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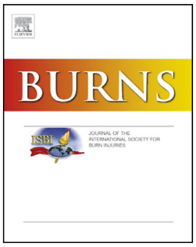

Perceived fatigue following pediatric burns

Moniek Akkerman [a,b,*], Leonora J. Mouton [b], Froukje Dijkstra [b], Anuschka S. Niemeijer [a,c], Marco van Brussel [d], Lucas H.V. van der Woude [b,e], Laurien M. Disseldorp [b], Marianne K. Nieuwenhuis [a,b]

[a] Association of Dutch Burn Centres, Burn Centre Martini Hospital, Groningen, The Netherlands
[b] University of Groningen, University Medical Centre Groningen, Centre for Human Movement Sciences, Groningen, The Netherlands
[c] Martini Academy, Martini Hospital, Groningen, The Netherlands
[d] Child Development & Exercise Centre, Wilhelmina Children's Hospital, University Medical Centre Utrecht, Utrecht, The Netherlands
[e] University of Groningen, University Medical Centre Groningen, Centre for Rehabilitation, Groningen, The Netherlands

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ABSTRACT

Purpose: Fatigue is a common consequence of numerous pediatric health conditions. In adult burn survivors, fatigue was found to be a major problem. The current cross-sectional study is aimed at determining the levels of perceived fatigue in pediatric burn survivors.

Methods: Perceived fatigue was assessed in 23 children and adolescents (15 boys and 8 girls, aged 6–18 years, with burns covering 10–46% of the total body surface area, 1–5 years post burn) using both child self- and parent proxy reports of the Pediatric Quality of Life Inventory Multidimensional Fatigue Scale. Outcomes were compared with reference values of non-burned peers.

Results: At group level, pediatric burn survivors did not report significantly more symptoms of fatigue than their non-burned peers. Individual assessments showed, however, that four children experienced substantial symptoms of fatigue according to the child self-reports, compared to ten children according to the parent proxy reports. Furthermore, parents reported significantly more symptoms of fatigue than the children themselves. Age, gender, extent of burn, length of hospital stay, and number of surgeries could not predict the level of perceived fatigue post-burn.

Conclusions: Our results suggest that fatigue is prevalent in at least part of the pediatric burn population after 1–5 years. However, the fact that parents reported significantly more symptoms of fatigue then the children themselves, hampers evident conclusions. It is essential for clinicians and therapists to consider both perspectives when evaluating pediatric fatigue after burn and to determine who needs special attention, the pediatric burn patient or its parent.

Abbreviations: TBSA, total body surface area; HRQOL, health-related quality of life; PedsQL MFS, Pediatric Quality of Life Inventory Multidimensional Fatigue Scale.

[*] *Corresponding author at*: Burn Centre Martini Hospital, P.O. Box 30.033, 9700 RM Groningen, The Netherlands.
E-mail address: m.akkerman@mzh.nl (M. Akkerman).

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1. Introduction

In the Netherlands, every year 700–800 patients are admitted to one of the three designated burn centres. Approximately 35% of this group is younger than 18 years of age [Dutch Burn Repository R3, 2015]. Burns suddenly disrupt daily life and are generally followed by extensive periods of hospital stay, dominated by painful wound treatments, and often accompanied by (multiple) surgical procedures. As survival rates have increased substantially over the past decades [1,2], it becomes more and more relevant to focus on long-term outcomes of health and quality of life of burn survivors. The ultimate goal of pediatric burn rehabilitation is to assist children in returning to their pre-injury functional status as soon as possible, while maximizing their emotional and cosmetic outcomes [3].

Fatigue is a commonly experienced consequence in numerous pediatric health conditions and has been associated with poorer functional outcome and diminished quality of life [4]. Fatigue can be defined as a '*persistent, overwhelming sense of tiredness, weakness or exhaustion, resulting in a decreased capacity for physical and/or mental work, which is unrelieved by sleep or rest*' [5,6]. In adult burn survivors, fatigue has been described as a major problem [7–9], even decades post burn [9]. An extreme sense of tiredness was reported to restrict their adjustment to daily life after burn [8,10]. Post burn fatigue might also limit children and adolescents in engaging in physical and cognitive daily activities, affecting their functional independence, school performance, peer relationships, sports participation, and social life. Additionally, restrictions in daily (physical) activities can have significant implications for cardiovascular health and associated diseases in the long term [11]. For these reasons, it is deemed important to evaluate functional outcome and health as well as perceived fatigue after pediatric burns. Surprisingly, fatigue has not been studied in this pediatric population thus far.

As the definition implies that fatigue is a subjective experience, it is preferably assessed using self-report. In pediatric populations, however, parents are also generally asked to report on their child's experience. The question is, how do parent proxy reports compare to those of their children? In the assessment of fatigue, imperfect agreement between child self- and parent proxy report has been frequently reported [12–19]. Previous studies in the pediatric burn population showed that parents tended to rate their child's health-related quality of life (HRQOL) [20,21] and psychological adjustment [22] worse than the children themselves. These findings highlight the importance in obtaining both perspectives when evaluating post burn fatigue.

The aim of the current cross-sectional study was therefore to determine the levels of perceived fatigue in pediatric burn survivors .5–5 years post burn, as reported by both the children and their parents.

2. Methods

2.1. Study population

Potentially eligible subjects were identified based on the Dutch Burn Repository R3. In the period from August till December 2012, children and adolescents aged 6–18 years were invited to participate if they had been admitted to one of the Dutch burn centres .5–5 years ago, with burns covering ≥10% of their total body surface area (TBSA), and/or a length of stay of more than six weeks. Furthermore, discharge and/or reconstructive surgeries had to be at least 2 months before the time of the assessment. Extensive (pre-existing) co morbidity, (mental) disabilities, and insufficient Dutch language proficiency, were criteria for exclusion. Written informed consent was obtained from all parents (or legal representatives) as well as from the subjects aged ≥12 years, before enrolment in the study. For subjects aged 18, parental informed consent was not required. The Medical Ethical Committee of the University Medical Centre Groningen approved this study (NL40183.042.12).

This study was part of a cross-sectional descriptive study on physical fitness and physical activity in children and adolescents after burn, as described by Disseldorp et al. [23]. The total study involved the assessment of physical fitness, physical activity, fatigue, and HRQOL; study procedures were described previously in detail [23]. For all subjects, age, gender, extent of burn, location of burns, presence of inhalation injury, number of surgeries and dates of the burn incident, admission and discharge were obtained from the Dutch Burn Repository R3.

2.2. Data collection and analysis

Perceived fatigue was assessed using the Dutch version [12] of the 18-item Pediatric Quality of Life Inventory Multidimensional Fatigue Scale (PedsQL MFS) [14], according to best evidence [24]. The PedsQL MFS was specifically designed to measure child and parent perceptions of fatigue in pediatric patients [14] and has been used in a variety of pediatric health conditions, including cancer [19,25], sickle cell disease [18], obesity [17], diabetes [16], arthritis [15,26], and hearing loss [27]. The Dutch version was shown to be valid and reliable, and Dutch reference values are available [12]. These fairly recent reference values (2011) were attained from 366 child reports and 393 parent reports of Dutch children and adolescents aged 5–18 years. Both child self- and parent proxy reports were obtained and scores were presented separately for three age categories: 5–7 (young child), 8–12 (child), and 13–18 (adolescent) years old [12].

The PedsQL MFS covers three subdomains: (1) General Fatigue (6 items, e.g., 'I feel tired', 'I feel too tired to do things that I like to do'), (2) Sleep/Rest fatigue (6 items, e.g., 'I feel tired when I wake up in the morning', 'I rest a lot') and (3) Cognitive Fatigue (6 items, e.g., 'It is hard for me to keep my attention on things', 'It is hard for me to remember what people just told me') [14].

The PedsQL MFS comprises parallel child self-report and parent proxy report forms [14]. Three versions of the child self-report forms were used corresponding to the three age categories: 5–7 (young child), 8–12 (child), and 13–18 (adolescent) years old. The parent proxy report form, designed to assess the parent's perceptions of their child's fatigue, was taken parallel to the child self-report forms. Items for each of the forms were essentially identical, differing only in developmentally appropriate language, or first or third person [15].

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