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Below the surface: Parents' views on the factors that influence treatment adherence in paediatric burn scar management — A qualitative study

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ARTICLE INFO

Article history:

Accepted 15 September 2017

Available online xxx

Keywords:

Paediatric burns

Scar management

Treatment adherence

Qualitative research

Interviews

ABSTRACT

Introduction: Parents have a crucial role to play in burn scar management for their children at a time that is extremely stressful for them and their child. Scar management treatments such as pressure garment therapy (PGT) require high levels of adherence. There has been a lack of research into the factors that may influence adherence in paediatric burn scar management. This qualitative research study has investigated parents' experiences of scar management and their attempts to adhere to treatment at home. The aim of this paper is to outline parents' views on the factors that influence adherence.

Methods: 25 parents of paediatric and adolescent burn patients took part in semi-structured interviews. Participants were recruited from three UK burns services. Interviews were conducted in a participant-focussed manner and topics for discussion included parents' accounts of treatment and their experience of PGT. A thematic analysis was undertaken.

Results: Four overarching themes describe parents' views and experiences of scar management and adherence. These are the transition from hospital to home; the practical realities of treatment; the emotional labour involved in treatment and; negotiating treatment and regime. The transition from hospital to home is a significant event for parents. They may be apprehensive about this at the same time as they desire that they and their child return to some sense of normality following the burn injury. Parents are required to adopt the role of therapeutic caregiver upon transition from hospital to home. Adherence to scar management is influenced by the practical realities of maintaining treatment (routine, division of care labour, hospital appointments) and the emotional labour involved in doing so. The latter demands that parents manage their own and their children's emotions. Approaches to adherence were often described as flexible in response to these influences.

Conclusions: Some parents negotiate the realities and demands of scar management successfully, whereas others do not. The emotional labour experienced by parents and their ability to cope with this is often a strong influence on their views regarding adherence to scar

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¹ Membership of the Pegasus Study Group is provided in the Acknowledgements.

<https://doi.org/10.1016/j.burns.2017.09.003>

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management. Further research is needed to explore how burns services and staff manage this at present, and whether simple interventions can help with the key practical and emotional influences on treatment adherence.

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1. Introduction

In 2011, 7634 people were admitted to hospital for the treatment of burn injuries in England and Wales [1]. Of these, 48% were aged below sixteen years, the age group most at risk of burn injury [1]. For some children and parents, the burn incident results in physical and emotional challenges that may have life changing implications [2]. For parents, the unexpected and often shocking changes to family dynamics are traumatic and require major adaptation to everyday tasks and duties [3]. In parallel to dealing with these changes parents have an important role to play in treatment maintenance and therefore subsequent outcomes for their children [4]. Research into the experiences of parents during initial resuscitation and acute rehabilitation following a burn injury demonstrates that this time is extremely stressful, characterised by uncertainty, fear [5] and high levels of distress [6,7]. Following discharge, rehabilitation may require long term treatment that seeks to reduce the impact of scarring for functional and aesthetic reasons [8]. Patients with poor scar outcomes may experience restricted movement and function, severe psychosocial impacts due to appearance, and may find difficulty in re-integrating into society. Scar management is therefore key and modalities such as pressure garment therapy (PGT) and creaming and massage require high levels of adherence for optimal outcomes [8].

Following inpatient treatment there is often less contact with clinical staff and less is known about parents' experiences. There is a lack of research describing factors that may influence treatment adherence in scar management [9]. Recent studies of adult patients' experiences of scar management give some insight into the lived realities of treatment, and how patients seek to maintain regimes [10,11]. Whilst PGT can be perceived as burdensome, adult patients also report benefits, including feelings of physical and psychological protection afforded by garments [10,11]. However, the complexities of maintaining paediatric scar management are different as the burden of care more often lies with the parent caregiver as well as the patient [12]. Indeed, there is need for a 'therapeutic triad', with interactions between professionals, parents and children being key to attempts to maintain treatment [12]. For some parents the realities of a demanding treatment agenda within day-to-day life, set against the intense psycho-social impacts of a child's burn injury, may make this especially difficult [13].

Here we present the findings of qualitative research that has investigated parents' experience of scar management and their attempts to adhere to this at home. The aim of this paper is to outline parents' views on the factors that influence adherence to burn scar management following discharge.

2. Methods

2.1. Study design

This qualitative research, informed by interpretive description [14] formed part of a wider mixed-methods feasibility study of PGT for the prevention of abnormal scarring after burn injury in adults and children (PEGASUS) [15,16]. One of the aims of the integrated qualitative research was to understand adult patients' and parents' experiences of scar management therapies, and predominantly PGT.

2.2. Sampling and recruitment

The sample consists of parents/carers (referred to as parents from this point) of paediatric burns patients aged 0-9 years who had at least six months' experience of PGT and had finished PGT no more than two years prior to data collection, or were a participant in a pilot trial of PGT that formed part of the PEGASUS study. Paediatric patients participating in the pilot trial were allocated to scar management with or without PGT. Participants were recruited by occupational therapists (OTs) and/or research nurses (RNs) in 3 of the PEGASUS pilot trial sites across England: Birmingham Children's Hospital, Royal Manchester Children's Hospital, and Queen Victoria Hospital, East Grinstead. Clinical staff provided information sheets to potential interviewees and took written consent to pass participant contact details on to the PEGASUS qualitative research team. A member of the qualitative research team then contacted potential interviewees, provided further information and answered questions as necessary, before arranging a suitable time, date and venue for the interview. Written informed consent was received from all participants prior to the start of data collection.

2.3. Ethics

A favourable opinion for the PEGASUS study was received from the West Midlands: Coventry and Warwickshire Research Ethics Committee (14/WM/0160).

2.4. Data collection

Semi-structured interviews were identified as an appropriate data collection method given that they facilitate an in-depth exploration of participant views [17]. Interviews were conducted by a trained non-clinical qualitative researcher who was independent of the child's clinical care team. Interviews were mainly conducted in the patient's home, which was the preferred venue; although a small number took place via telephone. A semi-structured discussion guide was developed based on the literature, discussions with our

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