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At home parent-administered dressing changes in paediatric burns aftercare: Interviews on parents' experiences of treatment

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Abstract

Objective: Paediatric burn injuries present physical and psychosocial effects for children and their parents, including disruption to family life. Some burns services in the UK enable parents to administer dressing changes at home to reduce the number of hospital visits. To date, there is no research on parents' experiences of administering dressing changes. The aim of this study was to describe parents' experiences of administering dressing changes in paediatric burns aftercare.

Methods: Semi-structured research interviews were conducted with a purposive sample of parents recruited from a paediatric burns centre in the UK. The interview addressed the initial offer of at-home dressing changes by clinicians; parental decision-making in relation to dressing changes; training and support received; and the experience of administering dressing changes, including practical and emotional considerations. Thematic analysis of the data was informed by the framework approach, including associative analysis using demographic and clinical characteristics.

Results: Seventeen participants were interviewed. Three themes of parents' experiences of administering dressing changes were identified including (1) *Parental Identity* concerning the newly undertaken responsibility and the impact on the parental role; (2) *Challenges*, physical or emotional, confronted or lessened by administering dressing changes; and (3) *Reassurance* provided by healthcare professionals and others to support parents to adopt and maintain parent-administered dressing changes.

Conclusion: The qualitative data reported here indicates that parents want to be involved in their child's care by administering dressing changes at home, provided they receive sufficient reassurance that they are able to manage the severity of their child's burn. Parents' concerns about the effectiveness of their dressing changes lacks empirical basis, and this study provides preliminary data to support the development and evaluation of best practice guidance for parent-administered dressing changes in paediatric burns aftercare.

Keywords: Aftercare, Dressing changes, Interviews, Paediatric burns

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1. Introduction

1.1. Background

Paediatric burns, involving thermal damage to the skin or other tissue, is one of the most common types of injury worldwide [1]. In the UK, incidence of medically attended paediatric burns includes over 6,639 hospital admissions annually [2], with the average cost to burns services per patient estimated at £63,157 for major burns [3]. Children with severe burns may present with multisystem injuries across major organ systems in addition to a localised wound. Children and their parents experience persistent anxiety, posttraumatic stress, depression, difficulties in social functioning [4], and reduced quality of life [5]. Mothers appear to be at greater risk of experiencing these psychological sequelae than their child [6], and parental post-traumatic response and family functioning is a major predictor of parent and child's quality of life [7-8], with implications for adherence to treatment potentially compounding poor patient outcomes [6]. Parents' perceptions of quality of care in paediatric burns, particularly participation in treatment, are associated with symptoms of posttraumatic stress disorder and depression, suggesting that paediatric burn care may benefit from increased parental involvement and by healthcare professionals being more attentive towards parents who themselves appear stressed or worried [9].

Acute burns management may include intensive treatment for multi-organ dysfunction, and surgery to prevent sepsis, secondary complications and achieve early wound closure. Following initial discharge from hospital, standard care involves regular attendance in outpatient clinics for wound management, including cleansing, debridement, application of topical antimicrobial agents, and dressing changes [10]. Children commonly identify dressing changes as the most distressing experience of their burn injury, with anxiety provoked by travelling to hospital representing a major component [11]. Interviews with mothers present during nurse-administered dressing changes in a paediatric burns service, found that mothers' want to be involved in their child's dressing changes and to fulfil their parental responsibilities to comfort and support their child [12]. At the same time, families experience financial burden related to the burn injury, largely due to travelling to the hospital, with lower income households disproportionately affected [13].

In most paediatric burns services in the UK, parents may opt to administer simple dressing changes at home [14]. Interviews with parents about administering other distressing non-burn procedures at home highlight unmet opportunities to support parents including receiving advice on minimising their child's distress, a break from the nursing role, emotional support for the parent including peer support, and mitigating anxieties about performing the technical aspects of the procedure [15]. However, there is a lack of research examining the experiences of parents administering dressing changes (PAD) for their child's burns at home, leaving a gap in understanding of how best to support parents throughout the PAD process.

1.2. Aim

The aim of this study was to describe parents' experiences of administering dressing changes at home in paediatric burns aftercare.

2. Methods

2.1. Ethical approval

Ethical approval for the PAD study was granted by East Midlands – Nottingham 1 Research Ethics Committee (reference: 19/EM/0216).

2.2. Study design

Qualitative semi-structured interviews were conducted to explore parents' experiences of administering dressing changes. The study design was reviewed and refined by our public involvement partners (comprising parents of children with burn injuries), and is reported here with regard to the Journal Article Reporting Standards for qualitative primary research [16].

2.3. Sampling and recruitment

Purposive sampling was conducted to achieve diversity according to demographic and clinical characteristics. DT (lead author) monitored recruitment across a range of demographic and clinical characteristics to ensure diversity of the sample. A background questionnaire was administered to collect data on demographic and clinical characteristics in order to monitor sample diversity. The study protocol indicated recruitment should continue until thematic saturation was reached. Parents were eligible to participate if they had a child under 16 years of age receiving care in the recruiting site; they had been offered the option to administer dressing changes at-home; they were 18 years of age or older; and able to communicate in English.

Parents were recruited from the Birmingham Children's Hospital Burns Service and were approached regarding the study by a member of their child's clinical care team. The clinical care team used patient notes and face-to-face discussion to confirm eligibility to participate. Parents expressing interest in participating were provided with a participant information sheet and asked to complete a contact details form. DT then contacted interested parents to discuss the research and answer any questions before agreeing a convenient time and place (the University, recruiting site, or parent's home) to conduct an interview. Written or verbal informed consent was received from participants prior to interview.

2.4. Data collection

An interview topic guide was developed by the research team, and reviewed and refined in collaboration with our public involvement partners with regard to the study aim, burns literature and clinical practice. The topic guide consisted of open-ended questions and prompts addressing how clinicians broached or offered parent-administered dressing changes; parents' reasons for accepting or declining at-home dressing changes; training and support received by parents to administer dressing changes; and experiences of administering dressing changes. The topic guide was reviewed after each interview and refined accordingly.

Interviews were undertaken by the lead author (DT) from 17 October 2019 to 30 January 2020. DT is a chartered psychologist with experience of conducting qualitative research and delivering psychological therapies independently of the recruiting paediatric burns centre. DT engaged in critical reflection following each interview, supervised by an experienced qualitative researcher (JM) who provided feedback on interview conduct. Interviews were audio-recorded and transcribed clean verbatim and anonymised by a professional transcriber for data analysis.

2.5. Data analysis

Thematic analysis of the data (audio-recordings, transcripts and notes taken at the time of the interview) was informed by the framework analytic approach [17]. This involved an initial process of familiarisation with the data by listening back to interview audio recordings, and reading transcripts and field notes. Each transcript was read line by line and codes developed and applied inductively. Codes were grouped into categories. DT and JM met to discuss the categories and codes applied across 3 initial interview transcripts to form a working coding framework. This was applied and

refined iteratively across the data. Charting of codes and illustrative quotes facilitated associative analysis within the sample and the development of thematic descriptions. This was shared with paediatric burns nurses (CT & LH) and public involvement partners who reviewed and helped to refine the analysis. Initial thematic interpretations were discussed amongst the team and with other qualitative researchers and refined with the aid of descriptive accounts of the data. Coding and data management was undertaken using QSR International's NVivo version 12 software [18].

3. Results

3.1. Sample characteristics

Fifty-one parents completed a study contact form. Of these, 17 participants were interviewed. Thematic saturation was reached after 17 interviews based on Guest, Namey & Chen's simple method (base size=5, run length=3, new information threshold= $\leq 5\%$) [19]. The majority of parents were employed, white British women between 22 and 51 years of age (Mean=35.7; SD=8.535). Of their children, most experienced a scald before the age of 4 years, covering between an estimated 1-37% total body surface area (Mean=10.45; SD=11.370). Parent demographics, and child demographics and clinical characteristics are presented in Table 1 and Table 2 respectively.

INSERT TABLE 1 AROUND HERE

INSERT TABLE 2 AROUND HERE

3.2. Themes

Three themes of parents' experiences of administering dressing changes were identified including (1) *Parental Identity and role* influencing reactions to and experience of PAD; (2) *Challenges*, physical or emotional, confronted or lessened by administering dressing changes; and (3) *Reassurance* provided by health care professionals and others to support parents to adopt and maintain parent-administered dressing changes. Each theme cuts across the timeline of the PAD process, from the point at-home dressing changes is broached to discharge. These themes predominantly focus on parent-administered dressing changes, though parents' accounts of administering dressing changes are enmeshed within the broader experience of caring for a child with a burn injury.

3.2.1. Parental Identity and Role

Participants' accounts of PAD demonstrated that the experience of undertaking this therapeutic role is framed by their identity as parents and the associated parental role. Parental identity in this context relates to a parent's commitment to care for their child. It describes a sense of self (self-image) as a parent that impacts on cognitive, behavioural and emotional experiences of PAD. Thus, *Parental Identity* functions here as an overarching theme that helps us to understand how parents experience *Challenges* and *Reassurance* relating to administering dressing changes. Over the course of the PAD process, parental identity manifests itself in *assuming the PAD role*, and *stoicism throughout the PAD process*.

3.2.1.1. Assuming the PAD role

When the prospect of administering dressing changes at home was first broached by nurses, parents consistently cited their parental identity as justification to assume the new responsibility of administering dressing changes:

164 *When we were sent home the very first time after being in there for such a long time it was just a*
165 *thing that I just never I suppose questioned... somebody questioned me whether I could do it, it*
166 *was just automatically [assumed] that I would be looking after my child at home... it was almost*
167 *a mother's duty, I just wanted to care for him and do it... going home, it never was an issue*
168 *because he was my son. (Parent 3)*

169 Often, as a result, parents did not describe the PAD offer as an option that could be refused, but
170 something that was tacitly accepted:

171 *So when we were initially given the option to go down that route to be fair it didn't sound like an*
172 *option, it was just the way that it was done. (Parent 2)*

173 However, parents admitted they would less readily accept the responsibility of administering
174 dressing changes, or consider declining the option outright, if they perceived the severity of their
175 child's burn injury to exceed their capabilities to undertake care without doing harm to their child.
176 Parent 11 illustrated this potential conundrum for parents considering PAD:

177 *I suppose if it had been the wound had been a lot worse and I felt that it was out of my*
178 *capabilities and I would be worried about it getting infected, had it been a much larger wound,*
179 *and perhaps from the feedback I had been getting I felt that it was more serious, that probably*
180 *has made me need to have a more serious think about being able to do it myself. (Parent 11)*

181 Another parent declined to administer dressing changes in the first instance due to the severity of
182 the burn injury, and later reconsidered:

183 *We weren't really confident in doing it ourselves, it was quite a bit of a scare when you looked at*
184 *it initially, because it was quite a deep burn to the first layer. We were offered that after we got*
185 *confident, after it was maybe five or six visits to the children's hospital... they did offer it to us*
186 *[earlier] but we declined. So it was about after five or six visits when the nurses were changing*
187 *his bandages then we decided to do it ourselves. (Parent 17)*

188 Parents thought that their child would prefer it if they administered the dressing changes. This was
189 apparent to parents of infants and older children and again tied to parental identity:

190 *He preferred me doing it than any other person that he doesn't know, like the nurses. (Parent 10)*

191 *I know him better than the nurses, and I know he was embarrassed having to undress below the*
192 *waist to go in and have the wound inspected. So for his mother to do it rather than a stranger*
193 *was also better for him. (Parent 11)*

194 Parents also recognised that the comfort they could provide within their own home could benefit
195 their child's experience of dressing changes, whilst conferring a sense of control for parents:

196 *He was calmer and happier at home to have them done as well, so I could see it was less*
197 *distressing for him to be at home, I could put the telly on to distract him, and it was me doing it*
198 *all as opposed to sat in a strange room with some strange people quickly trying to do it because*
199 *he's getting upset, whereas we could just take our time and do it at home, and I could just let*
200 *him lie down and chill out and stuff. So I could see it was better for him for me to do it at home.*
201 *(Parent 13)*

202 *When you're it at home you're comfortable, you're in control which is difficult sometimes when*
203 *somebody else is doing it. (Parent 17)*

For a minority of parents, the process of administering the dressing changes enabled parent and child to bond, reinforcing parental identity and maintenance of the PAD role:

It made her feel better... I suppose when somebody is massaging you gently and putting nice cream on it's quite a relaxing process although why we're doing it isn't very nice, but I think at the time she quite enjoyed having it done and it gave us time and we just chatted, not necessarily about the burn but about anything... I would say [that we bonded over the dressing changes], definitely. (Parent 6)

My son quite liked lying next to me and having his neck rubbed [as part of the dressing change routine], so I can't think of any negatives of doing it, because any time you spend with your children is good. (Parent 14)

3.2.1.2. Stoicism throughout the PAD process

Though parents consistently assumed the PAD responsibility for their child's benefit, they often did so while foregoing personal psychological support at considerable cost to their own wellbeing. Undeterred by these costs, parents demonstrated stoicism throughout the PAD process by appealing to their sense of parental identity. Stoicism can be defined as a lack of emotional expression or exercising emotional control. Parents consistently described efforts to conceal their emotional distress (due to the burn injury) from their children, and this emotional distress was heightened when having to confront the wound during dressing changes:

I think the same with my husband, as much as you might be feeling inside – upset and distressed by it – we wouldn't want to portray that because we think it would have made her feel worse. She was under enough stress and anxiety as it was. (Parent 6)

By focusing on their child's care, parents were able to exercise control over their emotions:

I think it was just getting the baby done, that's what just kept me going. (Parent 12)

However, parents focus on their child's care often occurred at their expense, wishing for healthcare professionals to focus on their child while marginalising their own wellbeing:

I only got diagnosed [with PTSD] after it was over, after the burn had healed, so [the nurses] wouldn't have known while it was happening... I just think that a children's hospital is for children, I know I am his mum but they should be more concerned about him and not the parent, so I preferred to go to the GP and not feel like I was taking a children's hospital's time... I think they should focus solely on the child. (Parent 9)

Whilst stoicism was dominant in parents' accounts of administering dressing changes, parents were divided between those who were potentially open to receiving emotional support from staff, and those who stated they were not. For example, one parent suggested they would have felt capable of talking about their emotions with nurses due to their professional experience in paediatric burns:

I think so [I would have been comfortable talking to the nurses about my feelings of guilt], because they are experienced, they are dealing with burns every single day, and really severe ones and everything, and I think I would have happily spoken to one of the nurses, yeah. (Parent 8)

Whereas another parent described feeling unable to talk about their emotions with staff despite being distressed during hospital visits early in the outpatient process:

I would have been too embarrassed to even talk about it... the thing is that even if I'd have just spoke to somebody about it, somebody who would have just listened really would have helped. But like I said it was just I didn't even want to speak to anybody. I will be honest one of the very first appointments I actually did leave the room and my partner sat in there and I sat in the car because I couldn't even bear to be in the room. (Parent 4)

For those parents reluctant to receive support from nurses, though open to psychological support, there remained a difficulty in accessing help to cope with the emotional challenges of the burn injury:

I did have one conversation with the psychologist a little bit further down the line, I can't remember exactly when it was in the timescale of things, but it might have been a couple of months after the burn happened, and I spoke to her about how I was feeling, and she help me look for a service closer to home to speak to somebody. I did enquire about one place but I couldn't get in. (Parent 13)

3.2.2. Challenges

Assuming the new responsibility of administering dressing changes forces parents to confront, or lessens challenges. Challenges confronted or lessened throughout the PAD process can be divided into (1) technical difficulties of administering dressing changes; (2) psychological distress experienced by parents; and (3) practical issues relating to PAD including travel burden, financial cost, and balancing competing responsibilities including employment and education.

3.2.2.1. Technical difficulties

Upon leaving the burns service, parents understood the procedure for administering dressing changes in theory. Though in practice, technical difficulties emerged for parents of children who struggled with tolerating discomfort associated with dressing changes for wounds in 'awkward' areas:

How am I going to restrain her to be able to do it on my own, because her burns were in an awkward place, the one that wasn't healing was under the right armpit, and a two year old toddler will not sit still so it was a bit of wiggle. (Parent 13)

Parents developed an emerging sense of mastery with practice, becoming better at assessing the quality of a dressing and their child's comfort with it:

You just learn, it's all trial and error, you think this is a better dressing, a bit fiddlier or whatever, but your child tells you how it feels as well, if it's comfortable, if it's not comfortable, he doesn't like that dressing, he does like that dressing, so you both work with each other when you get home. (Parent 3)

At the same time, parents ascribed a technical easing in administering dressing changes as their child's wound recovered. As the wound healed, there was greater margin for error when removing dressings:

It just became easier because of the skin healing. I think at the start the skin is very tender so you had to be really careful with it, and I think the only thing that they used to tell [us] is that you don't want to pull too hard [on dressings] and you don't want to break the skin because it's very fresh skin. (Parent 2)

3.2.2.2. Psychological distress

Parents reported a range of psychological experiences related to their child's burn injury including anxiety, guilt, rumination, and post-traumatic stress. Moreover, parents' distress could be heightened when having to confront their child's wound when administering dressing changes once home:

Once I had done the dressings which was literally five minutes, then it was hidden away. So you don't ever forget it but it's hidden. I suppose when you take the dressing off and you can see it, it's a hundred times worse for me, because then you know it's there and you can see it. (Parent 5)

Wound confrontation resulted in rumination on feelings of guilt, though PAD also offered an opportunity to overcome these feelings:

I think that's probably why at times, especially at the early time I felt like it was our fault... But I think actually by doing the dressings I felt like I was helping, doing something proactive to try and make the situation better. (Parent 8)

Anxiety predominated parents' accounts, expressed as a fear of causing physical pain, emotional distress, or harm including infection, damage to the skin and scarring when administering dressing changes:

The whole idea of us doing it at home was not... it was a bit intimidating and scary because you didn't want to do anything wrong, because there was talk of infection, there was talks of different things going on, so you almost felt a bit scared of taking an already vulnerable child home, and then having to do almost a clinical procedure in a sense at home, so it felt a bit intimidating at first... The first time was really nerve racking, it was really scary because like I was saying you don't want to hurt the child (Parent 2)

At first when I was first in that early stages and being sent home it was all very daunting, it's like bringing a new baby home, do I know how to care for this, will I be able to do this, am I doing it right? (Parent 3)

Parents anxiety extended beyond dressing changes, with worries of infection and scarring. This was related to the burn injury rather than the PAD process per se. However, parents were divided between those who viewed worry in a positive light and PAD as a means to enhance vigilance to infection (e.g. Parent 2 below), and those who recognised that it could contribute to exacerbating their own anxiety (e.g. Parent 12 below):

What I found helpful was just knowing about... what you want to do right, what you want to do wrong, so to know about infection, knowing about signs to worry about like if a rash appeared, or things that are not looking the right way. So all the information on what to look out for, what's really important. (Parent 2)

I don't know what the best word is, very overprotective with the children now. I think it's just anything that I think could... even anything at all I am very don't touch that, don't go there, it's

made me very nervous. But I think it's just going to take some time really, it's just a lot, and because it's only just ended about three/four weeks ago, so now it's just I am slowing winding down from going up there doing the bandage changes and that. So yeah I am getting better. I did have to go on some anxiety medication, just around the time just after it happened, because it was very stressful. (Parent 12)

Indeed, Parent 2 went on to describe how seeing the wound more often through the process of administering dressing changes gave them reassurance that healing was taking place and this helped parents to cope and move towards an acceptance of the injury:

The time that it went really well is one of the dressing changes I think we... at the start we were doing every other day changing, but as we progressed they just told us to do... maybe do the dressing change whenever the dressing gets weepy or gets dirty, so we were doing dressing changes less frequently, and I think the time that it really started being a bit positive is when you could feel the skin pigmentation coming back, so you almost know actually we've gone past the third stage which is lower layer of the skin healing, so we're now dealing with the pigmentation, I think that's when you feel really excited about actually he is going towards the right direction of healing. (Parent 2)

3.2.2.3. Travel and financial costs

A significant benefit of the opportunity to administer dressing changes at home was the reduction in frequency of travel to the burns service and the associated costs that were often a challenge to parents. This enabled parents to focus on competing commitments including employment and their child's education. For some it was a key reason for wanting to administer dressing changes at home:

The financial cost of hospital and petrol and the parking and just things like that, it all just added up to being additional stress at an already stressful time. (Parent 13)

The reason why we started doing that was after a couple of visits to the children's hospital it was just too much. I do shifts, I work six days a week, my wife works as well, and it was literally getting the time, and we lead a very busy life, we don't have any time to ourselves, we are just literally always at work, responsibilities and so it was just literally a case of [we've] got no time to go so let's get taught and do it ourselves. (Parent 17)

Reflecting the psychological distress described previously for those parents and children suffering from anxiety, the reduced travel burden of PAD resulted in fewer opportunities for trauma to resurface when travelling to the burns service:

I started to find it quite traumatic going back to the hospital so much as well because it just brought everything back to what happened every time. I would relive the day of the accident, relive the first few days when we were in the hospital, the first time he had a general anaesthetic and that sort of thing, I was reliving it all, every little minor detail, just on the drive there, because with over an hour to drive you do have thinking time (Parent 13)

3.2.3. Reassurance

Parental identity and the process of taking on the responsibility of administering dressing changes was underpinned by reassurance from a range of sources to empower parents to proceed and

maintain their PAD role. Reassurance here refers to a set of practices performed by healthcare professionals and others intended to alleviate parents' psychological distress or doubts impeding progress with PAD. Reassurance can be divided into several practices including (1) practical demonstration of administering dressing changes before initiating PAD; (2) accessibility of nurses throughout the PAD process; and (3) social support from family and peers.

3.2.3.1. HCP demonstration and subsequent access to nurses

The primacy of reassurance in preparing parents to begin and continue to administer dressing changes emerged in parents accounts:

I think putting psychologically [a lack of reassurance] will affect [parents], and this will cascade to touch other parts of their lives, because at that point like the way I was telling you with the anxiety we had for the surgery and after the surgery, so you don't know how the progress is going to be, how the healing is going to be, is it getting better, is it getting worse. At some point I was unsure. I have two pictures, and looking at the two pictures they were exactly the same or one was either bad, so I was like what is it, is it getting better, is it getting worse? (Parent 1)

Chiefly, parents relied on demonstrations of dressing changes to build confidence that they would be capable of taking on the PAD responsibility:

I suppose it was just like a practical demonstration really, so rather than them just going ahead and doing it, when we talked about us doing it at home... the nursing team didn't just go ahead and do it, they then showed us practically how to do it, and I think that was really good because if they would have just said you use this one and then you use this and then use this one I don't think I would felt confident, I needed to see it, I needed to watch them do it and for them to draw my attention to watching for us to be able to do it at home. (Parent 8)

For some parents, a demonstration sufficed to enable PAD. Others suggested that supplementary written information would also have been useful as an aide-memoire later on. One parent described taking their own notes during a nurse-administered dressing change and posited that these and could have been improved on with a 'PAD prescription', written information about PAD:

I was making my own notes so I had got something I could refer to at home to make sure that I was doing it right... I suppose it would be helpful if the nurses could have done that for me. I suppose you expect that you get a prescription and telling you how many tablets you need to take, I guess it would be useful that something perhaps could have been printed out or written for me with that information on. So, I didn't really think too much about the fact that I had to do it myself, I needed something so that I'd got a visual reminder once I got back home. (Parent 11)

However, despite demonstration of how to administer dressing changes and equipped with the knowledge of what to do, parents typically lacked confidence on the first occasion of changing their child's dressing at home. One parent indicated that the presence of a nurse who could observe good practice, would provide further confidence to proceed:

It could be that, maybe that again you don't want to do it, and they will be like 'okay we want to watch you, put on these gloves and give it a go while we watch you to see', that is after talking you through it, then maybe [it] gives confidence [on] the first time. (Parent 6)

Knowing that they could contact the nurses by phone or arrange a visit to the hospital reassured parents that they could seek professional advice, though this opportunity was rarely used:

405 *They gave me the number back to the burns unit and I never had to use it... I am sure*
406 *subconsciously knowing that there was somebody at the end of a line and like I say the... with my*
407 *hometown being so far from the hospital it probably was reassuring. (Parent 15)*

408 **3.2.3.2. Social support**

409 Social support here refers to any support available to parents through connections to individuals or
410 groups of others in their communities including, though not limited to other parents of children with
411 burns injuries, referred to here as *peers*. The availability of parents' familial network for practical
412 support with PAD and competing responsibilities, and someone to talk to, offered some
413 reassurance:

414 *A lot of [friends and family] came round and just would perhaps take our daughter out or they*
415 *would bring her gifts and things like that. But for us it was just knowing that there were people*
416 *there if we needed anybody. We did need people to support us with our other child, picking her*
417 *up from school and things like that, so you've got a network of people who can support with the*
418 *day to day when we're at the hospital or that side of things. (Parent 6)*

419 Of those unwilling to speak to nurses about how they are coping, parents indicated a preference for
420 family or peers as a source of authentic reassurance than healthcare professionals:

421 *I think the thing that made it a little bit different to maybe talking to a nurse or a doctor, I felt*
422 *almost like there's an agenda when it comes to a nurse or a doctor, asking you a question [to]*
423 *get something from you, they want to know either symptoms or they want to know... they want*
424 *to solve an issue if that makes sense? So, it felt more procedural or more calculated when you*
425 *had them. (Parent 2)*

426 Parents desired empathy and a sense of normalisation to help them to cope with their child's burn
427 injury. Some parents were unaware of the availability of support groups, and encountered only
428 glimpses of informal and spontaneous peer support to help see parents through the PAD process
429 and come to terms with their experiences after it was complete. Parent 17 described one instance of
430 informal parent-to-parent peer support involving reassurance and empathy, where the act of taking
431 time to talk with parents in similar circumstances acted as an emotional release to help overcome
432 distress caused by their child's burn injury:

433 *When I went to the second time when I went to get my child's bandage changed there was a lady*
434 *there she was a holding her son who was bandaged 75% of the body. The child actually spilt hot*
435 *water all over him, she was in so much distress, you know what I did, I was looking at her, I made*
436 *eye contact with this lady, she gave the child to her mother who was there, she came straight up*
437 *to me, my wife was with me, she gave me a big hug, she said, "I just need someone to hug." My*
438 *wife, it was not like I was another lady or anything, she just gave me a hug really tight, and all I*
439 *said to her, "Look everything is going to be fine, I know it's difficult especially looking at your*
440 *child," because I started crying myself to be quite fair, and she was just very emotionally*
441 *distressed that 'I have done that to my child'... I sat down with her for ten minutes and she*
442 *stopped crying, we were just giving her support, 'everything is going to be fine, I know it's*
443 *difficult now, my son he went through this, this is what happened and look at where we are now*
444 *with him, given time', time is a good healer, and just speaking to someone how has been through*
445 *it I think it helped that lady. (Parent 17)*

446 447 **4. Discussion**

This study describes parents' experiences of administering dressing changes at home in paediatric burns aftercare. It is the first paper to examine the practice of PAD from a parental perspective. Recent UK survey data demonstrate that a majority of paediatric burns services offer and support parent-administered dressing changes at home [14]. Exploring parental experience of this practice is one means to facilitate optimal parent and child-centred service provision.

There is already evidence that parents want to be involved in nurse-administered dressing changes in paediatric burns services [12]. This study goes one step further, finding that parents want to administer dressing changes at home if they receive sufficient reassurance that they are able to manage the severity of their child's burn and holistically see to their child's wellbeing. Study participants reinforced existing evidence that repeated travel to hospital for dressing changes provokes anxiety and incurs significant financial cost [11, 13]. Their accounts indicate that PAD can help to alleviate these burdens.

Parents' experience of PAD is closely linked to their parental identity and role. This is apparent in the decision to undertake PAD, which most study participants did not describe as a decision. UK survey data on PAD practice support this interpretation, with the majority of clinician respondents stating that 10% or fewer parents refuse to undertake dressings at home [14]. Parental identity also informs parents' approach to PAD, such as the stoicism that many display in the face of considerable personal emotional impact, and receiving reassurance that they are not doing their child harm. Some interviewees suggested that the process strengthened their bond with their children, reinforcing parental identity. The desire to fulfil responsibilities associated with being a mother was also highlighted in Morley and colleagues' qualitative research examining mothers' experiences of dressing changes at the burns unit [12].

The findings also clearly resonate with previous research focused on parents' experiences of administering potentially distressing non-burn healthcare procedures for their child at home [15]. Spiers and Beresford found that technical considerations were important in administering procedures [15]. However, they also described the significant emotional labour inherent for parents, which participants in this study talked about at length. PAD parents felt they could be a source of comfort for their children compared to nurse-administered procedures, and most did not perceive a choice in taking on the therapeutic role. As described in this study, parents often struggled to reduce their child's emotional distress. This has also been noted in qualitative research examining adherence to pressure garment therapy in at home paediatric burn scar management [20].

The emotional components of PAD and possible avenues for support are key findings of this study. Parents experience psychological distress when their child suffers a burn injury, including anxiety, posttraumatic stress, depression and reduced quality of life [4-5]. Emotional and psychological impact are a key component of the experience of PAD for most parents. For some parents, this may be tied to broader post-traumatic stress associated with the burn incident that may only become apparent later in the process of their child's recovery. PAD interacts with these psychological experiences in complex ways. For some parents, PAD appears to function as an adaptive coping mechanism by enabling parents to confront their child's burn wound, contribute to their recovery and overcome feelings of guilt that are brought to the fore by their involvement in the process. On the other hand, some parents were able to confront their child's burn injury, but not their emotions as they unsuccessfully sought to conceal or control their internal experiences while prioritising their child. Whilst we have not observed outpatient appointments and therefore cannot say definitively, the interviews suggest that psychological issues related to PAD were rarely addressed with nursing staff during outpatient appointments.

There are several learning points concerning how parents' psychological state could inform PAD practice. Firstly, consider the parents' choice to undertake PAD. Whilst tacitly agreeing to administer dressing changes, parents in this study had some reservations due to the severity of the burn wound or the stage of healing at which it was safe to take on PAD. Therefore, clinicians may consider emphasising parental choice, including the timing of PAD being determined by parents when they feel reasonably comfortable, reassured and informed about the role. Clear information regarding the potential or lack of potential to do harm is also important. Parents were concerned about causing physical pain and distress, infection, damage to healing skin, and long-term scar outcomes being determined by their technical proficiency. Additionally, there were some emotional challenges identified which might be anticipated and therefore addressed with parents early on, and which could also be part of monitoring of PAD progress (where this is not already the case). These include strategies for reducing emotional distress for the child such as how to approach dressings in awkward places, and how to approach keeping their child still or best address resistance. Prior research emphasises the importance of these emotional components for parent and child [15, 20]. Further research should determine how these technical issues might best be anticipated with written information and other support mechanisms, and monitored as parents progress through PAD. At present in the UK, written information is rarely provided to parents for PAD [14]. Parents in this study valued the accessibility of staff for ad hoc support, even if many never accessed this. Many parents also felt they would have benefited from being observed undertaking a dressing change as opposed to simply observing a staff demonstration. Whilst some parents reported clear social and peer support opportunities, other parents may not access them. Spiers and Beresford also suggested that active recognition of the role that parents are playing in their children's care was in itself a clear emotional support mechanism that nurses and other HCPs could easily adopt [15].

Some of the parents interviewed in this study acknowledged that psychological support may have helped them to cope with the experience of their child's burns injury, though either felt unable to seek support or were unable to access it locally. Left untreated, mental health problems can increase functional burden and impair people's capacity to cope with daily life [21]. People who causally attribute mental health difficulties to stressors are less likely to access help-seeking interventions than those who believe their distress has a biomedical basis [22]. The salience of a burn injury to one's child may therefore preclude some parents from seeking support given study participants tendency to describe their distress in terms of perceived guilt. One relevant approach to closing this treatment gap is mental health literacy intervention, comprising recognition of mental health problems and knowledge of prevention and treatment including stepped protocol from self-help and peer support for mild difficulties and direction to professional support for more severe problems [23]. However, further research is indicated to establish the feasibility and acceptability (to parents and nurses) of mental health literacy interventions in paediatric burns services.

4.1. Limitations

Purposive sampling enabled recruitment of a diverse range of parents with direct experience of PAD and data saturation appears to have been reached using conservative parameters for thematic saturation calculation [19]. The interviews produced in-depth insights into parents' experiences. These data are based on recruitment from one UK paediatric burns centre only, which may limit transferability. PAD practices vary across services, with at least one service in the UK offering a nurse outreach service at or closer to parents home [14]. We have not observed the practice that parents were talking about, or their interactions with staff during the process of PAD. Further research that addresses this may help refine support mechanisms and provide further guidance for staff and services.

5. Conclusions

What emerged most prominently from this study is the primacy of parental identity and a sense of responsibility throughout the process of administering dressing changes. Parents' efforts to conceal their psychological distress and forgo support that would otherwise help them to cope with the challenges involved in PAD introduces complications for nurses deciding how, when and for whom to offer reassurance or more involved support. Furthermore, the concerns parents reported here about the effectiveness of their dressing changes compared to nurse-administered dressing changes in hospital lacks empirical basis. This study provides a platform from which to develop and evaluate best practice guidance for parent-administered dressing changes in paediatric burns aftercare.

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Authors' contributions

JM, CT, YV & NM jointly conceived the research and all authors contributed to development of the study protocol. LH contributed to recruitment and interview design. DT conducted research interviews and lead on analysis, and all authors contributed to final analysis. DT drafted the initial manuscript. JM provided oversight of the research design, conduct and analysis, and helped with final manuscript revisions. All authors revised the manuscript for important intellectual content and gave approval of the final version.

Conflict of Interest

All named authors declare that there are no known conflicts of interest relating to this manuscript.

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Table 1 – Parent demographics

Variable	N
<i>Parental gender</i>	
Male	4
Female	13
<i>Parental age</i>	
18-24	2
25-29	3
30-34	2
35-39	3
40-44	4
45-49	2
50-54	1
<i>Parental ethnicity</i>	
White	11
Mixed	0
Asian	3
Black	3
Other	0
<i>Marital status</i>	
Single	5
Married/Civil Partnership	8
Cohabiting	1
Separated	1
Divorced	2
Widowed	0
<i>Qualification</i>	
O Levels/CSEs/GCSEs/Foundation Diploma	3
Apprenticeship	0
AS or A Levels/Advanced GNVQ	2
Degree (e.g. BA/BSc)	3
Higher Degree (e.g. MSc/PhD)	1
Professional Qualification	3
Other	4
No formal qualifications	1
<i>Employment status</i>	
Employed	15
Self-employed	0
Housewife/husband	1
Unemployed	1
Retired	0
Actively seeking employment	0

Table 2 – Child demographics and clinical characteristics

Variable	N
<i>Child gender</i>	
Male	12
Female	5
<i>Child age (years)</i>	
0-4	12
5-10	0
11-14	1
15-20	4
<i>Child ethnicity</i>	
White	11
Mixed	1
Asian	3
Black	2
Other	0
<i>Number of siblings</i>	
0	4
1	8
2	4
3	0
4	0
5	1
<i>Time since burn injury</i>	
0-3 months	5
4-6 months	5
7-9 months	0
10-12 months	1
Over 1 year	6
<i>Burn injury type</i>	
Scald	13
Radiation	0
Flame	1
Friction	0
Chemical	1
Contact	2
Electrical	0
Other	0
<i>Burn total body surface area percentage</i>	
1-9%	7
10-18%	1
19-27%	2
28-36%	0
37-45%	1

Don't know	6
<i>Burn area</i>	
Head and neck	1
Trunck	3
Arm	5
Genatalia	0
Leg	4
Multiple (head and neck, trunk and arm)	4
<i>Skin graft</i>	
Yes	6
No	11

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