Parent/ carer experiences of their child’s dressing changes taking place on a burns unit

Jessica Morley
Craig Murray
Field Supervisor
The service and study context

- Research proposed by a Clinical Psychologist at a paediatric psychological service within a children’s hospital
- Service delivery involved working with children and families who had had contact with the burns department at the hospital
- Service identified need to understand further the psychosocial support needed by these parents
Background

- Burns are one of the most prevalent types of paediatric injury within the UK\textsuperscript{1}
- The majority of paediatric burns occur in children under the age of five by accidental causes within the home predominantly involving food or drink preparation\textsuperscript{2}
- Within SRP service: 2012, 76% of the admissions to the burns unit were children under the age of five years old; the majority of paediatric patients admitted to this service had burns less than 30% of total body service area (TBSA); and 85% of burns were caused by scalds and contact burns
Background

• Sustaining a burn injury can have a negative impact on the child’s psycho-social functioning and is related to a higher incidence of short-term anxiety, stress, behavioural problems\(^3\) and PTSD\(^4\)

• Emotional and psychological impact of burn injury on the child’s parents/ caregivers is also evident - high risk of PTSD during the months shortly after their child’s burn injury\(^5\) and in later years\(^6\)

• British Burn Association recommendations - burn care strategy\(^7\)
  o Importance of addressing the psycho-social needs of patients, their families and/or caregivers undergoing or being present during burn care procedures
  o The need for psycho-social input spanning all aspects of service delivery from admission, rehabilitation, discharge and follow-up
  o That psycho-social wellbeing is the business of all members of the MDT and as a result suggests that all MDT staff receive relevant and up-to-date psychological training in order to support psychological needs within different service contexts
• Dressing changes for burns injury can be intensely painful for patients and subsequently difficult for staff to manage

• Pain displayed by children on a burns unit has been positively associated with their parents’ acute stress symptoms

• The majority of parents wish to be present during their child’s painful medical procedures

• Researchers have drawn attention to the importance of parental involvement to manage the child’s stress in the delivery of burn care but caution about the challenges to this once the parent becomes distressed themselves

The Present Study

• The contribution and participation of parents should be critically considered within service delivery and services (e.g., parental preferences and the likelihood that being present could cause them distress)

• Only one qualitative study was found in this topic area focused more generally on the whole journey of burns care from parents’ perspectives

• **Primary research question** - explore the experiences of parents who had been present during their child’s dressing change for burn injury

• **Aim** – to increase understanding of how parents specifically describe and experience this phase of their child’s burn care. Findings from this would also have important implications for paediatric burn care services in terms of addressing the psycho-social needs of parents and their children.
Methodology

• Ethical approval sought through NHS and via the local R&D department
• 90 potential participants approached through 2 stages of recruitment (second stage widened eligibility criteria) – Total of 5 recruited
• Participants – all mothers of children under 5 who had undergone a series of dressing changes for minor burn injury (completed within last 6 months)
• Semi-structured interviews conducted at parents’ homes, lasting approx 1 hour
• Interviews transcribed and analysed using Interpretative Phenomenological Analysis\(^{13}\) (IPA)
4 Final themes from the data

1. **Theme 1:** Needing to fulfil the responsibilities associated with being a mother
2. **Theme 2:** Emotional synchrony between mother and child
3. **Theme 3:** Experiences of being informed and knowing what to expect
4. **Theme 4:** The importance of establishing rapport with nurses performing dressing changes
Needing to fulfil the responsibilities associated with being a mother

- Participants related their experiences to their role of being a mother and its perceived responsibilities.
- This had a strong impact on participants’ decision to be present during dressing changes.
- Participants experienced difficulty fulfilling their role based on their own conflictual emotional reactions (being distressed) and limitations dictated by the situation (not being able to take pain away from their child or do what they would normally do to comfort child).
- This was experienced with a sense of guilt and loss of control.
- Those who were able to overcome these difficulties experienced this as taking ownership within the dressing changes.
Summary Theme – 2

Emotional synchrony between mother and child

• Parents could experience distress or calmness depending on their child’s reactions

• Those who displayed distress during dressing changes were aware this was having a negative impact on their child’s emotional reactions.

• For these parents, it was important to keep their outward expression of distress hidden in order to allow their child to remain calm.
Experiences of being informed and knowing what to expect

- Relatively novel situation for most participants and involved obtaining understanding and knowledge through others and through experiencing dressing changes first-hand
- Participants found this both beneficial and problematic
- **Helpful** - Knowing what the procedures would involve and how they might find it difficult to watch increased their sense of preparedness for the unexpected, feeling better equipped to cope
- **Hindrance** – One participant with expert knowledge: professional insight experienced as making her hyper-alert to any indications of seriousness
- Being informed therefore enhanced participants’ feelings of preparedness and control but could also illuminate the gravity of the situation and provoke anxiety
The importance of establishing rapport with nurses performing dressing changes

- Participants recounted building a sense of connection with nurses who were performing the dressing changes and reflected on how much they valued this experience.
- Sometimes based on difficult initial encounters with other hospital staff.
- Experiencing a desire to be understood and have their experiences normalised.
- Sharing something in common with nurses helped put participants’ at ease during dressing changes and helped decrease feelings of isolation and blame.
Discussion

- The themes identified highlight the importance of supporting parents with their participation within dressing changes.
- Participants identified the importance for parents:
  - Maintaining a role within dressing changes
  - Understanding how their reactions may impact on their child
  - Receiving information about dressing changes
  - Building a rapport with nursing staff performing the burn care
- Supports previous research finding:
  - Parents feel duty-bound to be present and responsible for their child’s well-being in hospital settings\(^\text{13}\)
  - The most prominent stress reported by parents was in relation to role alteration in terms of their reduced ability to provide safety to their child within burn care\(^\text{14}\)
  - Findings that parents experienced an increase sense of coping when they were able to participate in their child’s burn care\(^\text{15}\)
  - Findings showing that mothers and their infants can influence each other’s experiences of stress\(^\text{16}\)
  - Findings indicating that parents specifically value sensitive and supportive relationships established with nursing staff and conversely feel de-valued by nurses within less compassionate exchanges\(^\text{17}\)
Conclusions

• These findings have important implications in the development of appropriate service-related strategies that can address some of the issues raised
  o Promoting an environment in which parents feel able to take on a meaningful role
  o Specifically assess parental stress and improve the parent-child interaction in order help them better manage their child’s distress within these settings
  o Prepare parents for their child’s medical care and the child’s likely reactions in order to reduce the uncertainty and anxiety associated with being in these settings.

• Future research
  o Future research is needed to gain a greater understanding of the relationship between nurses and parents specifically in relation to dressing changes
Reflections

• I enjoyed this research as it fitted with me personally:
  o As a Research Assistant interviewed parents in their homes – familiar with this type of data collection, felt comfortable visiting people at home in a setting they feel at ease in, familiar with keeping self safe in research appointments etc.
  o Clinically – striving to understand people, wanting to understand from their personal perspective, hearing service-user voices and how understanding their experiences can help improve services.
  o Interest in child and family services

• I enjoyed transcribing! (I’m in the minority)
• I enjoyed generating themes - but hard to think of final titles (wish I had time for more feedback here)
• I wish I had lived closer to the service so I could have visited more, observed more dressing changes (did observe 1)
• Overall, great experience for thesis (especially applying through NHS ethics)
Thank you!

- Questions?
References


19. Hatfield, Cacioppo and Rapson’s (1994)

20. Leventhal and Johnson’s (1983)
IPA

• IPA adopts a realist ontological stance grounded in contextual constructivism: that knowledge is a construction of reality from a certain perspective

• **Interpretive**: The approach also recognises the impact of the researcher on the construction of this knowledge and considers the influence their standpoint will have on shaping the research and interpreting the data

• **Phenomenology** theoretical framework – the study of subjective experience

• Research questions: about people’s experiences and perspectives

• Sampling strategy: homogenous, small N

• Data collection: qualitative interview