Research in Developmental Disabilities 34 (2013) 29–39

Contents lists available at SciVerse ScienceDirect

Research in Developmental Disabilities

How disabling are pediatric burns? Functional independence in Dutch pediatric patients with burns

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ARTICLE INFO

Article history:
Received 12 April 2012
Received in revised form 12 July 2012
Accepted 16 July 2012
Available online 30 August 2012

Keywords:
Disability evaluation
Pediatric
Burns
WeeFIM® instrument
Rehabilitation

ABSTRACT

Although the attention for functional outcomes after burn injury has grown over the past decades, little is known about functional independence in performing activities of daily living in children after burn injury. Therefore, in this prospective cohort study functional independence was measured by burn care professionals with the WeeFIM® instrument in 119 pediatric patients with burns (age: 6 months–16 years; 58.8% boys) in the Netherlands. In order to identify whether functional independence was affected, participants' total scores on the WeeFIM® instrument were compared to American norm values. Of the participants assessed at 2 weeks post burn ($n = 117$), 3 months post burn ($n = 68$) and/or 6 months post burn ($n = 38$), 22, 9 and 9 participants showed affected performance, respectively. Improvements in WeeFIM® total scores for the total study population between 2 weeks and 6 months post burn were significant (Wilcoxon $T = 2.5$; $p < .001$, effect size = −0.59). Individual improvements were found to be significant for 30.3% of the assessed participants between 2 weeks and 3 months post burn, and for 12.1% between 3 and 6 months post burn. This study is unique in providing data on functional independence for this large and special population. However, a proportion of participants were lost to follow-up and the use of the WeeFIM® instrument in this specific population and setting has its limitations. To conclude, burn injury impacts functional independence in children, yet the vast majority of Dutch pediatric patients with burns returns to functional independence typical for age within 6 months post burn.

1. Introduction

Worldwide, millions of people get burned and many of them are children. In the United States (US) 33% of the patients with burns are under 20 years of age (American Burn Association, 2010). Young children between 0 and 4 years of age form a high risk group for burn injuries; they account for approximately 18% of all patients with burns (American Burn Association, 2010; Ormel, 2010). Due to improvements in burn care and treatment over the past decades attention shifted from mortality to functional outcomes. It is well known that burn injuries have a major impact on physical and psychological health. Burn

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http://dx.doi.org/10.1016/j.ridd.2012.07.012

injuries are often followed by an extensive period of physiological assault, pain, medication, bedrest and surgeries, which can result in a decrease in physical fitness (Cree et al., 2009; Disseldorp, Nieuwenhuis, Van Baar & Mouton, 2011; Jeschke et al., 2011) and even continuing serious physical disability (Sheridan et al., 2000). Scarring as sequela of burns can cause itch, contractures, and (difficulties with) altered body appearance. The esthetical concerns, the traumatic nature of the burn accident and the painful wound treatments are factors that can affect psychological/psychosocial health (Van Baar et al., 2006; Van Loey & Van Son, 2003). Psychopathology and psychological problems are identified in a significant minority of burn patients (Van Loey & Van Son, 2003). Health-related quality of life remains limited throughout the first year after burn injuries in >50% of the Dutch and Flemish children with burns (Van Baar et al., 2011). Thus, children who get a burn injury during their childhood may suffer from persistent consequences throughout adolescence and adulthood.

Childhood is a very important period for development as in this period children acquire a lot of skills in several domains, like social, motor and cognitive functioning. Burn accidents are stressful life events that may cause disturbances in a child's development (Gorga et al., 1999). However, the extent to which a burn injury influences the development of a child's functional independence is yet unknown. For example, burn wounds and scarring of the skin can interfere with independent performance of activities in daily living, such as ambulation, dressing and toileting. To detect risk factors for limited functioning due to burns and to enable early intervention, it is important to determine the level of actual functional independence in pediatric patients with burns.

Nowadays, the WeeFIM® instrument is widely used to assess functional independence in pediatric rehabilitation patients and children with disabilities. It has been proven to be a reliable and valid instrument in various countries: e.g. the US (Ottenbacher et al., 1996), Japan (Liu, Toikawa, Seki, Domen, & Chino, 1998), Thailand (Jongjit et al., 2006), and Turkey (Aybay, Erkin, Elhan, Sirzai, & Ozel, 2007); and patient groups: e.g. children with developmental disabilities (Msall et al., 1994), cerebral palsy (Tur et al., 2009), and spinal muscle atrophy (Chung, Wong, & Ip, 2004). The WeeFIM® instrument evaluates the child's functional level of independence within a developmental context while requiring only a short assessment time. The instrument evaluates performance on daily living tasks in the domains of self-care, mobility and cognition. Performance is evaluated by the need for assistance from a device or helper, varying from total assistance to total independence, and is rated by certified professionals. As independence in activities of daily living increases during development, age-specific references are provided with the WeeFIM® instrument (Uniform Data System for Medical Rehabilitation [UDSMR], 2006). The utility of the WeeFIM® instrument to describe diminished functional capacity in severely burned children aged 6–16 years was reported by Serghiou et al. (2008). Recently, the feasibility and reliability of the WeeFIM® instrument had been established as well in Dutch pediatric burn patients; including children with minor burns and/or younger than 6 years of age (Niemeijer, Reinders-Messelink, Disseldorp, & Nieuwenhuis, 2012).

The objective of this observational prospective cohort study is to describe the level of functional independence in pediatric patients with burns in the Netherlands measured by the WeeFIM® instrument. It aims to identify whether children aged from 6 months up to and including 16 years are affected in their functional independence at 2 weeks, 3 months and 6 months post burn, related to the child's age and the extent of the burn. Additionally, this study will indicate whether the instrument is responsive enough to detect improvement over time in this specific population and setting.

2. Methods

2.1. Participants

Children were eligible for this observational prospective cohort study if they were aged from 6 months up to and including 16 years and admitted to a Dutch burn center for at least 24 h between September, 2009 and October, 2010. Patients were excluded if they had been admitted to the burn center more than 14 days post burn, if neither the child nor the parents had Dutch language proficiency and in the case that the child had previously been diagnosed mentally and/or physically disabled. In total, 86% of the eligible children from two Dutch burn centers were included (Niemeijer et al., 2012), which amounted to a total of 119 participants.

The medical ethical committees of the participating hospitals approved of this study.

2.2. Instrument

The WeeFIM® instrument (UDSMR, 2006) was used to measure functional independence. The WeeFIM® instrument measures functional independence within a developmental context in children aged 6 months to 7 years and can be used with children over the age of 7 as long as they exhibit delays in functional abilities (UDSMR, 2006). As depicted in Table 1, the WeeFIM® instrument consists of 18 items covering three domains. For each item (task), the performance is rated on a 7-level ordinal scale. The maximum rating of 7 represents complete independence in performing the task. The minimum rating of 1 represents performance with total assistance provided by others or no performance of this task. The total score on the WeeFIM® instrument is the sum of the 18 items' scores and ranges from 18 to 126 points.

Before the WeeFIM® instrument was implemented in Dutch burn centers it was translated into Dutch and culturally adapted, as described by Niemeijer et al. (2012). The Dutch version of UDSMR's official WeeFIM® Mastery Test had been taken and passed by all nine raters (Niemeijer et al., 2012). The translated instrument was found feasible and reliable for use in Dutch burn centers and this population of pediatric burn patients (Niemeijer et al., 2012).