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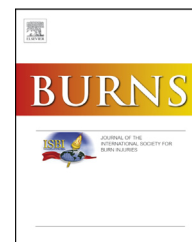

Parental presence or absence during paediatric burn wound care procedures

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ABSTRACT

Aim: Differing views on benefits and disadvantages of parental presence during their child's wound care after burn injury leave the topic surrounded by controversies. This study aimed to describe and explain parents' experiences of their presence or absence during wound care.
Methods: Shortly after the burn event, 22 semi-structured interviews were conducted with parents of children (0–16 years old) that underwent hospitalization in one of the three Dutch burn centers. Eighteen of these parents also participated in follow-up interviews three to six months after discharge. Interviews were analyzed using grounded theory methodology.
Results: Analyses resulted in themes that were integrated into a model, summarizing key aspects of parental presence during wound care. These aspects include parental cognitions and emotions (e.g., shared distress during wound care), parental abilities and needs (e.g., controlling own emotions, being responsive, and gaining overall control) and the role of burn care professionals.
Conclusion: Findings emphasize the distressing nature of wound care procedures. Despite the distress, parents expressed their preference to be present. The abilities to control their own emotions and to be responsive to the child's needs were considered beneficial for both the child and the parent. Importantly, being present increased a sense of control in parents that helped them to cope with the situation. For parents not present, the professional was the intermediary to provide information about the healing process that helped parents to deal with the situation. In sum, the proposed model provides avenues for professionals to assess parents' abilities and needs on a daily basis and to adequately support the child and parent during wound care.

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1. Introduction

Offering parents the possibility to be with their child and to participate in care is recognized as an important aspect of pediatric hospital care [1]. Parents express the wish for participation in their child's care and expect to be involved [2]. However, ways in which parents want to be involved are likely to differ depending on the nature of the pediatric illness or injury, the type of care concerned, and individual child and parent characteristics. Attending the wound care of their child with burns may be an additional stressor for parents on top of the burden of the burn incident and its consequences. However, parents may have good reasons to want to be present and support their child. In-depth research on parent experiences of their participation in wound care procedures after pediatric burn injury may elucidate under which circumstances parent participation leads to optimal outcomes for child and parent.

Potential benefits that have been described for parental presence during injections and other medical procedures include lower distress and higher satisfaction in parents, and prevention of child separation anxiety [3]. For burn wound care, presumed benefits include the opportunity for parents to comfort their child and model adaptive coping strategies. Nurses can also teach parents how to conduct wound care themselves, thereby stimulating adequate recovery after discharge [4,5].

Besides the assumed advantages of participation of parents in burn wound care procedures, it can also be distressing. Within the integrative model of pediatric medical traumatic stress, invasive procedures such as wound care have been described as events that may elicit traumatic stress reactions in both the child and its parents [6,7]. Empirically, parents have described observing pain and distress reactions in their children as the most difficult part of burn injury [8] and wound care in particular [9]. Stoddard et al. [10] found an association between the child's pain during hospitalization and parents' acute stress symptoms. In a study of De Young et al. [11], 18% of the parents qualified wound care as the most traumatic part of burn injury, while for 15% of the parents, this was the actual burn injury and the wound care. Similarly, in a qualitative study, wound care procedures were described as a source of trauma for parents [12]. Therefore, participation might be inappropriately stressful to parents and potentially associated with parental traumatic stress reactions.

When weighing the appropriateness of parental presence during wound care, besides invasiveness of the procedure and anticipated pain and emotions of the child, parental capabilities to participate are considered to be important [4,5,13]. These capabilities may relate to the parent's emotional state. For example, child preoperative anxiety has been shown lower in the presence of a calm parent, but not in the presence of an overly anxious parent [14]. It is well documented that in the acute aftermath of pediatric burn injury, parents have to deal with their own stress reactions and emotions related to the burn event, such as guilt [11,15]. This potentially impacts their decision and perceived ability to participate in wound care. Little research has, however, specifically addressed the role of parental capabilities and emotions in participation during wound care.

Given the differing views on the benefits and drawbacks of parent participation in their child's wound care, it is not surprising that different policies on parental presence exist in clinical practice. When considering parents' presence, parental views on their preferences and role during wound care are essential. Recently, Morley et al. [16] have described mothers' experiences regarding their young child's wound care. The study showed that mothers experienced a sense of duty to be present during wound care, related to their feelings of responsibility associated with being a parent. Findings also highlighted the need for appropriate support of mothers during dressing changes. These insights into the phenomenon of parental presence during wound care call for more studies in the wider parent population.

The present study aimed to increase our understanding of parents' experiences of their presence or absence during wound care, with the inclusion of a larger sample, and a wider child age range, with data of fathers and of parents that were present and those that were absent during wound care. Ultimately, the goal was to develop an integrative model describing the aspects that are important for professionals in burn care when considering parental presence or absence during wound care.

2. Methods

2.1. Participants and procedure

The present study that is focused on the perspective of parents is part of a larger qualitative study on parental presence during wound care. Another study will offer an in-depth evaluation of nurses' and child life specialists' perspectives on parental presence and will address nursing interventions [17]. To obtain the sample described in the current manuscript, parents were recruited from the three burn centers in the Netherlands between December 2014 and June 2016. In two of these burn centers, parents are offered the possibility to be present during their child's wound care procedures, while in one center parents are not present. In all centers, child life specialists are often present during wound care. While nurses primarily focus on the wound care, the child life specialist is only concerned with the child's and parent's wellbeing. In the burn center that does not offer parents the possibility to be present, the child life specialist partially takes over the parental role, in terms of distracting, comforting, and guiding the child through the procedure.

Parents of children under the age of 19 years were eligible to participate if their child underwent hospitalization for a burn injury and had at least undergone one wound care procedure. Parents were approached by a local researcher while they were still in the hospital. The researcher explained the purpose of the study and provided additional written information. Written informed consent was provided by all parents. To achieve variation in demographic- and child characteristics (i.e., child age, gender, burn severity, burn type), purposeful sampling was used. Child- and burn characteristics were obtained from the medical file and parents completed a

questionnaire for socio-demographic information. After 3–6 months, the interviewer contacted parents that participated in the first interview, to ask whether they still would like to participate in a follow-up interview.

In total, parents of 22 children participated in the study. Data saturation (i.e., the point were no new themes emerged) was reached after 18 interviews. To confirm this, four subsequent interviews were conducted. In 8 families, both parents were involved in the interview, while 14 interviews were conducted with the mother only. Follow-up interviews were conducted with 18 of the 22 families (11 mothers, 1 father, 6 couples). Table 1 shows child- and burn characteristics of the sample. The mean age of participating parents was 32.9 (ranging from 23 to 54) years for mothers and 38.5 (ranging from 30 to 46) years for fathers. Educational level of the parents was classified as low (19% of the parents), middle (39% of the parents) or high (42% of the parents). The majority of the parents were in a relationship (86%) and most of the parents were currently employed (81%). Eighty-four percent of the parents were born in the Netherlands.

The study was conducted according to the principles of the Declaration of Helsinki (revision, Fortaleza, Brasil, 2013). The Institutional Review Board of the Faculty of Social and Behavioural Sciences of Utrecht University approved the study (FETC15-085).

2.2. *Data collection*

In the first wave of data collection, semi-structured, face-to-face interviews were conducted in the burn center during hospitalization, with the exception of four interviews that were conducted shortly after discharge at the participants' home or in the burn center in case of check-up contacts. In the second wave of data collection, follow-up interviews were conducted at the families' home or in the burn center. Interviews were carried out by a trained emale researcher/psychologist (first author), except for one interview that was conducted by a trained psychologist from one of the burn centers. Interviews were digitally recorded. Mean duration of the interview was 62 min (range: 31–106 min) in the first wave, and 57 min (range: 41–78 min) in the second wave.

Topics within the interview guide of the first wave concerned the experience of being present or absent during child wound care procedures, for example in terms of having a choice to be present, reasons to be present or absent (i.e., 'Why did you decide to be present/absent?' and 'Which benefits does being present have?'), preparation, and the child's reaction. Also, the parents' role (i.e., 'Can you describe your role during wound care?'), thoughts and feelings during the procedures (i.e., 'Can you describe the thoughts that you had during wound care?') were addressed. The interview guide of the second wave was partially focused on the way parents looked back on the wound care procedures. Questions were open-ended and follow-up questions were asked to obtain a more in-depth understanding of the area of interest. In both data collection waves, first, two pilot interviews were carried out, to ensure the interview guides were workable and elicited appropriate information in terms of the study's goal. In line with the constant comparison method, based on the analyses of information obtained within the first interview phases, new topics and questions were added to the interview guide. During all interviews, the interviewer recorded field notes on relevant non-verbal cues as well as environmental factors that were important in interpreting the interview information.

Table 1 – Child- and burn characteristics (N = 22).

	M	SD	Median	Range
Child age (years)	6.5	5.8	3.2	0–16
TBSA (%)	9.0	7.1	7.7	3–34
Length of stay in hospital (in days)	15.6	10.7	11	4–40
			N	%
Child gender (boys)			11	50
≥1 surgery during initial hospitalization			11	50
Burn type				
Scald			16	73
Flame/fire			5	23
Electrical			1	4

Note. TBSA = estimated percentage total body surface area affected by partial- or full-thickness burns.

2.3. *Data analysis*

Recorded interviews were transcribed verbatim and names were replaced by pseudonyms. Interview transcripts were imported in the software program MAXQDA 12 (2016). A grounded theory methodology including thematic analysis was used [18]. Grounded theory is an inductive and systematic methodology that is used to construct theory grounded in qualitative data. As part of this methodology the constant comparison method [19] was used, whereby information from new interviews was compared with existing codes to identify similarities and differences. Following Strauss and Corbin [20] interview fragments were coded using respectively open, axial and selective coding. In the open coding process, the interviews were read line-by-line and fragments were extracted and assigned a code that summarized the meaning of the fragment. Axial coding was used to group and merge codes, and to reveal connections between the categories. In the selective coding process, the core categories and the final integrative model were established. The first five interviews were coded independently by the first and last author (researchers in psychology), after which differences were discussed until consensus was reached. Subsequent interviews were coded by the first author and discussed in detail with the last author. The second and third author (researchers in nursing) reviewed all transcripts. The analyses were continuously discussed within the research team. Throughout the process, memos were written and diagrams were drawn, which helped in constructing the final integrative model.

3. Results

Seven themes were identified from the interviews, that were grouped under two overarching categories (see Table 2). Each of the themes is discussed in detail below. In addition, the way parents looked back on the wound care procedures three to six months after discharge is addressed and finally, an integrative model summarizing central aspects of parental presence is presented.

3.1. *Cognitive-emotional impact of burn event and wound care*

3.1.1. *Burn event-related distress*

All parents described having experienced emotional reactions such as shock, fear, guilt, sadness and helplessness when witnessing or being informed about their child's burn injury. These emotions could extend into the period of hospitalization, although experienced to a lesser extent. Also, vivid memories of the burn event were reported, sometimes occurring in the form of intrusions or flashbacks.

3.1.2. *Shared distress*

Wound care procedures were distressing for children as well as parents. Children displayed pain and anxiety during wound care. Parents mainly described sadness, anxiety, feelings of guilt and powerlessness. In parents, emotions were elicited by witnessing their child's reaction to the procedure. This made parents to sympathize deeply with their child's suffering: *'It's difficult to describe, but it hurts you too. As a parent, as a father, it hurts me too of course'* [Father of 10-year-old boy (18)]. Feelings of powerlessness were experienced as a consequence of the inability to take away the pain from their child. Parents explicitly mentioned that if they had the opportunity to take over their child's pain, they would do so. During the interviews in the first wave, several parents started to cry when discussing this topic. Observing the child's pain also evoked thoughts about the parent's responsibility for the child's accident, accompanied by feelings of guilt.

Parental fear and anxiety were primarily evoked by observing the wounds and thinking about the consequences of the injury. Parents described it was intense, dramatic and disruptive to see the wounds. Initially, the wounds looked ugly and severe and stressed the gravity of the situation. During wound care, alongside the distress related to the wound care itself, many parents experienced feelings of uncertainty and worries about the future and the treatment: *'Will this get better, without an operation? Because you don't want your child to have an operation, that she has a skin transplant, and so on.'* [Mother of 4-year-old girl (16)]. Over time, distress reactions during wound care were reported to decrease for the child and parent; this process occurred faster in some parents than others. Habituation to the situation, the progress in wound healing, predictability of the procedures and decrease of pain were seen as contributing to this decrease.

Parents of children in the burn center that did not admit parents during wound care commonly experienced distress, prior, as well as during wound care procedures. Parents stated that the moment the nurses entered the room wearing a mask, a cap and protective clothing, the (young) child's fear and anguish became apparent. This also marked the upcoming moment the parent had to leave the room, further increasing distress in the child. Signs of separation anxiety were observed by parents, as they described that the child became sad, got upset, started crying, and stretched out their arms when they left the room. For some parents, the period of wound care was tense as they had difficulty taking their mind off from what was happening with their child. One parent initially reported worst-case scenarios to come up in her mind particularly during the wound care procedures: *'It was a nightmare. Especially the first time I was afraid the whole wound care she would be screaming hysterically and be in a lot of pain'* [Mother of 1-year-old girl (14)]. On the other hand, other parents were able to use this period to relax to some extent, to do some phone calls, or to have a little walk. Similar to the centers in which parents were present during wound care, parents reported their distress to decrease over time.

3.1.3. *The child's best interest*

When parents were offered the possibility to be present during wound care, a decisive factor was whether presence or absence was considered to be in the child's best interest. Most often, being present during wound care was described as 'natural' or 'obvious', or as a responsibility associated with the parental role. Most parents emphasized the necessity to 'put your child before yourself'. This involved not thinking about possible negative consequences for the parent, but only about perceived benefits for the child: *'Well yes, of course it's not nice to watch your child while she undergoes something uncomfortable, but at the same time that doesn't weigh up against leaving her alone there. That wouldn't be an option for me'* [Mother of 1-year-old girl (23)].

Some parents more deliberately weighed advantages and disadvantages in deciding on their presence or absence. As a result, a minority of parents concluded their (initial) absence during wound care to be in the child's best interest. This was driven by the parent's own emotional state or the anticipated reaction of the child: *'Of course I did it for him as well as for myself, because I didn't know if I could take it. And for the nurse too, I thought if I stay now, my son's going to put up a fight. And well, it'll be really difficult to care for the wound'* [Mother of 4-year-old boy (6)]. Yet, deciding not to be present could lead to an internal conflict. Guilt and feelings of letting down their child were present when the parent felt the child's need for their presence or the

Table 2 – The two overarching categories and the seven identified themes.

Cognitive-emotional impact of burn event and wound care
1. Burn event-related distress
2. Shared distress
3. The child's best interest
Parental abilities and needs
4. Controlling own emotions
5. Being responsive
6. Gaining overall control
• Information provision and understanding the situation
• Perception of meaningful contribution
7. Child- and parent-focused care

duty to be present, but at the same time felt unable to offer this. Regardless of the parents' decision, all parents appreciated the possibility to be present during wound care.

Parents that were not admitted to the wound care expressed their understanding for the hospital policy. They were told that being present during their child's wound care procedures would be very distressing and it would be potentially traumatic to see the wounds and see their child suffer. Moreover, by being absent, the child would not associate the parent with the pain experienced during wound care, resulting in the parent continuing to be 'a safe haven'. Although it often felt unnatural for parents to leave their child prior to the wound care, given the natural tendency to provide emotional support to their child, parents trusted the health care providers in knowing the policy was in the child's and family's best interest.

3.2. *Parental abilities and needs*

3.2.1. *Controlling own emotions*

Control of parents' own emotions was considered essential for presence during wound care. Parents emphasized the need to set aside their emotions, hide their emotions from their child or not get carried away by their child's emotions. Parents described 'staying strong' for their child and 'flipping the switch'. This was deemed necessary to meet the needs of the child during the procedures: *' . . . the first few days you switch off your emotions for his sake. And you block them out like, now my own feelings I'm going to put to one side because I've got to be there for him.'* [Mother of 3-year-old boy (13)]. Moreover, parents' own expression of distress was thought to affect their child's distress reactions and vice versa. Expression of parents' own emotions was deemed unhelpful, because the child would use their parent as a point of reference, thereby increasing child distress. Staying calm would therefore contribute to the child's emotion regulation too. Another unhelpful element of expressing their own emotions during wound care was that health care professionals would have to pay attention to the parent instead of the child, thereby delaying the procedure.

Several strategies of emotion control were mentioned by parents. A strong focus on the child, instead of the wounds and the procedures was argued to be helpful, as well as a practical mode in which parents focused on specific acts, instead of their thoughts: *'Just the focus only on her so that she can be in the silence with you. So just let everything happen around her and don't focus on all those people and things around her'* [Mother of 1-year-old girl (5)]. Also, a focus on positive outcomes and the positive contribution of wound care to their child's health helped parents to control their own emotions. Other parents described acceptance of their emotions, focusing on the 'here and now', or avoiding to look at the wounds. However, despite holding in their emotions during wound care, parents emphasized the need to express their emotions at another time and place: *'I know already in the evening that the wound care is planned for tomorrow. Even though I don't sleep well and can really feel that I'm tired, that I've almost run out of steam, that I've just got to do it for Laura. What I say, I think that when I'm home again I'm going to have a cry. Also because I've got to lie down on the bed for a bit to recover'* [Mother of 2-year-old girl (4)].

Sometimes, parents could not control their own emotions. Especially in the first days of hospitalization, some parents initially chose not to be present during wound care, because they felt overwhelmed by their emotions or had flashbacks of the burn event. Therefore, parents felt it was in their child's best interest if they were absent during wound care. When the other parent was able to take up the role in wound care, parents felt more confident about this decision. A minority of parents that chose to be present, experienced a physical (e.g., fainting) or emotional 'breakdown' during wound care: *'But if she starts crying while they're caring for her wound, then I'm going to as well. That's it really, you try the whole time to be strong and when she starts to cry, I cry with her. Then I can't say: now come on Karen, try to think about the beaches. Then I've forgotten all about them too, those beaches. Then I think: now, we won't be on those beaches for a while.'* [Mother of 16-year-old girl (7)].

The theme emotion control also became apparent in parents not present, as they expressed their understanding for the hospital policy because they assumed some parents would not be capable to be present during wound care. However, this was immediately followed by the statement this did not apply to their own situation: *' . . . there are enough people that are just scared of hospitals, who are scared of the whole medical world. Yes I can imagine if your child ends up there, that it's twice as bad. [. . .] It doesn't have that effect on me, but I've seen around me that it happens. [. . .] But I'm not an unstable parent.'* [Mother of 14-year-old boy (25)].

3.2.2. *Being responsive*

Identifying the child's needs and being responsive (i.e., adequately address the child's needs) were central to the parental role during wound care. Parents identified the child's need of safety, predictability, comfort, and distraction from pain, and tried to address these needs.

The familiarity of the parent to the child in a new and possibly frightening environment was thought to contribute to the child's feelings of safety, which was especially emphasized for young children. By being present, parents would convey the message that the child was in a safe place and that the child could rely on its parents. Parents also tried to increase predictability by guiding their child through the procedure, for example by explaining what nurses were doing. Comfort was provided by soothing or rocking the child, or holding the child's hand. Parents offered distraction by watching a video or play with their child. Parents could also serve as their child's 'spokesperson' in relation to the health care professionals, as they 'knew their child best' in terms of their character and preferences, hereby adjusting the procedure to the child's needs. This father explained intervening on the nurses' strategies during the first procedure, based on the knowledge of his son's preferences: *'That you can also let them know what he likes. Imagine they'd thrown the cup of water over him every day, then we'd probably have said: he really doesn't like that, can't we just do that differently, because you know how your child reacts.'* [Father 2-year-old boy (11)].

Parents who were absent during wound care could not address the child's needs at the moment of the procedure, but they emphasized being responsive afterwards. Parents described comforting and supporting the child and adjusting

their behavior to the child's needs shortly after being reunited with the child.

3.2.3. Gaining overall control

In the course of hospitalization, being present during wound care resulted in an increased sense of control in parents. In contrast, some of the parents that had no opportunity to be present, described a need for control that could not be met by being absent. In case of parental presence, control was gained from the information provided during wound care, a better understanding of the situation and from the idea that the parent meaningfully contributed to the procedure.

3.2.3.1. Information provision and understanding the situation. Parents expressed the benefits of observing their child's wound healing and the need for an understanding of the situation. Parents got more habituated to the burn wounds over time and seeing the wound closure helped parents to be positive towards the future and increased their sense of control. Parental presence also provided the opportunity to track the progress by taking pictures, that could be used to discuss the progress with the other parent or could be integrated in a photo-book on the child's hospitalization. Parents felt that by seeing the process themselves, reassurance was higher than when health care providers had only told them about the healing progress. Interpreting the wound healing was done with the help of nurses and doctors. It was a source of frustration when health care professionals provided only minimal information on the wound healing. Overall, the healing process provided hope and a sense of control, as parents saw their child improve day-by-day.

By being present parents also thought they could help in interpreting their child's behavior (e.g., whether crying was a display of discomfort or pain) as well as the situation as a whole. The wish to 'know what the nurses were doing to the child' was expressed by parents. Observing the nurses' behavior and the child's reaction led to a feeling of reassurance. Parents' expected imagining worst-case scenarios when they wouldn't have had the opportunity to accompany their child during wound care. Moreover, parents expressed the wish to 'see what their child had seen', to be better able to later talk about this with their (older) child. Being present was therefore thought to be contributing to the processing of the event for the child as well as the parent.

Some parents not allowed to be present expressed they were glad not being confronted with the burn wounds, which helped them to stay positive during the distressing hospitalization period. Other parents expressed the need to understand and know what was happening during wound care procedures and were interested in the wound healing process. By not being admitted to wound care, the wounds of their child stayed 'a secret' until a short period prior to discharge. One of the mothers described the discomfort of not having seen the burns of her son: *'Then I think: it's awful really that I wasn't able to see what the scar's like, where it starts, where it ends. And he did. He saw his legs in the morning. So he's got to tell me, if he feels like it, what his legs are like. And not once has he done that or wanted to'* [Mother of 13-year-old boy (26)]. Information provided by the nurses and child life specialist after wound care was, however, valued by all parents.

3.2.3.2. Perception of meaningful contribution. During hospitalization, most control was out of the parent's hands. Being present during wound care was regarded as one of the few things parents could do for their child: *'You can't take the pain away, you can't take away what happened. The only thing you can do is be with your child'* [Mother of a 2-year-old boy (11)]. Some parents contributed to wound care by washing or bathing their child, which led to a sense of empowerment: *'While they were caring for the wound, I could just hold the shower head over his hair and then what I could do as a parent, was just wash him. That's a nice thing to do and that stays with you. Then it gives you the feeling that you're looking after him instead of just standing there looking on'* [Mother of an 8-year-old boy (10)]. This suggests that a continuation of the parental role was valued by parents.

Most parents considered their role during wound care valuable and meaningful. Validation of the belief that their presence was valuable was found in their child's reactions: searching for physical contact with the parent, decreased distress over time, or the child's explicit wish for their parent's presence. However, a minority of parents questioned the added value of their presence. This was related to the (anticipated) behavior of their child with the parent present. One mother expected her child to show more resistance when she would be present, while another mother thought a complicating factor was her adolescent child being conscious of the mother's emotions. She reported her child trying to hide her suffering to some extent to prevent upsetting the parent.

3.2.4. Child- and parent-focused care

In all three burn centers, parents had a great trust in health care providers. A comparison was often made to the care provided at the Emergency Department of a local hospital, in which parents were not convinced by the capabilities of the staff and doubted whether the child received the best care. Upon arrival in the burn centers, parents felt relief when feeling 'their child was in good hands'. Parents felt that care in general as well as during wound care was adjusted to the child and parent.

During wound care, parents appreciated the staff's involvement with and focus on the child. Initiating contact with the child in a friendly, playful, and age-appropriate manner was regarded helpful for their child to be at ease. Also, staff paying attention to the child's reaction to specific procedures was appreciated. Explanation and predictability of the procedures, and adjusting the pace to the child's need was considered beneficial. Parents thought the distinction between the nurses and child life specialist (not involved in actual wound care) was relevant, as the child life specialist could be regarded a 'safe person'. The child life specialist also paid attention to the parent's emotions and needs. Parents identified the need for control in (older) children. Adolescents sometimes helped to remove the bandages or clean the wounds, and needed information about the length of the procedure. Providing children a choice also helped (e.g., with which body part to start the procedure). Additionally, rewarding the (younger) child after the procedure was considered beneficial.

Parents who were not present because of hospital policy also showed a very strong trust in the professional skills of

nurses and the child life specialist. Over time, they observed their child to become more at ease with the staff. Hearing back how their child had been doing during wound care increased parents' trust and appeared to result in less stress feelings during subsequent wound care procedures.

3.3. *Looking back at wound care after discharge*

Three to six months after discharge, overall, parents thought that either their presence or absence had been in their own and their child's best interest. Parents that had been present described being glad having had the opportunity to support their child and provide safety. Also, they mentioned perceived benefits for themselves, such as increased control and a better understanding of what their child had been through that opened avenues to talk about the event: '*Now, she still mentions it sometimes, that cleaning and peeling the skin off. And then she asks me: "do you remember there used to be a big hole there?". And then I say: "yes, I remember, you can still see the difference there", we know that. We were there. And otherwise you don't have that. So I do think that's an advantage.*' [Mother of 16-year-old girl (7)]. On the other hand, parents described vivid memories in terms of their child's pain, suffering and the view of the burn wounds, although these could not be classified as intrusive for most parents. Only two parents reported intrusive thoughts concerning the wound care procedures. Still, in their view, the perceived benefits for their child outweighed the disadvantages for the parent.

For parents that had not been allowed present during wound care, the strong trust in the health care professionals again emerged as the most important theme. Although the majority of the parents ultimately thought their absence had more advantages than their presence, about half of the parents mentioned they would have preferred to decide themselves. One mother also expressed the burden of not having seen her adolescent son's wounds in the first weeks of hospitalization. Because her son did not share his experiences on his wounds and the wound care, both his parents felt unable to relate to his experience and to adequately support their son on this issue after discharge. Memories of the wound care primarily concerned the child's distress when the nurses and child specialist entered the room and parents had to leave the child prior to the procedure. For three out of four parents, seeing the wounds for the first time shortly before discharge was 'shocking', while one parent described a more neutral feeling.

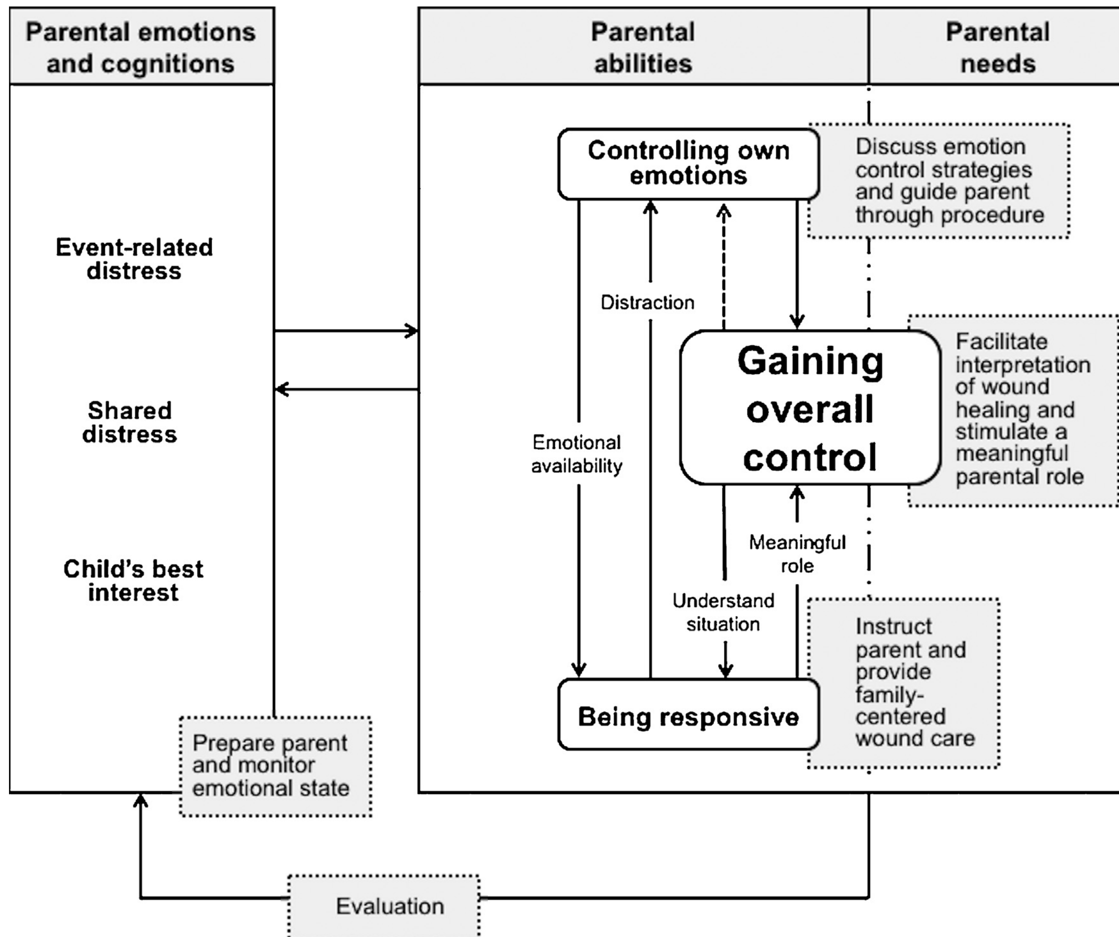

Fig. 1 – Integrative model of parental presence during their child's wound care procedures. Dotted-lined squares depict the role of burn care professionals.

3.4. *Integrative model of parental presence during wound care*

Based on the themes derived from the interviews, an integrative model was developed that represents important aspects when considering parental presence during wound care (Fig. 1). The parents' own emotions and ability to control these, and their ability to be responsive to the child's needs are considered essential and interrelated facets. By controlling their own distress reactions, parents may increase their emotional availability, and thereby their responsiveness to their child. Responsiveness may also increase emotion control, by a focus on the child, instead of parents' own feelings. Both emotion control and responsiveness are assumed to be related to gaining a sense of control, which is a central element in this model. Parental feelings of control concern an ability (e.g., acquiring a meaningful role during wound care), as well as a need (e.g., wanting to be informed). The process depicted in the model has a dynamic nature. This entails that aspects central to wound care may change on a daily basis. For example, the belief that parental presence is in the best interest of the child may change depending on the parental experiences of wound care the previous day. The model also gives direction for burn care professionals in supporting families in the context of wound care procedures.

4. Discussion

The purpose of this study was to describe and explain parents' experiences of presence or absence during their child's wound care procedures and to identify aspects that could be monitored by professionals. Based on qualitative interviews, an integrative model was developed, representing the aspects relevant to parental presence during wound care. This model gives directions for ways in which burn care professionals can enhance beneficial outcomes of parental presence (the blocks with a dashed border in Fig. 1 summarize the professional's role).

Many parents reported that they wished to attend their child's wound care, but that its distressing nature and their emotions related to the burn event influenced their decision. The emotional state of the parent prior to the first wound care appears to be a critical factor, as a small number of parents described overwhelming emotions that made them to decide not to be present initially. Also, observing the child's distress during the procedures and feeling hopeless in not being able to take away the pain from the child was reported to influence a parent's decision to be present at subsequent wound care procedures. Many parents felt that the benefit of their presence for their child outweighed the disadvantage of their own distress, except when parents' own emotions were that overwhelming that presence was not in the child's best interest. Preparation of the parent and monitoring and evaluation of the parent's state are considered important to support the parent.

In order to be present and to meet the needs of the child, parents in the current study considered control of their emotions desirable. Parental control of emotions will likely influence parental responsiveness during wound care [21]. Vice versa, being responsive and focus on the child may serve as distraction resulting in reduction of emotions. Findings are in agreement with previous studies that described parents wanting to 'stay strong' and 'put on a brave face' during hospitalization [12], and wound care in particular [16]. According to social referencing theory [22], by not expressing negative emotions such as fear or sadness as a parent during wound care, the child may interpret the situation more positively. This is especially salient to young children, who are more dependent on their parents when interpreting new and possibly frightening situations. However, control of emotions can be difficult in case of such a strong situation as seeing one's child suffer. Therefore, although parents indicated that the temporal suppression of their own emotions helped in supporting their child, they reported the need to express their emotions *after* wound care at a more appropriate time. Literature suggests that temporary suppression combined with later expression (i.e., emotion modulation) is associated with better psychological outcomes compared to emotional suppression without later expression [23].

Being present during wound care contributed to a sense of control in parents in two ways; by being informed and understanding the situation, and by experiencing a meaningfully contributing parental role. The parents' wish to be informed about their child's hospital care was also reported in previous studies [2,24]. In case of parental absence during wound care, it was not possible to observe the child's behavior and the wound healing, or to take up a meaningful role, thereby reducing opportunities to gain control. In these cases, adequate information provision and trust in burn care professionals were important factors, that also appeared to contribute to feelings of reassurance. Nevertheless, some parents expressed their regret of not having seen the wounds and not knowing what their child had gone through, leaving them with feelings of having missed a principal part of the process, and preventing them to discuss this with their (older) child.

An essential aspect of the ability to be responsive, that in turn added to parents' overall sense of control, was whether parents perceived their behavior and role during wound care as meaningful and valuable. Parents' perception of a meaningfully contributing role entail self-efficacy beliefs, i.e., "parents' beliefs in their ability to influence their child and the environment in ways that would foster the child's development and success" [25, p. 342]. Research in another pediatric population confirmed higher parents' self-efficacy beliefs in their ability to keep their child calm during invasive procedures to be related to parents' experiencing lower negative affective reactions at the time of the procedure [26]. This may be particularly salient in the burns population as a prior study reported that parents may feel deskilled [27]. In the current study, when parents did not perceive their role as valuable, i.e., when they felt like a passive bystander (in adolescent patients), this was reported to have a detrimental effect on their wellbeing. Stimulating self-efficacy beliefs may improve outcomes of parental presence.

The results quite unequivocally indicated that although wound care procedures were a stressful experience for

parents, parents wished to be present. The stressful nature has also been reported in previous studies [9,12,16], with one of these studies reporting the occurrence of parental intrusions related to wound care [12]. Parents in the current study reported emotional memories concerning wound care after discharge, but these memories were not judged as intrusive or troublesome by most parents. The non-intrusive nature of the wound care memories in the current study is perhaps due to the child-focused and calm atmosphere during wound care, the role of the nurses and particularly the role of child life specialist, who exclusively focused on the child's and parent's wellbeing during wound care procedures. An aspect that might explain why parents prefer to be present relates to their perception of increased predictability and control, seeing the wound healing progress and the continuation of their parental role. These aspects may predominate their own distress and might lead to more positive appraisals of the situation. Although from the present study no conclusions can be drawn in terms of the potential risk of parental presence during wound care of eliciting traumatic stress reactions, minimization of potentially traumatic aspects of wound care (e.g., loss of control) is warranted.

Of notice, the age of the child may be a factor of significance when considering parental presence during wound care procedures. Based on the young child's reactions and parental feelings associated with leaving the room prior to wound care, it seems that the balance tips in favor of parental presence. With school-aged children and adolescents, presence of the parent needs to be discussed not only with the parents but also with the child.

4.1. *Clinical implications*

The results of the current study indicate several recommendations for clinical practice. Strategies to support the child and parents may be carried out by any team member involved in wound care, depending on the burn team's composition. Burn care professionals could offer procedural preparation to decrease anticipatory anxiety and feelings of uncertainty. They can do this by addressing the procedures' process and by discussing the role of the parent during wound care. The parent's emotional state may also be assessed prior to wound care and it may be discussed which parent will be present. Ideally, procedural preparation and assessment should be provided before the first wound care procedure (shortly after admission), as research has shown parent's psychological state to be related to the parent's behavior during the first procedure [21].

Professionals could try to help in reducing the intensity of parental emotions by creating calmness and trust in a positive atmosphere and by providing detailed information and guiding the parents through the procedure. Prior to wound care, the role of parental emotions may specifically be discussed by addressing the influence of parental emotions on the child's distress, as well as possible emotion control strategies to be used during wound care (e.g., focus on positive outcomes, focus on the 'here and now'). Moreover, the professionals can use instruction or modeling to show parents how to guide the child through the procedure, and emphasize that when emotions appear, they will help the parent and child to overcome this situation. After wound care, parents should be offered the opportunity to express their emotions and concerns. Moreover, the procedure in terms of the parental role and influence on the child should be evaluated.

Reports of parents that were present during wound care indicate that burn care professionals may inform parents and enhance parental feelings of control by helping parents interpreting the wounds. When parents cannot observe the situation and the child's behavior directly because they are not present during wound care, burn care professionals have an essential role in informing parents about these issues after wound care. Furthermore, burn care professionals may enhance parents' self-efficacy beliefs and skills by modeling responsive behavior, reinforcing parents' helpful behaviors, emphasizing the value of their presence, explicitly addressing the influence of parental behaviors on their child, and by offering parents concrete tasks, such as bathing the child.

4.2. *Strengths and limitations*

With the inclusion of burn centers with different policies on parental presence, the current study benefits from the perspectives of parents who were present and parents who were absent during wound care. Another strength of the study is the large and diverse sample, including fathers and parents of school-aged children and adolescents. Still, the relatively high proportion of native Dutch parents and parents with a high education in the current sample may not be representative of the entire population of families that are admitted to the Dutch burn centers. It is unknown whether findings are generalizable to parents who experience substantial language difficulties (such as recently immigrated families). Also, findings must be read keeping in mind the wound care contexts of the particular burn centers under study, which are often characterized by the presence of two nurses and one child life specialist. The composition of the team carrying out the wound care procedures, is a relevant topic for further study. In addition, the current findings elicit relevant questions that should be addressed in future quantitative studies, such as whether burn severity is related to parents' experiences and after how many procedures parents feel more comfortable with the process. Last, this study was carried out in children that did not receive Intensive Care (IC) or after IC. Therefore, findings may not be generalized to wound care procedures carried out during the IC-phase.

5. Conclusion

Overall, findings suggest that parents should be offered the choice for presence or absence during wound care. Despite the undeniable distress evoked by being present during wound care procedures, the benefits of being present often exceed the disadvantages in terms of the ultimate gain of control. This study suggests that parental capabilities such as emotion control during the procedure in order to be there for the child and consequently, to act as a responsive parent, foster beneficial outcomes of their presence. Central aspects to

consider for professionals therefore include preparing the parent, assessing the parent's emotional state, instructing and guiding the parent through the procedure, explaining the wound healing progress, stimulating a meaningful parental role and evaluating the procedure. Parents failing to cope with the situation could be offered room to withdraw, be it temporarily or definite. In these cases, good communication and adequate information on the wounds' progress and child behavior during procedures offered by professionals are imperative.

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Conflicts of interest

The authors declare there are no conflicts of interest.

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