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# At home parent-administered dressing changes in paediatric burns aftercare: A survey of burns centres' practice

Dean M Thompson<sup>a,\*</sup>, Clare Thomas<sup>b</sup>, Lisa Hyde<sup>b</sup>, Yvonne Wilson<sup>b,c</sup>, Naiem Moiemem<sup>b,c,d</sup>, Jonathan Mathers<sup>a</sup>

<sup>a</sup> Institute of Applied Health Research, University of Birmingham, Edgbaston, Birmingham, UK

<sup>b</sup> Birmingham Children's Hospital, Birmingham Women's and Children's NHS Foundation Trust, Birmingham, UK

<sup>c</sup> University Hospitals Birmingham NHS Foundation Trust, Birmingham, UK

<sup>d</sup> The Scar Free Foundation Centre for Conflict Wound Research, Queen Elizabeth Hospital, University Hospitals Birmingham Foundation Trust, Birmingham, UK

## Abstract

*Objective:* Following paediatric burn injury, dressings are initially changed in outpatient clinics, necessitating regular visits with substantial burden for parents, children and services. This can potentially be lessened if some parents go on to administer dressing changes for their child at home. However, there is a lack of data regarding support for parent-administered dressing changes. The aim of this study was to describe current practice and views regarding at-home parent-administered dressing changes (PAD) in the UK.

*Methods:* An online survey was distributed to 20 paediatric burns services in England and Wales. The survey used fixed and free-text responses to collect data on whether PAD is offered and the reasons for this; patient and parent eligibility criteria; training and support; and respondents' views on the advantages and disadvantages of PAD. Analysis comprised simple descriptive statistics and simple content analysis of free-text responses.

*Results:* Thirteen responses were received (response rate= 65%). Eleven respondents indicated their service offers PAD. Two respondents reported their service does not offer PAD due to alternative nurse outreach appointments (n=1), and service resource limitations (n=1), though another respondent indicated service cost savings. Twelve respondents regard PAD positively (n=8) or very positively (n=4). Most respondents reported that 10% or fewer parents refuse PAD when offered (n=7). Perceived advantages of PAD included reduced travel burden (n=9), patient better able to cope with dressing changes (n=8), better school and work attendance for child and parent respectively (n=6), and reduced financial impact on families (n=4). There are no formal eligibility criteria for PAD, though 5 respondents described informal criteria in place in their service, predominantly involving dressing frequency (n=5), and size or complexity of wound (n=4).

*Conclusion:* The survey indicates that most paediatric burns services support PAD. However, the absence of formal eligibility criteria, and informal criteria open to interpretation, risks inequity of support received by children and their families. Further research should evaluate whether this inequity extends to variable clinical outcomes to determine what works for who and under what circumstances when supporting parents in paediatric burns aftercare.

**Keywords:** Aftercare, Dressing changes, Paediatric burns, Survey

\* *Corresponding author at:* Room 239, Murray Learning Centre, University of Birmingham, Edgbaston, University of Birmingham, B15 2TT, UK. Tel.: +44 121 41 58056  
Email address: [d.m.thompson@bham.ac.uk](mailto:d.m.thompson@bham.ac.uk) (D.M. Thompson)

## 40 **1. Introduction**

### 41 **1.1. Background**

42 Paediatric burns involve an injury to the skin or other tissue caused by heat or other source such as  
43 friction or chemicals [1], leading to a heightened risk of mental health problems for children and  
44 their parents [2-3]. Paediatric burns are among the most expensive types of injury due to the  
45 medical costs of long-term care in burns services, and the indirect costs associated with informal  
46 care provided by parents resulting in time off work, productivity losses, and the associated decline in  
47 tax receipts [4]. Conservative estimates of direct healthcare costs alone are placed at £63,157 for  
48 major burns per patient in the UK [5].

49 For children with burn injuries, standard practice following initial discharge from hospital is for  
50 regular attendance at an outpatient clinic for dressing changes until the wound has healed [6].  
51 However, due to the costs involved in burns care for patients and services, the development and  
52 assessment of cost-effective alternatives is considered a priority in burns health service delivery  
53 research [7].

54 Travelling to hospital for dressing changes is one of the most distressing experiences associated with  
55 burn injuries according to children [8]. There is demand among parents of children with burn injuries  
56 to be more involved in their child's care, including opting into dressing changes at home [9]. This  
57 presents complex practical and emotional challenges for some parents, including anxieties regarding  
58 the technical aspects of the procedure combined with a reluctance to acknowledge distress and seek  
59 psychological support from nurses [10]. However, there is no evidence describing the parent  
60 administered dressing changes (PAD) uptake and support across paediatric burns services, nor  
61 consensus on how healthcare professionals should support parents, risking variation in outcomes for  
62 paediatric burns patients.

### 63 **1.2. Aim**

64 The aim of this study was to describe current practice and healthcare professionals' views regarding  
65 at-home parent-administered dressing changes in the UK.

66

## 67 **2. Methods**

### 68 **2.1. Ethical approval**

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

### 71 **2.2. Study design and data collection**

72 A survey was administered to healthcare professionals (HCP) to gather descriptions of current  
73 practice and views on PAD. The survey was developed in LimeSurvey [11], and comprised fixed  
74 response (categorical and Likert scale) and open-ended free-text questions about (1) the burns  
75 service the respondent is based in; (2) the availability of parent-administered dressing changes  
76 (PAD); (3) eligibility criteria for families to be considered a candidate for PAD; and (4) resources  
77 available to support parents to administer dressing changes. We were primarily interested in PAD  
78 practice, though respondents' views on PAD were gathered to supplement and qualify unexpected  
79 findings. The survey was piloted by 3 paediatric burns nurses each based in a different service, who  
80 were asked to complete the survey and comment on usability and relevance of questions and  
81 response format.

## 82 **2.3. Sampling and recruitment**

83 Comprehensive sampling of paediatric burns centres, facilities and units in England and Wales was  
84 conducted. Twenty services were identified through the research teams' knowledge of paediatric  
85 burns service provision and confirmed by reviewing services listed on the British Burns Association  
86 website [12]. A designated HCP at each service was identified to receive the survey to avoid  
87 contradictory responses about PAD practice between individuals within services that may have  
88 emerged from inexperience or other characteristics, to avoid skewing responses towards local  
89 services affiliated with the authors, and to avoid duplication of effort by clinicians in busy services.  
90 Nominated respondents were asked to consult their colleagues to establish local PAD practice. A  
91 survey invitation email was sent to each designated HCP on 22 November 2019, including a link to  
92 complete the survey. Designated HCPs could request that a colleague complete the survey on their  
93 behalf, though only one survey was returnable per service. Reminders to complete the survey were  
94 sent once per week until the survey closed on 15 January 2020.

## 95 **2.4. Data analysis**

96 Free-text survey item responses underwent simple content analysis [13]. DT (lead author) organised  
97 responses into themes. Categorical data were tabulated and analysed using simple descriptive  
98 statistics.

99

## 100 **3. Results**

### 101 **3.1. Survey respondent information**

102 Thirteen responses were received (65% response rate). Twelve respondents identified as a nurse,  
103 sister or matron (Table 1). The majority of respondents had 10 or more years' experience in  
104 paediatric burns (n=8), working with a full spectrum of burn severities (n=7).

105 \*\*\*INSERT TABLE 1 AROUND HERE\*\*\*

### 106 **3.2. Availability of parent-administered dressing changes**

107 Eleven services offer PAD to their patient population, predominantly to ease the burden on families  
108 of traveling to the burns service (n=6); and because parents can manage to dress less severe and less  
109 complex wounds (n=5; Table 2). Most services have offered PAD to parents for at least 4 years (n=9).  
110 Two services do not offer PAD to patients due to service resource limitations (n=1), and alternative  
111 nurse outreach available including at-home dressing changes (n=1).

112 \*\*\*INSERT TABLE 2 AROUND HERE\*\*\*

### 113 **3.3. Parents' eligibility to administer dressing changes**

114 Five services use informal criteria to determine eligibility for at-home dressing changes (Table 3).  
115 Most respondents estimated their services admit approximately 16-45 new patients per month  
116 (n=10), with 15 or fewer eligible for PAD (n=8). Clinical eligibility criteria predominantly concerned,  
117 the frequency of dressing changes required (n=5), and the size or complexity of the wound (n=4).  
118 Non-clinical criteria included parental willingness (n=3), competence (n=2), confidence (n=1), and  
119 adequate parental understanding of PAD to administer dressing changes (n=1), parents  
120 demonstrating appropriate help seeking behaviours (n=1), travel burden to appointments (n=1), and  
121 unspecified social factors (n=1). No services possessed formal written policies to determine eligibility  
122 for at-home dressing changes.

123 Respondents reported that PAD is offered to parents in the treatment pathway when the wound had  
124 sufficiently healed (n=5), based on the size or complexity of the wound (n=4), after an estimated 1-2  
125 or 4-5 dressing changes (n=2), when the wound becomes 'less distressing' (n=1), when a simplified  
126 dressing was indicated (n=1), after progression to adhesive dressings (n=1), when less frequent  
127 dressings were required (n=1), or if the child would benefit from access to a regular bath or shower  
128 with dressing changes (n=1).

129 \*\*\*INSERT TABLE 3 AROUND HERE\*\*\*

### 130 **3.4. Support offered to parents who administer dressing changes**

131 Two respondents acknowledged the use of parental observation as an act of training parents in  
132 preparation for administering dressing changes (Table 4). However, training delivered to parents to  
133 administer dressing changes largely comprised verbal (n=8) and written instruction (n=3), and  
134 demonstration (n=4). Two services identified open access to ongoing telephone contact with HCPs  
135 and further appointments as forms of support for parents.

136 Two respondents reported access to a burns service psychologist, and a further five stated that  
137 parents could receive psychological support from other members of the paediatric burns team (e.g.  
138 nurses). Respondents reported referring or signposting parents to psychologists (n=7), GPs (n=3),  
139 websites (n=2), a health visitor (1), or burns charities (n=1). All respondents offering PAD stated that  
140 psychological support available to parents who administer dressing changes does not differ from  
141 that received by parents who do not engage in the PAD process (n=11).

142 Ten respondents reported monitoring progress with PAD at outpatient appointments; four reported  
143 using telephone appointments, and one outreach service provision. Use of photographs, and review  
144 of parents' coping and willingness to proceed with at-home dressing changes were each identified as  
145 a means of monitoring PAD progress by one respondent.

146 \*\*\*INSERT TABLE 4 AROUND HERE\*\*\*

### 147 **3.5. Healthcare professionals' views on parent administered dressing changes**

148 Respondents had a 'positive' (n=8), 'very positive' (n=4), or 'neutral' (n=1) view of PAD. Respondents  
149 identified a range of advantages of PAD, including reduced travel (n=9), improved coping through  
150 PAD (n=8), improved school attendance for the child (n=6), reduced absences at work (n=6), reduced  
151 frequency of hospital visits (n=5), reduced financial impact on families (n=4), flexibility of when to  
152 administer dressing changes (n=3), control over procedure (n=2), reduced disruption to family  
153 routine (n=2), greater capacity for burns service (n=2), superior unspecified clinical outcomes (n=2),  
154 enhanced family-centred care (n=2), improved continuity of care via parent (n=1), improved parental  
155 monitoring of child's wound (n=1), improved quality of life for child (n=1), more thorough washing of  
156 wound (n=1), more time for parents to care for other dependents (n=1), parents are more aware of  
157 their child's needs (n=1), parents feel better for having contributed to child's care (n=1), reduced  
158 anxiety for child and parent (n=1), reduced appointment waiting times (n=1), reduced contamination  
159 brought to hospital (n=1), and service cost savings (n=1).

160 Most respondents estimated that fewer than 10% of parents refuse to administer dressing changes  
161 (n=7), though the majority opt into administering dressing changes (n=9). Two respondents were  
162 unsure of the rate at which parents refuse PAD. Disadvantages of PAD include parents' delay or  
163 inability to recognise infection (n=4), healthcare professionals not in a position to review care (n=4),  
164 a lack of parental confidence (n=3), child resistant to PAD (n=2), cleanliness of the home  
165 environment (n=2), parental anxiety (n=2), potential for inadequate dressing change (n=2), child

misses out on other care (e.g. physiotherapy) (n=1), child's distress at first home dressing (n=1), lack of time (unspecified) (n=1), parental loss of confidence (n=1), potential for adverse clinical outcomes (n=1), technically difficulty of dressing changes (n=1), and unexpected issues may arise (n=1).

Reasons for parents' uptake of PAD include travel burden (n=7), size and complexity of burn (n=5), parental confidence (n=5), fear of causing pain (n=5), child's capacity to cope (n=4), parental avoidance of the burn wound (n=4), parents' fear of inadequate dressing changes (n=4), dressing simplicity (n=3), waiting for appointments (n=2), demonstration or instructions (n=2), a need for a second person to support at-home dressing changes (n=2), reassurance of follow-up appointments (n=2), availability of a bath or shower at home(n=1), availability of childcare(n=1), fear (unspecified) (n=1), fear of causing damage (n=1), financial impact (n=1), flexibility of time of administration (n=1), pain management at home rather than hospital (n=1), parental distress (n=1), parents' perceived responsibility for burn incident (n=1), parents prefer not to have the responsibility (n=1), preference for nurse-administered dressing changes (n=1), school attendance (n=1), wish to fulfil parental role (n=1), and work attendance (n=1). Two respondents noted parents' concerns after beginning to administer dressing changes including distress displayed by their child (n=1), parents' distress (n=1), worry about the appearance of the burn (n=1), and forgetting the PAD procedure (n=1).

182

#### 183 **4. Discussion**

184 This study describes paediatric burns clinicians' practice and views on at home parent-administered  
185 dressing changes in paediatric burns aftercare (PAD). Exploring variation in care through survey data  
186 is one way to identify good practice to develop consensus-led clinical guidelines that can be widely  
187 shared across paediatric burns services to support the entirety of the PAD process. Furthermore,  
188 identifying clinicians' views on current practice can assist in the design of acceptable strategies to  
189 support paediatric burns aftercare and anticipate facilitators and barriers for implementation.

190 Recent interviews with parents indicate that there is demand for the option to administer dressing  
191 changes at home in the UK [10]. This survey demonstrates that the majority of UK paediatric burns  
192 services offer PAD, supported by clinicians who overwhelmingly hold positive views of this practice.  
193 Clinicians' views on the advantages of PAD resonate with parents' experiences, predominated by  
194 reduced travel burden, increased school and work attendance, and better coping demonstrated by  
195 children at home with their parents [8]. However, some services do not offer PAD. These findings  
196 suggest that at least one UK paediatric burns service does not offer PAD due to perceived service  
197 costs. In contrast, one survey respondent in this study reported that PAD reduces service costs. Cost-  
198 effectiveness research has already been identified as a priority for burns health service delivery  
199 research [7]. This study demonstrates a lack of consensus in perceived costs associated with PAD,  
200 and emphasises the need for robust cost-benefit analysis and a comprehensive dissemination plan  
201 to build consensus and facilitate the implementation of clinical guidelines across services.

202 This survey found that some paediatric burns clinicians refer parents to websites for health-related  
203 information and support following their child's burn injury. However, it is unclear whether the  
204 websites referred to contain effective, relevant and safe information. Appropriate websites and  
205 other information sources should be identified or designed based on evidence-based information  
206 and materials, and rigorously evaluated [14]. Considering some parents prefer not seek help from  
207 paediatric burns clinicians for their own wellbeing [10], websites may represent the only information  
208 and support received. Therefore, further research should explore the components of effective  
209 information provision in paediatric burns and PAD to provide a quality standards framework for

210 resources to offer reassurance to parents and services. Nonetheless, this survey corroborates other  
211 UK burns service survey data indicating that most services recognise the need to provide  
212 psychological support for parents, with most services surveyed signposting parents to external  
213 psychological support [15]. Lawrence and colleagues also found that burns patients are more likely  
214 to receive mental health care after discharge in the UK [15], and our recent interview data suggests  
215 that parents prefer the focus of care to be on their child while marginalising their own needs,  
216 especially in the early stages of burns care [10]. However, incidence of clinically significant anxiety  
217 and depression are substantially higher before discharge [16]. This risks parental functional  
218 impairment and potential negative cognitive, emotional and social development outcomes for the  
219 child while this need is unmet [17], suggesting that parents and children may benefit from more  
220 readily accessible psychological support in paediatric burns services. This survey demonstrates that  
221 few services offer this at present. This is of particular concern for services supporting at-home  
222 treatments like PAD, which poses its own emotional challenges such as the need to confront the  
223 burn wound and the post-traumatic stress associated with this [10]. Unattended parental anxiety  
224 and depression following paediatric burn injuries is associated with functional impairment [3], with  
225 potential implications for adherence to best wound management and infection prevention practices,  
226 which was one of the key reservations clinicians hold about PAD according to this survey this study.  
227 Further research should consider when and how best to assess parental need for psychosocial  
228 support.

229 According to survey respondents, no UK paediatric burns service uses formal eligibility criteria to  
230 determine which parents should be supported to administer dressing changes for their child.  
231 Informal criteria included clinicians' subjective assessment of wound complexity and the patient's  
232 pain tolerance. In the absence of formal eligibility criteria for PAD, and with informal criteria open to  
233 interpretation, there is risk of inequity of care and support received by children and their families  
234 between and within services. Further research should evaluate whether this inequity extends to  
235 variable clinical outcomes to determine what works for whom and under what circumstances.

#### 236 **4.1. Limitations**

237 These data are based on the experiences of one clinician representing each paediatric burns service,  
238 and may reflect individual practice at odds with standard practice in their service. The clinicians  
239 responding to this survey had accumulated a combined 150 years' experience working in paediatric  
240 burns care and were also advised to consult with colleagues before responding, although some  
241 respondents may have relied on individual professional experience. This approach may have limited  
242 the reliability of the survey data. On the other hand, the recruitment of one nominated respondent  
243 per service helped to avoid contradictory responses about PAD practice between individuals within  
244 services that may have emerged from inexperience or other characteristics, to avoid skewing  
245 responses towards local services affiliated with the authors, and to avoid duplication of effort by  
246 clinicians in busy services. Furthermore, all respondents indicated that there are no formal eligibility  
247 criteria for PAD. Thus, we may still infer potential variation in care from this study. Furthermore, this  
248 study did not directly observe the clinical practice described by survey respondents and did not  
249 follow-up with respondents to clarify what outcome domains were perceived to benefit from PAD.  
250 As a result, the level of detail on the support offered to families is limited here by the information  
251 reported by clinicians. Observational research is necessary to elaborate on the PAD offer for families.

252

#### 253 **5. Conclusions**

254 This survey provides an overview of current practice and clinicians' views on parent-administered  
255 dressing changes (PAD) in paediatric burns aftercare. Clinicians indicated that most UK paediatric  
256 burns services support PAD, though they each appear to do so in different ways, at different times  
257 and for children with different demographics and clinical characteristics. These data indicate  
258 variability in practice across the UK. Clinicians' views on the advantages of PAD align with evidence  
259 on parents' experiences of at-home dressing changes, including reduced travel burden, improved  
260 child coping, and better school and work attendance for children and parents respectively [10]. In  
261 the absence of formal service-wide eligibility criteria and clinical guidelines to support parents and  
262 clinicians throughout the PAD process, nurses rely on clinical judgement with each patient and their  
263 family. These data lay the groundwork for developing further research to establish and standardise  
264 best practice.

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### 268 **Authors' contributions**

269 JM, CT, YV & NM jointly conceived the research and all authors contributed to development of the  
270 study protocol. CT, LH, & DT contributed to recruitment, and JM, CT, LH & DT designed the survey.  
271 DT developed and administered the survey tool and lead on analysis, and all authors contributed to  
272 final analysis. DT drafted the initial manuscript. JM provided oversight of the research design,  
273 conduct and analysis, and helped with final manuscript revisions. All authors revised the manuscript  
274 for important intellectual content and gave approval of the final version.

### 275 **Conflict of Interest**

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

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- 329

Table 1 – Survey respondent information

Variable	N
<i>Respondent role</i>	
Nurse (Research)	1
Nurse (Advanced Practitioner)	1
Nurse (Trainee Advanced Practitioner)	1
Nurse (unspecified)	4
Sister (Senior)	1
Sister (Junior)	1
Sister (unspecified)	2
Ward Matron	1
Consultant Surgeon	1
<i>Respondent experience in paediatric burns (years)</i>	
0-4	1
5-9	4
10-14	4
15-19	2
20-24	0
25-29	2
<i>New admissions per month</i>	
15 or fewer	1
16-30	5
31-45	5
46-60	0
61 or greater	2
<i>Burns treated</i>	
All	7
Less than 30%	4
Less than 10%	1
Less than 5%	1
<i>Service type</i>	
Centre	7
Facility	2
Unit	4

**Table 2 – Availability of parent-administered dressing changes**

Variable	N
<i>How long PAD has been offered by service</i>	
Less than 1 year	0
1-2	1
2-4	1
4-6	3
More than 6 years	6
<i>Factors influencing service to offer PAD</i>	
Travel burden	6
Size or complexity of burn	5
Parental understanding	3
Superior unspecified outcomes for families	2
Child's pain tolerance and comfort	2
Parental willingness	2
Superior unspecified outcomes	1
Simplicity of dressings	1
Facial burn	1
Access to home facilities to support PAD	1
Nursing assessment	1
Parent-child relationship	1
Parental confidence	1
Social factors	1
<i>Factors influencing service not to offer PAD</i>	
Nurse outreach available	1
Service resource limitations	1

334

335

**Table 3 – Eligibility of parents to administer dressing changes**

Variable	N
<i>Informal clinical eligibility criteria for PAD</i>	
Dressing frequency	5
Size or complexity of burn	4
Location of burn	2
Additional therapies indicated	1
Analgesia indicated	1
Availability for monitoring (10-14 day intervals)	1
Burn progression	1
Child's pain tolerance and comfort	1
<i>Informal non-clinical eligibility criteria for PAD</i>	
Parental competence to administer dressing changes	3
Parental willingness to administer dressing changes	3
Appropriate help-seeking behaviour of parents	1
Parental confidence to administer dressing changes	1
Social factors	1
Travel burden	1
<i>Number of patients eligible for PAD per month</i>	
15 or fewer	8
16-30	2
31-45	1
46-60	0
61 or more	0
<i>Treatment pathway time-point when is PAD offered</i>	
Healing wound	5
Size or complexity of burn	4
After 1-2 dressing changes	1
After 4-5 dressing changes	1
At treatment progression to adhesive dressings	1
Bath or shower required after 1 week	1
Distressing wound	1
Dressing simplicity	1
Frequency of dressing changes	1

**Table 4 – Support offered to parents who administer dressing changes**

Variable	N
<i>Training &amp; information given to PAD parents</i>	
Verbal instruction	8
Demonstration	4
Written instruction	3
Ongoing telephone support	2
Open access to appointments	2
Parents observe dressings in clinic	2
Discussion of potential issues	1
Step-by-step guide	1
<i>Psychosocial support offered to PAD parents by burns service</i>	
Contact with healthcare professional in burns service	5
Burns service psychologist	2
<i>External psychological or social support signposted for PAD parents</i>	
Unspecified referral to psychological support	7
GP	3
Burns charities	1
Burns service website for social support	1
Emergency department	1
Health visitor	1
None	1
Unspecified website	1
<i>PAD monitor &amp; follow-up</i>	
Outpatient appointment in burns service	10
Telephone appointments	4
Outreach service	1
Patient photographs sent by family	1
Review families' coping	1
Review willingness to proceed	1