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DOI:
10.1016/j.burns.2021.03.012

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Document Version
Peer reviewed version

Citation for published version (Harvard):
Thompson, D, Thomas, C, Hyde, L, Wilson, Y, Moiemen, N & Mathers, J 2021, 'At home parent-administered dressing changes in paediatric burns aftercare: a survey of burns centres' practice', *Burns*. https://doi.org/10.1016/j.burns.2021.03.012

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

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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

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1. Introduction

1.1. Background

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

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

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

1.2. Aim

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

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 and data collection

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

2.3. Sampling and recruitment

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

2.4. Data analysis

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

3. Results

3.1. Survey respondent information

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

INSERT TABLE 1 AROUND HERE

3.2. Availability of parent-administered dressing changes

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

INSERT TABLE 2 AROUND HERE

3.3. Parents' eligibility to administer dressing changes

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

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

INSERT TABLE 3 AROUND HERE

3.4. Support offered to parents who administer dressing changes

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

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

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

INSERT TABLE 4 AROUND HERE

3.5. Healthcare professionals' views on parent administered dressing changes

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

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

4. Discussion

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

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

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

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

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

4.1. Limitations

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

5. Conclusions

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

Funding

This project was funded by University of Birmingham College of Medical and Dental Sciences Research Development Fund.

Authors' contributions

JM, CT, YV & NM jointly conceived the research and all authors contributed to development of the study protocol. CT, LH, & DT contributed to recruitment, and JM, CT, LH & DT designed the survey. DT developed and administered the survey tool 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.

Acknowledgements

We would like to thank the healthcare professionals who kindly responded to the survey. We would also like to acknowledge the contribution of our public involvement partners.

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Table 1 – Survey respondent information	
Variable	N
Respondent role	
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
Respondent experience in paediatric burns (years)	
0-4	1
5-9	4
10-14	4
15-19	2
20-24	0
25-29	2
New admissions per month	
15 or fewer	1
16-30	5
31-45	5
46-60	0
61 or greater	2
Burns treated	
All	7
Less than 30%	4
Less than 10%	1
Less than 5%	1
Service type	
Centre	7
Facility	2
Unit	4

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Table 2 – Availability of parent-administered dressing changes	
Variable	N
How long PAD has been offered by service	
Less than 1 year	0
1-2	1
2-4	1
4-6	3
More than 6 years	6
Factors influencing service to offer PAD	
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
Factors influencing service not to offer PAD	
Nurse outreach available	1
Service resource limitations	1

Table 3 – Eligibility of parents to administer dressing changes	
Variable	N
Informal clinical eligibility criteria for PAD	
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
Informal non-clinical eligibility criteria for PAD	
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
Number of patients eligible for PAD per month	
15 or fewer	8
16-30	2
31-45	1
46-60	0
61 or more	0
Treatment pathway time-point when is PAD offered	
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
Training & information given to PAD parents	
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
Psychosocial support offered to PAD parents by burns service	
Contact with healthcare professional in burns service	5
Burns service psychologist	2
External psychological or social support signposted for PAD parents	
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
PAD monitor & follow-up	
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

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