child and perceived needs for support during hospitalisation at a burn centre".

Asgjerd L. Moi (RN, PhD, Associate Professor) is appointed associated professor at the Department of Health and Caring Sciences at Western Norway University of Applied Sciences, Norway, and is the leader of the master program in intensive care nursing. Since 2013 she has also led the research group "Patient related Outcomes and Patient Safety in the acute and critical ill (POPS)" at the same department. She is a burn intensive care nurse and holds a position as researcher at the Department of Plastic, Hand and Reconstructive Surgery, National Burn Centre, Haukeland University Hospital, Norway. Her main research interest is outcomes research in both critically ill patients and their families, using both quantitative and qualitative methods.

Eva Gjengedal (RN, PhD, Professor Emerita) is employed at the Department of Global Public Health and Primary Care at the university of Bergen. She is an intensive care nurse and her main research interests are empirical research on illness experiences (critically and chronically ill patients), health care providers' interaction with people with dementia and the role of art in communicating life with dementia.

Pia Dreyer (RN, PhD, Professor in Nursing) is employed both at the Department of Public Health, Section of Nursing, Aarhus University Denmark, Intensive care unit at Aarhus University Hospital Denmark and Department of Global Public Health and Primary Care at the university of Bergen Norway. She is a nurse researcher within the context of ICU nursing and Home mechanical ventilation. She has a special interest in sound, music and sleep. Methodologically she works with phenomenology and hermeneutics and has developed a Ricoeur-inspired interpretation method. She is currently Chief Editor for the journal Nordic Nursing Research and Chairman of The Danish Nursing Society (DASYS).

ORCID

Lina S. T Lernevall http://orcid.org/0000-0001-8104-1127
A. L. Moi http://orcid.org/0000-0002-7158-1792
E. Gjengedal http://orcid.org/0000-0002-9208-3151
P. Dreyer http://orcid.org/0000-0002-3581-7438

References

Arabiat, D., Whitehead, L., Foster, M., Shields, L., & Harris, L. (2018). Parents' experiences of family centred care practices. *Journal of Pediatric Nursing*, *42*, 39–44. https://doi.org/10.1016/j.pedn.2018.06.012

Bakker, A., Maertens, K. J., Van Son, M. J., & Van Loey, N. E. (2013). Psychological consequences of pediatric burns from a child and family perspective: A review of the empirical literature. *Clinical Psychology Review*, *33*(3), 361–371. https://doi.org/10.1016/j.cpr.2012.12.006

Barnelova. (1981). Lov om barn og foreldre (barnelova). (LOV-1981-04-08-7). *Lovdata*. https://lovdata.no/dokument/NL/lov/1981-04-08–7

Barnett, B. S., Mulenga, M., Kiser, M. M., & Charles, A. G. (2017). Qualitative analysis of a psychological supportive counseling group for burn survivors and families in Malawi. *Burns*, *43*(3), 602–607. https://doi.org/10.1016/j.burns.2016.09.027

Brown, E. A., De Young, A., Kimble, R., & Kenardy, J. (2019). Impact of Parental Acute Psychological Distress on Young Child Pain-Related Behavior Through Differences in Parenting Behavior During Pediatric Burn Wound Care. *Journal of Clinical Psychology in Medical Settings*, *26*(4), 516–529. https://doi.org/10.1007/s10880-018-9596-1

Brusselaers, N., Monstrey, S., Vogelaers, D., Hoste, E., & Blot, S. (2010). Severe burn injury in Europe: A systematic review of the incidence, etiology, morbidity, and mortality. *Critical Care*, *14*(5), R188. https://doi.org/10.1186/cc9300

Cahners, S. S. (1979). Group meetings benefit families of burned children. *Scandinavian Journal of Plastic and Reconstructive Surgery*, *13*(1), 169–171. https://doi.org/10.3109/02844317909013049

De Young, A. C., Hendrikz, J., Kenardy, J. A., Cobham, V. E., & Kimble, R. M. (2014). Prospective evaluation of parent distress following pediatric burns and identification of risk factors for young child and parent posttraumatic stress disorder. *Journal of Child and Adolescent Psychopharmacology*, *24*(1), 9–17. https://doi.org/10.1089/cap.2013.0066

Dreyer, P. S., & Pedersen, B. D. (2009). Distanciation in Ricoeur's theory of interpretation: Narrations in a study of life experiences of living with chronic illness and home mechanical ventilation. *Nursing Inquiry*, *16*(1), 64–73. https://doi.org/10.1111/j.1440-1800.2009.00433.x

Egberts, M., van de Schoot, R., Geenen, R., & Van Loey, N. (2017). Parents' posttraumatic stress after burns in their school-aged child: A prospective study. *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association*, *36*(5), 419–428. https://doi.org/10.1037/hea0000448

Egberts, M. R., de Jong, A. E. E., Hofland, H. W. C., Geenen, R., & Van Loey, N. E. E. (2018a). Parental presence or absence during paediatric burn wound care procedures. *Burns*, *44* (4), 850–860. https://doi.org/10.1016/j.burns.2017.11.016

Egberts, M. R., van de Schoot, R., Geenen, R., & Van Loey, N. E. E. (2018b). Mother, father and child traumatic stress reactions after paediatric burn: Within-family co-occurrence and parent-child discrepancies in appraisals of child stress. *Burns*, *44*(4), 861–869. https://doi.org/10.1016/j.burns.2018.01.003

El Hamaoui, Y., Yaalaoui, S., Chihabeddine, K., Boukind, E., & Moussaoui, D. (2006). Depression in mothers of burned children. *Archives of Women's Mental Health*, *9*(3), 117–119. https://doi.org/10.1007/s00737-006-0124-1

Engström, Å., Dicksson, E., & Contreras, P. (2015). The desire of parents to be involved and present. *Nursing in Critical Care*, *20*(6), 322–330. https://doi.org/10.1111/nicc.12103

Foster, M., Whitehead, L., & Maybee, P. (2016). The parents', hospitalized child's, and health care providers' perceptions and experiences of family-centered care within a pediatric critical care setting: A synthesis of quantitative research. *Journal of Family Nursing*, *22*(1), 6–73. https://doi.org/10.1177/1074840715618193

Frenkel, L. (2008). A support group for parents of burned children: A South African children's hospital burns unit. *Burns*, *34* (4), 565–569. https://doi.org/10.1016/j.burns.2007.09.016

Greenhalgh, D. G. (2019). Management of Burns. *The New England Journal of Medicine*, *380*(24), 2349–2359. https://doi.org/10.1056/nejmra1807442

Griffiths, C. (2017). How are parents affected when their child has an appearance-altering injury? *Journal of Aesthetic Nursing*, *5*(2), 79–81. https://doi.org/10.12968/joan.2016.5.2.79

Harrison, T. M. (2010). Family-centered pediatric nursing care: State of the science. *Journal of Pediatric Nursing*, *25* (5), 335–343. https://doi.org/10.1016/j.pedn.2009.01.006

Hawkins, L., Centifanti, L. C. M., Holman, N., & Taylor, P. (2019). Parental adjustment following pediatric burn injury: The role of guilt, shame, and self-compassion. *Journal of Pediatric Psychology*, *44*(2), 229. https://doi.org/10.1093/jpepsy/jsy079

Heath, J., Williamson, H., Williams, L., & Harcourt, D. (2018). Parent-perceived isolation and barriers to psychosocial support: A qualitative study to investigate how peer support might help parents of burn-injured children. *Scars, Burns & Healing*, *4*, 205951311876380. https://doi.org/10.1177/2059513118763801

Henderson, V. (1964). The nature of nursing. *The American Journal of Nursing*, *64*(8), 62–68. DOI:10.1097/00000446-196408000-00029

Jackson, J. C., Santoro, M. J., Ely, T. M., Boehm, L., Kiehl, A. L., Anderson, L. S., & Ely, E. W. (2014). Improving patient care through the prism of psychology: Application of Maslow's hierarchy to sedation, delirium, and early mobility in the intensive care unit. *Journal of Critical Care*, *29*(3), 438. https://doi.org/10.1016/j.jcrc.2014.01.009

Kim, L. K., Martin, H. C. O., & Holland, A. J. (2012). Medical management of paediatric burn injuries: Best practice. *Journal of Paediatrics and Child Health*, *48*(4), 290–295. https://doi.org/10.1111/j.1440-1754.2011.02128.x

Kornhaber, R., Childs, C., & Cleary, M. (2018). Experiences of guilt, shame and blame in those affected by burns: A qualitative systematic review. *Burns*, *44*(5), 1026–1039. https://doi.org/10.1016/j.burns.2017.11.012

Landolt, A. M., Grubenmann, A. S., & Meuli, A. M. (2002). Family impact greatest: Predictors of quality of life and psychological adjustment in pediatric burn survivors. *The Journal of Trauma: Injury, Infection, and Critical Care*, *53*(6), 1146–1151. https://doi.org/10.1097/00005373-200212000-00019

Leon, M. A., & Knapp, M. S. (2008). Involving family systems in critical care nursing: Challenges and opportunities. *Dimensions of Critical Care Nursing*, *27*(6), 255–262. https://doi.org/10.1097/01.DCC.0000338866.47164.6d

Lernevall, L. S. T., Moi, A. L., Cleary, M., Kornhaber, R., & Dreyer, P. (2019a). Support needs of parents of hospitalised children with a burn injury: An integrative review. *Burns*. 46(4), 77–781 https://doi.org/10.1016/j.burns.2019.04.021

Lernevall, L. S. T., Moi, A. L., Gjengedal, E., & Dreyer, P. (2019b). Staff members' experience of providing parental support in a national burn centre. *The Open Nursing Journal*, *13*(1), 211–219. https://doi.org/10.2174/1874434601913010211

Lieberman, A. F. (2004). Traumatic stress and quality of attachment: Reality and internalization in disorders of infant mental health. *Infant Mental Health Journal*, *25*(4), 336–351. https://doi.org/10.1002/imhj.20009

McGarry, S., Elliott, C., McDonald, A., Valentine, J., Wood, F., & Girdler, S. (2015). "This is not just a little accident": A qualitative understanding of paediatric burns from the perspective of parents. *Disability and Rehabilitation*, *37*(1), 41–50. https://doi.org/10.3109/09638288.2014.892640

Mohammadhossini, S., Ahmadi, F., Gheibizadeh, M., Saki Malehi, A., & Zarea, K. (2019). Comprehensive physical domain care needs of burn patients: A qualitative study. *Clinical, Cosmetic and Investigational Dermatology*, *12*, 573–581. https://doi.org/10.2147/CCID.S215517

O'Brien, C. B., Harris, B. I., Beckman, J. T., Reed, A. D., & Cook, A. D. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, *89*(9), 1245–1251. https://doi.org/10.1097/ACM.0000000000000388

Onarheim, H., Brekke, R., Heisterkamp, H., & Guttormsen, A. B. (2014). *Burns admitted to Norwegian hospitals in 2012 - A national survey*. The 17th Congress of the International Society for Burn Injuries (ISBI), Sydney, Australia.

Orem, D. E. (1971). *Nursing: Concepts of practice*. McGraw-Hill Book Company.

Pardo, G. D., García, I. M., Marrero, F. D. R. M., & Cía, T. G. (2008). Psychological impact of burns on children treated in a severe burns unit. *Burns*, *34*(7), 986–993. https://doi.org/10.1016/j.burns.2008.01.016

QSR International Pty Ltd. (2019). *NVivo qualitative data analysis software, Version 12 Plus*. https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

Ravindran, V., Rempel, G. R., & Ogilvie, L. (2013a). Embracing survival: A grounded theory study of parenting children who have sustained burns. *Burns*, *39*(4), 589–598. https://doi.org/10.1016/j.burns.2012.12.016

Ravindran, V., Rempel, G. R., & Ogilvie, L. (2013b). Parenting burn-injured children in India: A grounded theory study. *International Journal of Nursing Studies*, *50*(6), 786–796. https://doi.org/10.1016/j.ijnurstu.2012.06.011

REC. (2019). *REC regional committees for medical and health research ethics*. https://helseforskning.etikkom.no/?_ikbLanguageCode=us

Ricoeur, P. (1976). *Interpretation theory: Discourse and the surplus of meaning*. Texas Christian University Press, Fort Worth, Tex.

Rivlin, E., Forshaw, A., Polowyj, G., & Woodruff, B. (1986). A multidisciplinary group approach to counselling the parents of burned children. *Burns, Including Thermal Injury*, *12*(7), 479–483. https://doi.org/10.1016/0305-4179(86)90073-2

Simons, M. A., Ziviani, J., & Copley, J. (2010). Predicting functional outcome for children on admission after burn injury: Do parents hold the key? *Journal of Burn Care & Research: Official Publication of the American Burn Association*, *31*(5), 750–765. https://doi.org/10.1097/BCR.0b013e3181eebe88

Sveen, J., Andersson, G., Buhrman, B., Sjoberg, F., & Willebrand, M. (2017). Internet-based information and support program for parents of children with burns: A randomized controlled trial. *Burns*, *43*(3), 583–591. https://doi.org/10.1016/j.burns.2016.08.039

Sveen, J., & Willebrand, M. (2018). Feelings of guilt and embitterment in parents of children with burns and its associations with depression. *Burns*, *44*(5), 1135–1140. https://doi.org/10.1016/j.burns.2018.02.005

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Wiechman, S. A., & Patterson, D. R. (2004). ABC of burns: Psychosocial aspects of burn injuries. *British Medical Journal*, *329*(7462), 391–393. https://doi.org/10.1136/bmj.329.7462.391

World Medical Association. (1964/2013). *WMA Declaration of Helsinki – Ethical principles for medical research involving human subjects*. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

Zahavi, D. (2019). *Phenomenology the basics*. Routledge.

Appendix I–X

Appendix I: Information letter to staff members (in Norwegian).

Appendix II: Information letter to psychologists (in Norwegian).

Appendix III: Information letter to parents of burn-injured children (in Norwegian).

Appendix IV: The interview guide for the focus group interviews with staff members and leaders (in Norwegian).

Appendix V: The interview guide for the semi-structured interviews with parents of burn-injured children (in Norwegian).

Appendix VI: The interview guide for the semi-structured interviews with parents of burn-injured children at their three-month follow-up appointment (in Norwegian).

Appendix VII: Ethical approval of the research project by the Norwegian Regional Committees for Medical and Health Research Ethics (REC) – 01.03.2017 (in Norwegian).

Appendix VIII: Ethical approval of project changes by the Norwegian Regional Committees for Medical and Health Research Ethics (REC) – 11.12.2017 (in Norwegian).

Appendix IX: Ethical approval to use interpretor by the Norwegian Regional Committees for Medical and Health Research Ethics (REC) – 20.02.2018 (in Norwegian).

Appendix X: Information letter to parents of burn-injured children (in English).

Appendix I

Information letter to staff members (in Norwegian)

[redacted]

UNIVERSITETET I BERGEN

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

FORELDRES ERFARINGER MED BRANNSKADER OG BEHOV FOR STØTTE PÅ EN BRANNSKADEAVDELING

Dette er et spørsmål til deg som arbeider ved [redacted], om å delta i et forskningsprosjekt som omhandler foreldre til brannskadde barns behov for støtte gjennom oppholdet.
En alvorlig brannskade hos barn innebærer en betydelig belastning for hele barnets familie. Foreldre får store endringer i sine omsorgsoppgaver for barnet, og mange vil i tillegg være utsatt for stressreaksjoner som kan påvirke livene og foreldrerollen under og i etterkant av sykehusoppholdet. Hensikten med denne studien er å få økte kunnskaper om foreldres behov, for deretter å utvikle et program som sikrer foreldre til brannskadde barn optimal omsorg og støtte. Både foreldre og medlemmer i brannskadeteamet vil bli invitert til å delta i studien.
Studien er et PhD prosjekt. Prosjektet er et samarbeid mellom [redacted] [redacted]; Institutt for Global helse og Samfunnsmedisin, Universitetet i Bergen; Institutt for sykepleiefag, Høgskulen på Vestlandet og Aarhus Universitet, Danmark.
[redacted] er forskningsansvarlig institusjon. PhD-stipendiat Lina S. D. Lernevall er prosjektleder.

HVA INNEBÆRER PROSJEKTET?

Du vil bli intervjuet i et fokusgruppeintervju sammen med 6-8 andre kollegaer fra [redacted] (eksempelvis sykepleier, plastikk-kirurg, psykolog, sosionom og fysioterapeut). Spørsmålene vil omhandle erfaringer dere har relatert til omsorgen og behandlingen av barn, og hva foreldre til brannskadde barn trenger/har behov for i den akutte fasen fra personalet som jobber på [redacted].
To fra forskningsgruppen, en intervjuer og en sekretær, vil være tilstede under gruppediskusjonen, **men det er dere som deltar, som er aktive i diskusjonen.**
Det vil bli anmodet om taushetsplikt innad i gruppen. Fokusgruppeintervjuet vil bli tatt opp på digital lydopptaker og vare 1-2 timer.

I prosjektet vil vi også be om noen bakgrunnsopplysninger om deg som: profesjon, alder, kjønn, yrkeserfaring og erfaring fra [redacted].

MULIGE FORDELER OG ULEMPER

Ved å delta vil du få anledning til å bruke dine kunnskaper og erfaringer fra behandlingen av brannskadde barn og foreldre og drøfte deres behov for profesjonell støtte sammen med kolleger. Med din viten og erfaring vil du bidra til å hjelpe fremtidige foreldre til brannskadede barn og øke kunnskapen hos de ansatte.
Ulempen er at det kan føles vanskelig å avsette den nødvendige tiden til dette når dagene er opptatt med mange gjøremål. Det vil ikke ha noen konsekvenser for din videre ansettelse om du velger å delta eller ikke.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side og skriver dit telefonnummer, og sender mail til prosjektleder Lina S. D. Lernevall. Husk å ta med denne samtykkeerklæring til intervjuet. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger, med mindre de allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte:

Prosjektleder: **PhD-stipendiat, sykepleier** Lina S. D. Lernevall
Mobil: [redacted] eller [redacted]
E-mail: [redacted] eller [redacted]

Medveileder: **Førsteamanuensis, intensivsykepleier** Asgjerd L. Moi
Mobil: [redacted]
E-mail: [redacted]

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Informasjon om deg vil bli anonymisert eller slettet senest fem år etter prosjektslutt.

Lydfiler destrueres ved projektslutt og transkriptene oppbevares avidentifisert på forskningsserver, [redacted] [redacted].

OPPFØLGINGSPROSJEKT

Det kan være at fokusgruppeintervjuene skal gjentas i fremtiden. Da vil du bli kontaktet igjen og invitert til deltakelse i nytt intervju. Det er valgfritt om du vil delta.

GODKJENNING

Prosjektet er godkjent av øverste ledelse ved [redacted] og Regional komite for medisinsk og helsefaglig forskningsetikk, Saksnr. hos REK: 2017/54/REK vest.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Jeg skriver samtidig under på at jeg har fått skriftlig og muntlig informasjon om dette forskningsprosjekt.

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

og telefonnummer

Jeg bekrefter å ha gitt informasjon om prosjektet

Sted og dato

Signatur

Rolle i prosjektet

Appendix II

Information letter to psychologists (in Norwegian)

Til PSYKOLOGENE

Mars 2017

Informasjonsskriv til deg som er psykolog tilknyttet [redacted]

Kort resyme om hensikten med studien:
Prosjektet fokuserer på foreldre som kommer inn på et brannskadesenter med deres brannskadde barn (under 12 år). Formålet med studie er å forstå hva foreldrene trenger i den mest akutte fasen fra det multi-disiplinære behandlingsteamet, og å utarbeide en konkret strategi for foreldrestøtte. Foreldrene vil bli intervjuet om sine erfaringer to-tre uker og tre måneder etter skaden har skjedd.

Dere psykologer tilser alle foreldre til brannskadede barn og skal stå for å inkludere foreldre til studien. Når dere møter foreldrene, ber vi dere om å tenke over om en eller begge foreldre kan inkluderes i denne doktorgradstudien.
Vi ønsker å intervjue ca. 20 foreldre (altså foreldre til minimum 10 barn), og vi vil gi beskjed til dere, når vi har oppnådd det ønskede antallet.

Inklusjonskriterier:

- Kan foreldrene snakke og forstå norsk (trenger ikke være etnisk norsk).
- Har foreldrene et barn under 12 år innlagt med brannskade på [redacted] (barnet må som minimum ha vært innlagt i **minst 1 døgn** på [redacted]).
- Har foreldrene et brannskadet barn, der skaden skyldes en ulykke. (De familier der skaden er påført barnet skal ikke inngå i studien.)

Fremgangsmåte:

1) Dere tilser alle foreldre til barn som blir brannskadet.
2) Oppfyller en eller begge foreldre inklusjonskriteriene?
3) Hvis de oppfyller inklusjonskriteriene skal dere forteller kort om denne studien og utlevere konvolutt med informasjon til foreldrene. I en stor [redacted] konvolutt ligger informasjonsskriv og en ferdig frankert svarkonvolutt adressert til medveileder Asgjerd L. Moi.
4) Dere skal fortelle foreldrene at dersom de ønsker å delta skal de undertegne samtykkeerklæringen på siste side og skriver deres telefonnummer, og sende dette i den ferdig adresserte og frankerte svarkonvolutten.
5) De som ønsker å delta vil deretter bli kontaktet av doktorgradsstudent Lina S. D. Lernevall, og det vil bli avtalt dato for intervju på dertil egnet sted på [redacted] eller på pasienthotellet.
6) Dere skal notere ned hvor mange dere utleverer informasjonsbrev. (Slik vi kan se hvor mange av de inviterte, som ønsker å delta).

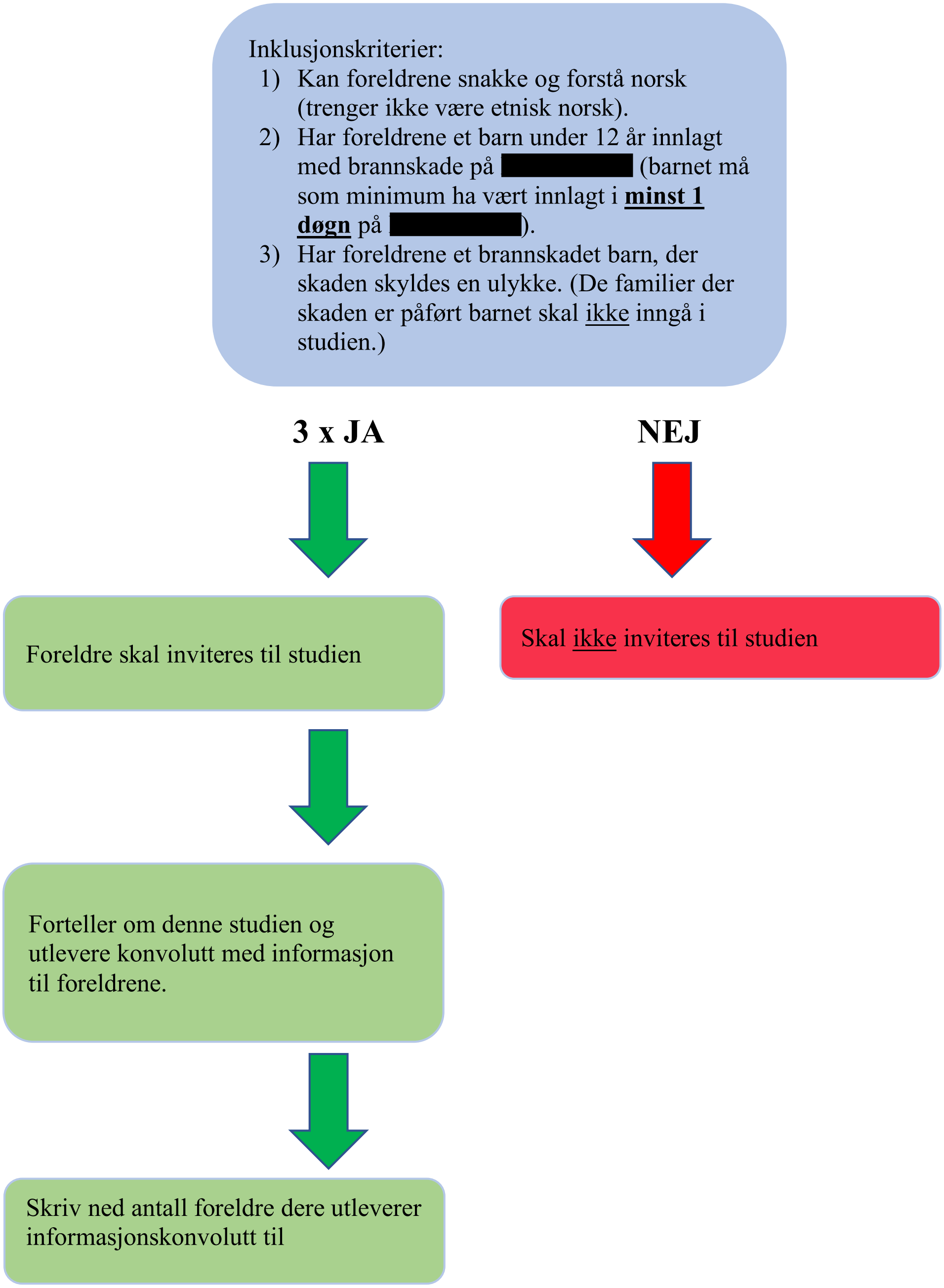
Be foreldrene å kontakte Lina S. D. Lernevall hvis de har spørsmål.

Prosjektleder: PhD-stipendiat, Sykepleier med tidligere erfaring fra [redacted],
Master of Science in Nursing Lina S. D. Lernevall
E-mail: [redacted] eller [redacted]
Mobil: [redacted]

Til PSYKOLOGENE

Mars 2017

Skal foreldre inviteres til PhD'en eller ikke?



Inklusjonskriterier:

1) Kan foreldrene snakke og forstå norsk (trenger ikke være etnisk norsk).
2) Har foreldrene et barn under 12 år innlagt med brannskade på [redacted] (barnet må som minimum ha vært innlagt i **minst 1 døgn** på [redacted]).
3) Har foreldrene et brannskadet barn, der skaden skyldes en ulykke. (De familier der skaden er påført barnet skal ikke inngå i studien.)

3 x JA

Foreldre skal inviteres til studien

Forteller om denne studien og utlevere konvolutt med informasjon til foreldrene.

Skriv ned antall foreldre dere utleverer informasjonskonvolutt til

NEJ

Skal ikke inviteres til studien

Appendix III

Information letter to parents of burn-injured children (in Norwegian)

[redacted]

UNIVERSITETET I BERGEN

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

FORELDRES ERFARINGER MED BRANNSKADER OG BEHOV FOR STØTTE PÅ EN BRANNSKADEAVDELING

Dette er et spørsmål til deg som forelder til et barn som har blitt behandlet ved [redacted], [redacted], om å delta i et forskningsprosjekt som omhandler foreldre til brannskadde barns behov for støtte gjennom oppholdet.
En alvorlig brannskade hos barn innebærer en betydelig belastning for hele barnets familie. Hensikten med denne studien er å få økte kunnskaper om foreldres behov, for deretter å utvikle et program som sikrer foreldre til brannskadde barn optimal omsorg og støtte. Både foreldre og medlemmer i brannskadeteamet vil bli invitert til å delta i studien.

Studien er et PhD prosjekt. Prosjektet er et samarbeid mellom [redacted], [redacted] [redacted]; Institutt for Global helse og Samfunnsmedisin, Universitetet i Bergen; Institutt for sykepleiefag, Høgskulen på Vestlandet og Aarhus Universitet, Danmark.
[redacted] er forskningsansvarlig institusjon. PhD-stipendiat Lina S. D. Lernevall er prosjektleder.

HVA INNEBÆRER PROSJEKTET?

Du inviteres til å delta i to intervju. (2-3 uker og 3 måneder etter skaden har skjedd). Om du ønsker å bli intervjuet individuelt eller sammen som par, er etter dit eget ønske og behov. Spørsmålene vil omhandle erfaringer du har hatt relatert til omsorgen og behandlingen ved [redacted], og hvilke behov for støtte og oppfølging du har hatt som forelder til et brannskadet barn (fra sykepleiere, leger, psykolog, fysioterapeut, sosionom og andre).
Intervjuet vil bli tatt opp på digital lydopptaker og vil vare 1 til 2 timer.

I prosjektet vil vi også be om noen bakgrunnsopplysninger om deg som: alder, kjønn, relasjon til pasienten, utdanning, yrke og tidligere erfaringer med helsetjenesten.

MULIGE FORDELER OG ULEMPER

Ved å delta vil du få anledning til å gi uttrykk for dine erfaringer fra behandlingen av ditt barn og med dette bidra til å øke kunnskapen om foreldre til brannskadede barns behov.
For mange vil det kunne være godt å få snakke om dette, men for noen kan dette også vekke til live ubehagelige minner og sterke følelser.

Det får INGEN betydning for behandlingen av dit barn, om du velger å delta eller ikke å delta. Ditt barn vil få samme profesjonelle hjelp uansett om du deltar i dette forskningsprosjektet eller ei.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side og skriver dit telefonnummer, og sender svaret med den ferdig frankerte svarkonvolutt til medveileder Asgjerd L. Moi. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for den videre behandling av dit barn.
Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte:

Prosjektleder: **PhD-stipendiat, sykepleier** Lina S. D. Lernevall
Mobil:[redacted]eller [redacted]
E-mail:[redacted] eller [redacted]

Medveileder: **Førsteamanuensis, intensivsykepleier** Asgjerd L. Moi
Mobil:[redacted]
E-mail:[redacted]

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste.

Prosjektleder har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte. Informasjon om deg vil bli anonymisert eller slettet senest fem år etter prosjektslutt.

Lydfiler destrueres ved projektslutt og transkriptene oppbevares avidentifisert på forskningsserver,[redacted] [redacted].

OPPFØLGINGSPROSJEKT

Vi ber også om å oppbevare navneliste og de innsamlede intervjuene i 5 år med tanke på en eventuell oppfølgingsstudie. Da vil du bli kontaktet og invitert til å delta igjen. Det er valgfritt om du vil delta i en eventuell oppfølgingsstudie.

ØKONOMI

Dersom du ved senere intervju (etter de to planlagte intervjuene) skal reise til intervjuet vil du få reisegodtgjørelse.
Dette forskningsprosjekt er økonomisk støttet av Helse-Vest RHF.

GODKJENNING

Prosjektet er godkjent av øverste ledelse ved [redacted] og Regional komite for medisinsk og helsefaglig forskningsetikk, Saksnr. hos REK: 2017/54/REK vest.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Jeg skriver samtidig under på at jeg har fått skriftlig og muntlig informasjon om dette forskningsprosjekt.

Sted og dato	Deltakers signatur
	Deltakers navn med trykte bokstaver og telefonnummer

Jeg bekrefter å ha gitt informasjon om prosjektet

Sted og dato	Signatur
	Rolle i prosjektet

Appendix IV

The interview guide for the focus group interviews with staff members and leaders
(in Norwegian)

Intervjuguide – Fokusgruppeintervju med ansatte

1. Først tar vi en runde, hvor alle presenterer seg selv
   – Navn, profesjon og hvor lang tid du har jobbet med brannskader. Dette er for å registrere stemmen din på opptakeren.
2. Så er det dere, som skal snakke sammen. Kan dere beskrive, hva dere mener er viktig for å støtte og hjelpe foreldre til brannskadde barn?
   (Hva trenger foreldre til brannskadde barn i den akutte fasen, den første tiden på brannskadeavdelingen?)
3. Beskriv en situasjon som du synes var særlig flott i forhold til støtte til foreldre med brannskadde barn? Hva opplevde du som betydningsfullt i situasjonen?

Buffer (Brukes kun eventuelt hvis samtalen går tregt):

4. Nå skal dere beskrive det dere mener har betydning i støtten til foreldre til brannskadde barn?
   Beskriv gjerne så detaljert som mulig.
5. Så skal dere beskrive det dere mener personalet kan bli bedre på i forhold til å støtte foreldre til brannskadde barn?
   Beskriv gjerne så detaljert som mulig.
6. Hva er betydningsfullt for deg når du gir støtte til foreldrene?
7. Hvis dere skulle lage en intervensjon for å støtte foreldre til barn med brannskader, hva ville dere da legge vekt på?

Debrifing:

Når er intervjuet snart slutt og jeg vil gjerne høre, om noen av dere har en avsluttende kommentar?
Avslutningsvis lurer jeg på hvordan det har vært å delta i dette intervjuet?

Appendix V

The interview guide for the semi-structured interviews with parents of burn-injured children (in Norwegian)

Intervjuguide individuelt intervju – Forelder/Foreldre

Fakta/Innledning: Alder, kjønn, relasjon til barnet, utdanning, yrke og tidligere erfaringer med helsetjenesten (Fra infoskriv)	**Oppfølgingsspørsmål**	**Oppfølging - stikkord**
1. Vil du/dere først si navnet dit/deres, hvor gammel du/dere er og hvem du/dere er forelder til (Navn/alder)? 2. Vil du/dere fortelle hvordan brannskaden skjedde?	2. Husker du/dere skadeprosenten?	
Opplevelse:		
3. Hvordan var din/deres opplevelse/r av å komme inn på brannskadeavdelingen?		3. Følelser, inntrykk.
4. Hva var betydningsfullt for deg/dere da du/dere kom til avdelingen?	4. Kan du/dere evt. beskrive konkrete situasjoner?	4. Støtte, omsorg, informasjon, praktiske gjøremål.
5. Hvordan opplevde du/dere dagen på avdelingen gjennom sykehusoppholdet?		5. Personalet, praktisk, organisatorisk.
6. Hvordan har du/dere opplevd personalet på avdelingen?	6. Kan du/dere beskrive en konkret situasjon? Hvilke personale var det?	6. Sykepleier, leger, psykolog, fysioterapeut og andre.
7. Har du/dere har opplevet at du/dere fik støtte i forhold til å va forelder til et brannskadet barn?	7. Kan du/dere beskrive en konkret situasjon?	
8. Har du/dere opplevet at du manglet støtte i forhold til å va forelder til et brannskadet barn?	8. Kan du/dere beskrive en konkret situasjon?	
9. Hvis du/dere mener noe kan gjøres bedre i fremtiden, hva vil ditt/deres råd være?	9. Kan du/dere beskrive en situasjon?	
10. Har du/dere blitt forberedt på overflytting/hjemreisen? Hvordan skjedde det?	10. Hvordan opplevde/s du/dere det?	10. Tanker, følelser.
Debrifing:		
11. Nu er intervjuet snart slut. Er det noe du ønsker å si, som du ikke har fått sagt? 12. Avslutningsvis vil jeg spørre deg, hvordan har det vært å delta i dette intervju?		

Appendix VI

The interview guide for the semi-structured interviews with parents of burn-injured children at their three-month follow-up appointment (in Norwegian)

Intervjuguide individuelt intervju – Forelder/Foreldre til tre måneders kontroll

Innledning: Nå er det X måneder siden vi møttes, og jeg er spent på å høre hva som har skjedd siden sist.	**Oppfølgingsspørsmål**	**Oppfølging - stikkord**
Vi snakket om … (oppsummere fra siste intervju). Har du/dere noe du/dere vil kommentere i forhold til min oppsummering?		
Er det noe dere har tenkt/kommet på siden sist, som dere vil legge til?		
Opplevelse:		
3. Hvordan var din/deres opplevelse/r av å komme inn på brannskadeavdelingen?		3. Følelser, inntrykk.
4. Hva var betydningsfullt for deg/dere da du/dere kom til avdelingen?	4. Kan du/dere evt. beskrive konkrete situasjoner?	4. Støtte, omsorg, informasjon, praktiske gjøremål.
5. Hvordan opplevde du/dere dagen på avdelingen gjennom sykehus-oppholdet?		5. Personalet, praktisk, organisatorisk.
6. Hvordan har du/dere opplevd personalet på avdelingen?	6. Kan du/dere beskrive en konkret situasjon? Hvilke personale var det?	6. Sykepleier, leger, psykolog, fysioterapeut og andre.
7. Har du/dere har opplevet at du/dere fik støtte i forhold til å va forelder til et brannskadet barn?	7. Kan du/dere beskrive en konkret situasjon?	
8. Har du/dere opplevet at du manglet støtte i forhold til å va forelder til et brannskadet barn?	8. Kan du/dere beskrive en konkret situasjon?	
9. Hvis du/dere mener noe kan gjøres bedre i fremtiden, hva vil ditt/deres råd være?	9. Kan du/dere beskrive en situasjon?	
10. Ble du/dere forberedt på overflytting/hjemreisen? Hvordan skjedde det?	10. Hvordan opplevde/s du/dere det?	10. Tanker, følelser.
Debrifing:		
11. Nu er intervjuet snart slut. Er der noe du ønsker å si, som du ikke har gått sagt? 12. Avslutningsvis vil jeg spørre deg, hvordan har det vært å delta i dette intervjuet?		

Appendix VII

Ethical approval of the research project by the Norwegian Regional Committees for Medical and Health Research Ethics (REC) – 01.03.2017 (in Norwegian)

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Anna Stephansen	55978496	01.03.2017	2017/54/REK vest
			Deres dato:	
			10.01.2017	

Vår referanse må oppgis ved alle henvendelser

Lina S. D. Lernevall
[redacted]

2017/54 Foreldres erfaringer med brannskader og behov for støtte på en brannskadeavdeling

Forskningsansvarlig: [redacted]
Prosjektleder: Lina S. D. Lernevall

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) i møtet 09.02.2017. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Prosjektomtale
Prosjektet fokuserer på foreldre som kommer inn på et brannskadesenter med deres brannskadde barn (under 12 år). Formålet er å forstå hva foreldrene trenger i den mest akutte fasen fra det multidisiplinære behandlingsteamet, og å utarbeide en konkret strategi for foreldrestøtte. Foreldrene (n=20) vil bli intervjuet om sine erfaringer to-tre uker og tre måneder etter skaden har skjedd. Det vil også bli gjennomført to-tre fokusgruppeintervju a 6-8 personer fra det multidisiplinære teamet. Basert på opplysninger fra intervjuene vil det utvikles 50 utsagn om foreldres oppfølgingsbehov. Utsagnene vil bli rangert (Q-sort) av 40 foreldre som kommer til kontroll i poliklinikken maks to år etter utskrivelsen og 40 personale fra det multidisiplinære teamet. Deretter utvikles en intervensjon som prøves ut for nytte og gjennomførbarhet på foreldre til to brannskadde barn.

Vurdering
Forsvarlighet
Foreldre blir utsatt for langtidig stress i den akutte situasjonen når store brannskader oppstår. REK Vest mener at dette er et prisverdig prosjekt som vil undersøke om det er noe man kan gjøre for å støtte foreldre i den akutte situasjonen. Komiteen mener at studien er godt gjennomarbeidet. Studien vurderes som viktig og forsvarlig å gjennomføre slik den er lagt opp.

Rekruttering
Prosjektledere opplyser at det er ledelsen som skal velge ut informanter i studien. REK vest gjør oppmerksom på at hovedregel om samtykke jfr. § 13 er at samtykket skal være informert, frivillig, uttrykkelig og dokumenterbart. Dersom forskningsdeltakeren kan anses å være i et avhengighetsforhold til den som ber om samtykke, at forskningsdeltakeren vil kunne føle seg presset til å gi samtykke, skal det informerte samtykket innhentes av en annen som forskningsdeltakeren ikke har slikt forhold til.

REK vest gjør oppmerksom på at personene i studien deltar frivillig og at det ikke er ønskelig å utøve noe press overfor denne gruppen.

REK vest forstår det slik at ledelsen foreslår kandidater som har relevant erfaring det vil si, de som har jobbet med barn. Komiteen gjør oppmerksom på at ledelsen kan tilrettelegge for å delta i intervju i arbeidstiden, men kan ikke pålegge deltakelsen i studien. De ansatte må få lov til å velge fritt om de har lyst til å bidra til prosjektet.

Informasjonsskrivet
Det nevnes i andre avsnitt at '….det er viktig for forelder å få nødvendig oppfølging og støtte …' REK vest mener at dette er en hypotese som skal undersøkes gjennom studien. Setningen må omformuleres.

Prosjektslutt og håndtering av data
Prosjektlederen informerer at lydfiler destrueres ved prosjektslutt og transkriptene oppbevares avidentifisert på forskningsserver, [redacted]. Koblingsnøkkel oppbevares sikkert på forskningsserver i fem år for eventuell oppfølging av studien. REK har ingen innvendinger til dette.

Vilkår
Informasjonsskrivet må revideres i henhold til komiteens merknader og sendes til REK vest til post@helseforskning.etikkom.no.

Vedtak
REK vest godkjenner prosjektet på betingelse av at ovennevnte vilkår tas til følge.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK vest på eget skjema senest 31.07.2021, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK vest dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Marit Grønning
Prof. dr.med
Komiteleder

Anna Stephansen
Kontorsjef

Kopi til: [redacted]

Appendix VIII

Ethical approval of project changes by the Norwegian Regional Committees for Medical and Health Research Ethics (REC) – 11.12.2017 (in Norwegian)

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Camilla Gjerstad	55978499	11.12.2017	2017/54/REK vest
			Deres dato:	
			04.12.2017	

Vår referanse må oppgis ved alle henvendelser

Lina S. D. Lernevall
[redacted]

2017/54 Foreldres erfaringer med brannskader og behov for støtte på en brannskadeavdeling

Forskningsansvarlig: [redacted]
Prosjektleder: Lina S. D. Lernevall

Vi viser til søknad om prosjektendring datert 04.12.2017 for ovennevnte forskningsprosjekt. Søknaden er behandlet av leder for REK vest på fullmakt, med hjemmel i helseforskningsloven § 11.

Prosjektendring
Endret antall deltakere:
Det var opprinnelig planlagt å gjennomføre 2-3 fokusgruppeintervju á 6-8 personer fra det multidisiplinære teamet ved [redacted]. Underveis ble dette noe endret til 4 intervju med i alt 21 personer. Dette er samme antall deltakere som først oppgitt, men fordelt på 4 intervju.

Endret rekrutteringsprosedyre:
Psykologen, som er tilknyttet [redacted], vil spørre foreldre om deltakelse. De som ønsker å delta, vil få skriftlig informasjon, og det avtales et møte med forsker.

Prosjektleder spør om om å endre rekrutteringen på en av to følgende måter:
1. Når psykologene inviterer foreldre, spør de samtidig om forsker kan ringe foreldrene om et par dager, for å høre om de har bestemt seg for å delta.
2. Når psykologene inviterer foreldre, spør de samtidig om de kan komme innom avdelingen etter et par dager for å høre om de har bestemt seg. Psykologene kan da motta eller evt. postlegge samtykkeerklæringen.

Begrunnelsen for å endre rekrutteringsprosedyre er at det har vist seg vanskelig å rekruttere deltakere.

Vurdering
REK vest ved leder har vurdert endringssøknaden. REK vest ber om at rekrutteringen skjer på en slik måte at deltakerne opplever minst mulig press om å delta. REK vest ber derfor om at rekrutteringen legges opp slik:
Foreldrene informeres om studien og forespørres av psykologen om forsker kan sende en påminnelse på sms om studien noen dager etter at de har fått informasjonsskrivet.

Vedtak
REK vest godkjenner prosjektendringen på betingelse av at ovennevnte vilkår tas til følge.

Klageadgang
Du kan klage på komiteens vedtak, jf. helseforskningsloven § 10 og forvaltningsloven § 28 flg. Klagen

sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Marit Grønning
dr.med. professor
leder

Camilla Gjerstad
rådgiver

Kopi til: [redacted]

Appendix IX

Ethical approval to use interpretor by the Norwegian Regional Committees for Medical and Health Research Ethics (REC) – 20.02.2018 (in Norwegian)

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK vest	Jessica Svärd	55978497	20.02.2018	2017/54/REK vest
			Deres dato:	Deres referanse:
			24.01.2018	

Vår referanse må oppgis ved alle henvendelser

Lina S. D. Lernevall
[redacted]

2017/54 Foreldres erfaringer med brannskader og behov for støtte på en brannskadeavdeling

Forskningsansvarlig: [redacted]
Prosjektleder: Lina S. D. Lernevall

Vi viser til søknad om prosjektendring datert 24.01.2018 for ovennevnte forskningsprosjekt. Søknaden er behandlet av sekretariatet for REK vest på fullmakt, med hjemmel i helseforskningsloven § 11.

Vurdering

Målet med denne doktorgraden er å lage et støtteprogram til foreldre som har brannskadede barn som får behandling på [redacted]. I den forbindelse vil foreldre til brannskadde barn bli intervjuet om deres opplevelser knyttet til sykehusoppholdet. Det viser seg at inntil 1/3 av barna som legges inn på [redacted] er fra utenlandske familier, der foreldrene kan så dårlig norsk at de trenger tolk for å kommunisere med helsepersonellet.

Omsøkt endring

Stipendiaten ønsker å inkludere også foreldre som ikke kan norsk godt nok til å delta i et intervju på norsk. Det er viktig å inkludere deres opplevelser i denne studien. For at stipendiaten skal ha mulighet til å forstå deres opplevelser på en tilfredsstillende måte, vil en tolk være nødvendig.

Tidligere inklusjonskriterier:

"Foreldre:
- Som kan snakke og forstå norsk.
- Som har et barn under 12 år innlagt med brannskade ved et nasjonalt brannskadesenter
- Som har et brannskadet barn der skaden skyldes en ulykke".

Endret kriterie:

"Foreldre:
- Som har et barn under 12 år innlagt med brannskade ved et nasjonalt brannskadesenter
- Som har et brannskadet barn der skaden skyldes en ulykke".

Et nytt informasjonsskriv på engelsk er vedlagt prosjektendringen.

REK vest ved leder har vurdert prosjektendringen.

Vurdering

REK vest har ingen innvending til endring av inklusjons- og eksklusjonskriteriet, men har noen merknader til informasjonsskrivet.

Det har kommet med en skrivefeil i tittelen "Porrible (skal være possible) benefits and expected..."

Vilkår

Et revidert informasjonsskriv sendes REK vest på post@helseforskning.etikkom.no.

Vedtak
Prosjektendringen godkjennes på betingelse av at ovennevnte vilkår tas til følge.

Klageadgang
Du kan klage på komiteens vedtak, jf. helseforskningsloven § 10 og forvaltningsloven § 28 flg. Klagen sendes til REK vest. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK vest, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Jessica Svärd
rådgiver

Kopi til: [redacted]

Appendix X

Information letter to parents of burn-injured children (in English)

[redacted]

UNIVERSITETET I BERGEN

INVITATION TO PARTICIPATE IN A RESEARCH PROJECT

PARENTS EXPERIENCES OF BURN INJURY IN THEIR CHILD AND NEEDS FOR SUPPORT DURING HOSPITALIZATION AT A BURN CARE CENTRE.

As a parent to a burn injured child treated at [redacted] [redacted], you are invited to participate in a research project about support to parents to burn injured children.
A burn injury affect not only the child but also the parents. Based on the experiences of the parents this study aims to develop a support program for parents to burn injured children.
Both parents to burn injured children and the staff will be interviewed separately.

This study is a Ph.D. project (Doctoral project).
The project is a collaboration between: [redacted] [redacted]. Department of Global Public Health and Primary Care at the University of Bergen. Faculty of Health and Social Sciences, Department of Nursing at Western Norway University of Applied Sciences. And Section of Science in Nursing at Aarhus University in Denmark.
[redacted] is the research institution responsible. Ph.D. candidate Lina S. D. Lernevall is project managers.

WHAT IS THE STUDY ABOUT?

You will be invited to participate in two interviews. (2-3 weeks and 3 months after the accident has happened).
You can be interviewed alone or together with you partner. This is your choice.
You will be asked about you experience in relation to the care and treatment at [redacted] [redacted], what support you need and follow-up you have received (from nurses, doctors, psychologists, physiotherapists, social worker and others).
The interview will be digitally recorded and the interview will take 1-2 hours.

You will also be asked about some personal information such as: age, sex, relation to the patient, education, profession and previous experiences with health systems.

POSSIBLE BENEFITS AND EXPECTED DISADVANTAGES OF TAKING PART

When participating you will be able to talk about you experience about the treatment of your child, and thereby contribute to the knowledge about parents to burn injured children.
For many parents it will be positive to talk about it all, but for some it can also awaken unpleasant memories and strong feelings.

If you participate or not, will NOT affect the care or the treatment of your child. Your child will get the same professional care regardless of your choice of participation in this project.

VOLUNTARY PARTICIPATION AND THE POSSIBILITY TO WITHDRAW CONSENT

Participation in this study is voluntary. If you wish to take part, you will need to sign the declaration of consent on the last page. You can, at any given time and without reason withdraw your consent. This will not have any consequences for any future treatment of your child.
If you decide to withdraw your participation in the project, you can demand that your personal health data be deleted, unless however, the personal health data and tests have already been analysed or used in scientific publications. If you at a later point, wish to withdraw your consent or you have any questions regarding the project, you can contact:

Project manager: **Ph.D.-candidate, nurse** Lina S. D. Lernevall
Mobile: [redacted] or [redacted]
E-mail: [redacted] or [redacted]

Co-supervisor: **Associated professor, intensive care nurse** Asgjerd L. Moi
Mobile: [redacted]
E-mail: [redacted]

WHAT WILL HAPPEN TO YOUR HEALTH INFORMATION?

The information that is recorded about you will only be used as described in the purpose of the study. You have the right to access which information is recorded about you and the right to stipulate that any error in the information that is recorded is corrected.

All information will be processed and used without your name or personal identification number, or any other information that is directly identifiable to you.

The Project Manager has the responsibility for the daily operations/running of the Research Project and that any information about you will be handled in a secure manner. Information about you will be anonymised or deleted a maximum of 5 years after the project has ended.

Interview-records will be deleted at the end of this project and the transcriptions will be kept anonymous at the research server at [redacted].

FOLLOW-UP STUDY

We ask to keep the personal information and the interviews for 5 years as we might make a follow-up study. If that happens you will be contacted again and invited to participate again. It will be up to you if you would like to participate.

FINANCE

If you were to participate in another interview (after 2 planned interviews) and need to travel to the interview, you will receive travel allowance.

This research project is financed by Helse-Vest RHF.

APPROVAL

The Project is approved by the leaders at [redacted] [redacted] and Regional Committee for Medical and Health Research Ethics, Reference number from REC: 2017/54/REK vest.

CONSENT FOR PARTICIPATING IN THE RESEARCH PROJECT

I AM WILLING TO PARTICIPATE IN THE RESEARCH PROJECT

I hereby sign that I have received oral and written information about this research project.

Place and Date

Participant's Signature

Participant's Name (in BLOCK LETTERS)

and **telephone number**

I confirm that I have given the information about the research project.

Place and Date

Signature

Role in the research project

NORDIC ECOLABEL
241 PRINTED MATTER 731

Graphic design: Communication Division, UIB / Print: Skipnes Kommunikasjon AS

uib.no

ISBN: 9788230865620 (print)
9788230848739 (PDF)