



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. Gjengedal²  and P. Dreyer^{2,4} 

¹Department of Plastic, Hand and Reconstructive Surgery, National Burn Centre, Haukeland University Hospital, Bergen, Norway.

²Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway.

³Department of Health and Caring Sciences, Western Norway University of Applied Sciences, Bergen, Norway.

⁴Department 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

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
<p>“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”.</p> <p>“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”.</p> <p>“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”.</p> <p>“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”.</p> <p>“I think that body posture and the way you are and the way you meet them. Showing respect is important as well”.</p> <p>“They are in a crisis situation when they arrive”.</p> <p>“And they need information in a crisis situation like that. What is going to happen now?”</p> <p>“We try to take care of them as soon as they come in the door”.</p> <p>“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”.</p> <p>“That someone can look after the parents, while others take care of the child”.</p> <p>“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”.</p> <p>“You can do this and this”.</p> <p>““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”.</p> <p>“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”. ...</p>	<p>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.</p> <p>...</p>	<p>Creating a safe, secure and trusting environment from the moment parents enter the burn centre</p>

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

- Wichman 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]
- 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]
- 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]
- 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>]
- 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]
- 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]
- 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]
- 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.
- Brekke RJ, Heisterkamp H, Guttormsen AB, Onarheim H. Høy forekomst av brannskade hos småbarn i innvandrerfamilier. Vitenskapelige forhandlinger, 90 Hostmøtet i Norsk Kirurgisk Forening; Holmenkollen Park Hotell, Oslo, Norway 2014.
- Forskrift om barns opphold i helseinstitusjon av 1. desember 2000 nr 1217, 2000.
- 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]
- 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]
- 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]
- 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]
- 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]
- 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]
- 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]
- 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>]
- 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]
- 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]
- 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]
- 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]
- 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/psj016>] [PMID: 15788717]
- 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/psp090>] [PMID: 19846581]
- Fukunishi I. Posttraumatic stress symptoms and depression in mothers of children with severe burn injuries. *Psychol Rep* 1998; 83(1): 331-5.

- [26] [http://dx.doi.org/10.2466/pr0.1998.83.1.331] [PMID: 9775690] 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: <https://www.ssb.no/befolkning/fakta/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 universitetssjukehus. *Brannskadar: Helse Bergen 2019*. Available from: <https://helse-bergen.no/behandlinger/brannskadar>
- [45] QSR International Pty Ltd. *invenorNVivo 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]