Letter to the Editor

www.SupportingChildrenWithBurns.co.uk: A website developed with parents and professionals for the psychosocial support of parents of burn-injured children

Dear Editor,

It is well known within the burns community that parents suffer psychologically and emotionally when their child is injured (Bakker, Van der Heijden, Van Son, & Van Loey, 2013). However, not all parents want, or feel able, to access support following their child's injury (Heath, Williamson, Williams, & Harcourt, 2018). Factors contributing to difficulty accessing support can include psychological barriers such as guilt (Hawkins, Centifanti, Holman, & Taylor, 2018), and real-world barriers such as the distance to the hospital at which support is offered (Heath et al., 2018). Further investigation of these issues using a UK-based survey found that when support was accessed, face-to-face engagement in professionally-led support was the most popular avenue reported, but many parents and carers wanted and sought support online (unpublished PhD research).

Nowadays, it is common for people to search for health information online (Office for National Statistics, 2018). Many parents look for information about how to help their child but, due to their blinkered focus on their child's needs, they often do not seek support that could be beneficial to them and their own adjustment post-injury (Heath et al., 2018). Based on the findings of mixed-method PhD research, it was concluded that an online resource disseminating parent stories, burn-focused information, and psychoeducation may be beneficial for a much wider audience than traditional face-to-face support for those families affected by a child's burn-injuries.

For parents' individual needs to be more adequately addressed, they should be offered a range of information and support options following a stepped care model (Bessell, Dures, Semple, & Jackson, 2012; Rumsey & Harcourt, 2012). Within this model of care, SupportingChildrenWithBurns.co.uk fits with those offering targeted population-based interventions. As different parents and carers have different needs and emotional responses following their child's burn-injury, this online resource allows individuals to search for information that is personally relevant to them. Hosting information online, which has been informed by the experiences of other parents (peers), allows parents to access relevant information, at a time that is convenient, without having to travel or arrange childcare, or find the courage to ask others, especially when feelings of guilt or a focus on the child are acting as barriers to other forms of support.

To this end, SupportingChildrenWithBurns.co.uk was developed and tested using a participatory action approach (Greenwood, Whyte, & Harkavy, 1993) with UK-based parents, burn care professionals, and members of support organisations to ensure that the information presented was trustworthy, appropriate, and could meet the identified needs of parents (Heath, Williamson, Williams, & Harcourt, 2019). During the first 12 months of its public existence (17th October 2018 to 16th October 2019), the website SupportingChildrenWithBurns.co.uk was visited 2,316 times by 1,754 new users; an average of 174 visits per month. Users were located around the world with the top 5 countries from which the website was accessed being the UK (49.3%), USA (42.1%), Australia (2.9%), Canada (0.7%), and The Netherlands (0.5%). One hundred and sixty-six users navigated the website for over 10 minutes and a further 29 interacted with the website for over 30 minutes in one session.

For the first six months post-release (as part of the PhD research), the website contained a link to a survey which allowed users to provide feedback on their experience of using the website. Although relatively few users provided feedback (n = 27), that which was received was extremely positive;

SupportingChildrenWithBurns.co.uk was considered a highly acceptable and accessible psychosocial intervention.

Seventy-eight percent of SupportingChildrenWithBurns.co.uk users rated that they would be 'extremely likely' to recommend the website to others, with the remaining 22% stating that they would be 'likely' to recommend it. Some of those providing feedback also completed Part 2 of the eHealth Impact Questionnaire (Kelly, Jenkinson, & Ziebland, 2013). This questionnaire consists of three scales (26 items in total) asking for the participants views on the health-related website under examination. The three scales relate to: 1) Confidence and identification (this reflects confidence to discuss health with others and a person's ability to identify with the website), 2) Information and presentation (this reflects trust and suitability of website content), and 3) Understanding and motivation (this reflects understanding and learning about relevant information and motivation to take action). The responses to this questionnaire, although from a small self-selecting sample (n = 10), were overwhelmingly positive. Potential scores on each scale of the eHIQ-Part 2 ranged from 0-100, with higher scores indicating more positive responses. Median scores (and the interquartile range) for the scales were: 100 (11.81) for confidence and identification, 82.81 (12.50) for information and presentation, and 95.83 (13.89) for understanding and motivation.

In addition to this preliminary positive feedback in the public domain, the research contributing to the development of SupportingChildrenWithBurns.co.uk, and that evaluating its performance to date, has received oral presentation awards from the British Burn Association (2017) and the Australian and New Zealand Burn Association (2019) demonstrating the perceived value of this resource by professionals. It is believed that the website is an accessible online resource that allows staff to signpost parents and carers to information and support, which can be accessed in their own time, when they feel ready. SupportingChildrenWithBurns.co.uk could help to normalise parents' experience of their child's injury, reducing perceived isolation.

Hosting information and peers' personal experiences online offers promising and exciting opportunities to empower parents and carers, whilst providing advice to encourage self-care and formal or informal support seeking when necessary. Additionally, professionals can use parents' accounts, quotes, and videos to illustrate issues during pedagogic training. We hope your readers will agree that UK-based parents and professionals have contributed to an innovative patient-centred resource, tailored to meet the specific (sometimes unmet) needs of parents and carers of children with a burn injury, that is a valuable addition to paediatric burn care. We invite the dissemination of this resource as well as further evaluation of its impact on the emotional wellbeing of parents and carers following a child's burn-injury.

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