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

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11
12 **Abstract**

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

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

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

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

36 *Keywords:* Aftercare, Dressing changes, Interviews, Paediatric burns

37
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38 **1. Introduction**

39 **1.1. Background**

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

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

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

73 **1.2. Aim**

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

76

77 **2. Methods**

78 **2.1. Ethical approval**

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

81 **2.2. Study design**

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

86 **2.3. Sampling and recruitment**

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

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

103 **2.4. Data collection**

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

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

117 **2.5. Data analysis**

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

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

130

131 **3. Results**

132 **3.1. Sample characteristics**

133 Fifty-one parents completed a study contact form. Of these, 17 participants were interviewed.
134 Thematic saturation was reached after 17 interviews based on Guest, Namey & Chen's simple
135 method (base size=5, run length=3, new information threshold= $\leq 5\%$) [19]. The majority of parents
136 were employed, white British women between 22 and 51 years of age (Mean=35.7; SD=8.535). Of
137 their children, most experienced a scald before the age of 4 years, covering between an estimated 1-
138 37% total body surface area (Mean=10.45; SD=11.370). Parent demographics, and child
139 demographics and clinical characteristics are presented in Table 1 and Table 2 respectively.

140 ***INSERT TABLE 1 AROUND HERE***

141 ***INSERT TABLE 2 AROUND HERE***

142 **3.2. Themes**

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

151 **3.2.1. Parental Identity and Role**

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

160 **3.2.1.1. Assuming the PAD role**

161 When the prospect of administering dressing changes at home was first broached by nurses, parents
162 consistently cited their parental identity as justification to assume the new responsibility of
163 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)*

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

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

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

214

215 **3.2.1.2. Stoicism throughout the PAD process**

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

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

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

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

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

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

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

239 *I think so [I would have been comfortable talking to the nurses about my feelings of guilt],*
240 *because they are experienced, they are dealing with burns every single day, and really severe*
241 *ones and everything, and I think I would have happily spoken to one of the nurses, yeah. (Parent*
242 *8)*

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

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

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

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

258

259 **3.2.2. Challenges**

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

265 **3.2.2.1. Technical difficulties**

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

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

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

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

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

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

286

287 **3.2.2.2. Psychological distress**

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

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

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

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

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

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

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

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

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

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

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

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

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

339

340 **3.2.2.3. Travel and financial costs**

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

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

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

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

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

360

361 **3.2.3. Reassurance**

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

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

369 **3.2.3.1. HCP demonstration and subsequent access to nurses**

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

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

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

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

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

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

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

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

403 Knowing that they could contact the nurses by phone or arrange a visit to the hospital reassured
404 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**

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

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

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

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

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

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

516 Some of the parents interviewed in this study acknowledged that psychological support may have
517 helped them to cope with the experience of their child's burns injury, though either felt unable to
518 seek support or were unable to access it locally. Left untreated, mental health problems can increase
519 functional burden and impair peoples' capacity to cope with daily life [21]. People who causally
520 attribute mental health difficulties to stressors are less likely to access help-seeking interventions
521 than those who believe their distress has a biomedical basis [22]. The salience of a burn injury to
522 one's child may therefore preclude some parents from seeking support given study participants
523 tendency to describe their distress in terms of perceived guilt. One relevant approach to closing this
524 treatment gap is mental health literacy intervention, comprising recognition of mental health
525 problems and knowledge of prevention and treatment including stepped protocol from self-help and
526 peer support for mild difficulties and direction to professional support for more severe problems
527 [23]. However, further research is indicated to establish the feasibility and acceptability (to parents
528 and nurses) of mental health literacy interventions in paediatric burns services.

529 **4.1. Limitations**

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

539 **5. Conclusions**

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

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551 **Authors' contributions**

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

558 **Conflict of Interest**

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

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627

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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631

632