Collaborating with burn patients and their families to develop the CARe Burn Scales: a portfolio of burn-specific quality of life PROMs for use in paediatric and adult burn care

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Background

- Around 250,000 people experience a burn injury each year in the UK (National Burn Care Review)

- Recent medical advances, survivorship rates have increased - many people now living with their injuries

- Irrespective of burn size/severity…a person’s physical, psychological a significant impact on physical, psychological and social well being.

- Vital to identify burn patients needs in order to provide appropriate support/treatment
The need for a UK burn-specific PROM

Two published systematic reviews: adult and paediatric burn care (Griffiths et al, 2015; 2017):

- No burn-specific PROMs developed in the UK
- Not all aspects of QoL affected by burn-injury were measured e.g. avoidance behaviours, positive growth, trauma
- Few PROMs developed in collaboration with patients
- Therefore, a need for a burn-specific QoL PROM for the NHS burn service
Aim of the project:

• To develop three patient reported outcome measures (i.e. PROMs) to assess quality of life in children, young people and adults living with a burn injury
Overview of the project so far

52 In-depth concept elicitation interviews with patients, family members and health professionals

2 systematic reviews of current PROMs used in child, adolescent and adult burn care

First draft of PROMs developed

30 cognitive debriefing interviews with patients and health professionals used to gain feedback

>700 participants recruited to test the psychometric properties of the draft PROMs

Three final draft PROMs for children, young people and adults with a burn injury

Rasch analysis employed to shorten, refine, and finalise each PROM

Further patient testing of PROMs to determine reliability and validity
Collaborating with patients and family members to develop PROMs


Method

- For each age appropriate PROM (child, young person and adult):
  - **In-depth concept elicitation interviews (telephone or face to face):** item generation and the development of the conceptual framework
  - **Cognitive debriefing interviews** to ascertain the relevance and comprehension of the PROM to the patient group
Interview data: Conceptual Framework for Child scale (aged 0-8, parent report) (n=12 parents of children with a burn)

*Parents asked: what are your child’s experiences of living with a burn? Any concerns? Coping strategies?*
Child scale example items

- Created items asking about **observable behaviours** that parents have seen their child do to improve reliability of scale….(Pantell & Lewis 1987; Eiser & Morse 2001)

- Consistent with parent feedback…easier to answer observable behaviours… edited scale in line with this

  - **Scar dissatisfaction**: how frequently has your child………….cried or got upset when looking at their burn wounds/scars

  - **Social situations**… …. showed interest in their play activities

  - **Trauma**….. … acted out the event that caused their injury during play
Interview data: Conceptual Framework for Young Person Scale (aged 8-17) (n=9 young people and n =7 parents interviewed)

Young people asked: what are your experiences of living with a burn? How has health been affected? Any concerns? Coping strategies?

Similarities/ differences between scales…?
Interview data: Conceptual Framework for Adult Scale (aged 18 and over) (n=11 adults with a burn and n=5 family members interviewed)

Adults asked: what are your experiences of living with a burn? How has health been affected? Any concerns? Coping strategies?

- Physical functioning
- Social functioning:
  - Social situations
  - Avoidance behaviours
  - Work
  - Family
  - Friends
- Psychological functioning:
  - Trauma symptoms
  - Positive self-worth
  - Negative mood
  - Romantic appeal
- Wound/scar dissatisfaction:
  - Wound/scar discomfort
  - Discomfort with treatments
  - Concerns about wound/scars
- Positive experiences after a burn

Similarities/differences between scales…?
Cognitive debriefing interviews

- 23 cognitive debriefing interviews (parents, adults and young people) and 7 health professionals provided feedback on draft PROMs

- Reviewing the PROMs: Did they understand the instructions? Were the items easy/hard to understand? Any additional items/domains to add?

Results
- Additional items were suggested and improvements to readability of questions- making items more simple

- Overall all participants reported that the PROMs were acceptable to patients and consistent with the support provided by HPs
Reflections of working with patients to develop PROMs

Pros

• Extremely insightful …patients often suggested items/domains that clinicians/researchers had not. i.e. positive experiences of living with a burn

• Important to interview different age groups…similar but different domains and items

• Improvements for readability of PROMs - very different meanings to patients!

• Patients feedback- all reported that it was a positive experience…felt empowered by offering their opinions and many wanted to continue to help in future research

Challenges

• Sometimes conflicting opinions hard to condense into one PROM
Psychometric analysis: Child, Young Person and Adult PROMs

Participants:
- 246 parents of children (0-8)
- 179 young people (8-17)
- 324 adults (18+)

Recruitment:
- 11 NHS Burn Services
- Burn-related charities and organisations

Rasch analysis:
- Currently reducing child and young person PROMs to the final items
- Adult PROM reduced from 209 to 47 items
- 14 domains
- Results supported conceptual framework- small amendment

Data analysis due to be complete very shortly!
Current Studies

- Validation of the CAR\textsuperscript{e} Burn Scales
  - Comparison with standardised QoL PROMs used in burns

- Development of Parental Coping PROM
  - QoL and coping in parents supporting a child with a burn

- Testing feasibility of online platform
  - Using CAR\textsuperscript{e} Burn Scales in two NHS Burn Service in Bristol

- IBID
  - CAR\textsuperscript{e} Burn Scales to become core outcomes measures for NHS Burn Service
www.careburnscales.org.uk

The CAR® Burn Scales will be available for clinical use at the end of this summer!
If you would like to know more, please email Catrin.Griffiths@uwe.ac.uk

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Thank-you for listening!
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