On physical functioning after pediatric burns

Physical fitness and functional independence

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Chapter 1  General introduction


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Chapter 6  Summary + General discussion
Chapter 1. General introduction

Burns are a global public health problem. A burn injury is one of the most traumatic injuries a person can live through and burns and their management were already documented in cave paintings from more than 3,500 years ago. Knowledge and treatment have evidently evolved through the ages and, over the last decades in particular, this has led to an enormous increase of the survival rate in patients with burns. Since more patients survive, including those with very extensive burns, the focus in burn care and research has expanded towards the life after burns in order to enhance quality of life, for example through improving scar outcomes and/or physical functioning. This is in line with the present trend which emphasizes the importance of physical fitness and physical activity in people of all ages, in both health and disease (among others: ). Physical functioning after (pediatric) burns is a relatively unexplored research area in which clinically relevant progress can be made. The Association of Dutch Burn Centers, as one of the few institutes worldwide to address this issue, initiated a unique multidimensional research program from which first results are brought together in this dissertation. This introductory chapter will provide information on burns, the consequences of burns and on physical functioning within this context and, at the end, a brief outline of this dissertation is presented.

Burns

A burn is an injury that destroys layers of the skin by exposure to heat, chemicals, electricity or radiation. Burn injury can vary from very mild to very severe. The severity of a burn injury depends on the extent of burn, the depth of the injury and the location of the injury, as well as on patient characteristics. The extent of burn is expressed as the percentage of the total body surface area (% TBSA) involved. As a reference: the size of a persons’ handprint (including the palm and fingers) is approximately 1% of their TBSA. In the Netherlands most burns are <5% TBSA and about a quarter are 6-10% TBSA, whereas burns >40% TBSA are scarce, especially among children. The terms minor, moderate and major burns refer, in this dissertation, primarily to the extent of burn. The depth of the injury reflects the damage of skin tissue and depends on the temperature, the duration of exposure to heat and the cause of the injury. In superficial partial thickness burns and deep partial thickness burns, a part of the dermis is destroyed, whereas in full-thickness burns the dermis is completely destroyed and sub-dermal tissues like fat, muscle and bone can be damaged as well. Most burns are heterogeneous in depth. With regard to healing, superficial partial thickness burns will in general heal within 14–21 days without surgery. In contrast, in areas with deep partial thickness and/or full-thickness burns spontaneous skin regeneration would take too long or is not
possible. Consequently, surgical treatment is required. The location of the injury is especially of relevance when the injury is in a functional or otherwise particular area, like involving a joint, the face, hand or genitals. Patient characteristics like age, i.e. very young or elderly patients, or health status, e.g. comorbidity, can be of relevance as well to the impact of the burn injury. As each burn patient and each burn injury is different, personalized and specialized care are essential.

**Epidemiology & treatment**

Worldwide it is estimated that each year almost 11 million people require burn-related medical attention and 265,000 people die as a result of burns. In the Netherlands about 65,000 people are injured by burns every year and these injuries are most often scalds (54%), which means that the injuries are caused by skin contact with hot liquids or gasses. The most common example is the child that pulls a cup of tea or soup from the table or kitchen counter, causing scalds on the upper body. Other causes are skin contact with a hot object (15%), fire or flames (13%), explosions (5%) or chemical substances (4%).

As burns vary from very mild to severe injury, only a part requires professional treatment. Emergency departments in the Netherlands treat on average 10,100 inhabitants per year, of which 78% for burns due to home and leisure accidents (52% male) and 22% due to occupational accidents (72% male). About 1,700 patients per year require hospital admission. A smaller number of patients with burns require specialized care in a burn center. Referral criteria for a burn center include a.o. the extent of burn, (>5% TBSA (children) or >10% TBSA (adults)), deep burns and/or burns in particular areas like the face or hands, but also doubt regarding the circumstances of injury (i.e. child abuse). The three dedicated burn centers in the Netherlands, located in Beverwijk, Rotterdam and Groningen, treat ±2,000 people in the outpatient clinic and additionally admit ±750 patients. In these burn centers multidisciplinary teams including a.o. burn physicians, surgeons, nurses, physical and occupational therapists, psychiatrists, nutritionists, psychologists and child life specialists provide specialized care and treatment. In the acute phase, for example, this may consist of fluid resuscitation as well as wound care including ointments, dressings and in deep burns also surgery, which mostly involves wound excision followed by skin grafting. Pain interventions are vital, especially for the wound dressing changes. Furthermore, specialized care is important in rehabilitation, psychosocial support and after care. Rehabilitation is mainly performed by physical and occupational therapists, who are involved from early after admission. Much attention is also paid to after care, since burns may leave noticeable scars and often have a psychosocial impact. For instance, children are supported in their return to school by burn center staff, e.g. to enhance acceptance of the child with his/her new appearance by the social surroundings.

Social support is also provided apart from the burn center by several organizations, for instance...
(pediatric) burns camps are organized to facilitate companionship with other burn survivors and to enhance self-esteem on top of having pleasure and fun.²⁸

**Pediatric burns**

Children form an important subgroup in burn care and research. Young children in the age of 0-4 years are more often treated than any other age group and account for 25% of the burn center admissions.²⁴ Young children’s natural curiosity, motor immaturity and/or incapability to recognize a dangerous situation and its consequences, make that children form an important risk group for burn accidents. Besides that, their young skin is thinner and their physiology is more delicate during growth and physical maturation. A certain thermal impact can thus have more impact on children than on adults, e.g. resulting in a deeper burn and/or more severe illness.

For Dutch children with burns, the median length of stay in the burn center is 7-10 days, with 30% of the preschool- and 46% of school-aged children hospitalized for 14 days or longer.²⁹

Lastly, burn consequences will persist from childhood through adolescence to adulthood. For example, pediatric burn patients are at risk for scar contractures causing discomfort and diminished flexibility later in life, because their body grows but their scars do not.³⁰ To release such contractures, reconstructive surgery is often necessary. To prevent difficulties later in life, adequate medical care and psychosocial support are essential in the pediatric burn population.

**Physical consequences of burns**

The skin is the largest organ in the human body. Skin is important for esthetic appearance, but its most important functions are protection against pathogens and damage, regulation of fluid evaporation, sensation, thermoregulation and its role in the immune system. Burns interfere with all functions of the skin as well as with other physiological processes and physical functions, which will be pointed out subsequently.

The most well-known consequence of burns is (severe) scarring. Scars are areas of fibrous tissue that replace the normal skin after wound repair. Scars can have an aberrant color and increased thickness or relief. Scar maturation may take as long as two years. During this period, burn patients (of all ages) are at risk for development of scar contractures. Besides the esthetic outcomes, scars affect other functions of the skin in the longer term. For instance, sensation is changed and the regulation of body temperature can be affected as evaporation is reduced in scar tissue and sweat glands do not grow back after deep burns.

Less well-known is the variety of both local and systemic physiological responses after extensive burns. Although many of these responses contribute to combating infection or to forming skin or scar tissue, some of the associated metabolic and hormonal changes interfere with the musculoskeletal
and cardiovascular systems, the immune system and/or organ function.\textsuperscript{31} An extensive description of the pathophysiological impact goes beyond the scope of this introduction, but since there is growing evidence that it can negatively affect patient recovery, long-term outcomes and future morbidity after burns\textsuperscript{32-35}, the most relevant effects will be briefly described: hypermetabolism and muscle catabolism.

The pathophysiologic response after extensive burns is initiated by the release of inflammatory mediators and stress hormones and depends inter alia on the extent of burn and genetics.\textsuperscript{22} Elevated levels of catabolic hormones like catecholamines, such as epinephrine and cortisol, cause hypermetabolism. In a severe hypermetabolic state the patient’s heart rate, blood pressure (circulation) and oxygen and glucose consumption are elevated (e.g. high energy expenditure), and it can lead to insulin resistance and loss of bone density.\textsuperscript{32, 34} Hypermetabolism can persist for over one year post burn.\textsuperscript{36} The second serious effect relevant for this dissertation is muscle protein degradation. In this catabolic burn response lean body mass is sacrificed to mobilize proteins and amino acids, in order to meet the immense energy requirements and metabolic demands (i.e. for wound healing).\textsuperscript{37} This results in substantial loss of skeletal muscle, and thus muscle strength, but also in impaired immune function and wound healing.\textsuperscript{22, 31, 38} After extensive pediatric burns, muscle catabolism was found to persist at least nine months post burn.\textsuperscript{39}

**Physical functioning**

Physical functioning stands for the ability to function without limitations in the course of daily life and comprises those activities identified by an individual as essential to support his/her physical, social, and psychological well-being.\textsuperscript{40} In this dissertation, physical functioning is operationalized as (levels of) functional independence and physical fitness in a pediatric population. In this context functional independence reflects one’s performance (what someone really does; behavior in daily life), whereas physical fitness mainly reflects one’s capacities (what someone is capable of; maximal achievement, often measured in a laboratory setting).

Functional independence, firstly, refers to the level of independency in the execution of tasks of daily living; e.g. does the child bathe and dress itself, without parental assistance? Acquiring functional independence is an essential part of childhood development, alike the acquaintance of skills in the motor, social, and cognitive domains. However, functional independence is not only related to the child’s capacities, but also influenced by environmental and social factors.
Table 1. Glossary of terms: definitions by Caspersen, Powell & Christenson (1985)

| Physical fitness: A set of attributes that people have or achieve relating to their ability to perform physical activity. |
| Physical activity: Any bodily movement produced by skeletal muscles that results in energy expenditure. |
| Body composition: A health-related component of physical fitness that relates to the relative amounts of muscle, fat, bone and other vital parts of the body. |
| Muscular strength: A health-related component of physical fitness that relates to the amount of external force that a muscle can exert. |
| Muscular endurance: A health-related component of physical fitness that relates to the ability of muscle groups to exert external force for many repetitions or successive exertions. |
| Flexibility: A health-related component of physical fitness that relates to the range of motion available at a joint. |
| Cardiorespiratory endurance: A health-related component of physical fitness that relates to the ability of the circulatory and respiratory systems to supply fuel during sustained physical activity and to eliminate fatigue products after supplying fuel. |

Physical fitness, secondly, is defined as a set of attributes that people have or achieve relating to their ability to perform physical activity, see Table 1. This dissertation focuses on health-related components of physical fitness: body composition, muscular strength, muscular endurance, cardiorespiratory endurance and flexibility, see Table 1. All components are required for activities of daily living. Moreover, a good level of physical fitness is related to a lower risk of illness and an improved quality of life. In particular, the component ‘cardiorespiratory endurance’ is considered one of the most important health markers, as well as a predictor of morbidity and mortality and it is often used as equivalent for ‘physical fitness’. It is mostly measured as aerobic capacity (maximum amount of oxygen consumed by the body during intense exercises in a given time frame) in a graded cardiorespiratory exercise test. In clinical research, this is thought of as an integrated measure of the functional status of most systems in the body, e.g. the skeletomuscular, cardiorespiratory, psychoneurological and metabolic system, which are all challenged during the exercise test. Note that since all components of physical fitness are involved, deficits in each component can influence the outcome.

The concept of physical functioning is primarily used to describe patient outcome. After disease or trauma, limitations in physical functioning are highly prevalent. Patients of all sorts are at risk to get into the so-called negative spiral of deconditioning as depicted in Figure 1, where illness leads consecutively to inactivity, to ongoing deconditioning and deterioration of functioning and, finally, can lead to disability. Besides the deconditioning effects of inactivity, e.g. a decrease in aerobic capacity and muscle atrophy, the local or systemic effects of the disease or injury also affect physical functioning.
The spiral of deconditioning is highly undesirable, especially during childhood and adolescence since these are crucial periods to set a solid physical foundation and to adopt a healthy, active lifestyle which can help prevent disease and deficits later in life. Moreover, limitations in physical functioning are linked to a decreased quality of life, increased risk of disability and depression, and increased health care costs and should therefore be prevented or resolved.45

Physical functioning after burns

Functional independence
Pediatric burns can cause disturbances in a child’s development and thus in functional independence.47 In the short term burn wounds or scarring of the skin interfere with independent performance of activities in daily living (ADL), such as ambulation, dressing and toileting. Furthermore, clinical practice shows that the stress, guilt and anxiety that parents experience after their child’s burn injury48 results in overprotectiveness and pampering by some parents. When parents take over, this limits the child in its (development of) functional independence. Influence of parental factors on functional outcome has been reported before.49 Even in the long term, difficulties in the performance of ADL were reported to be persistent after pediatric burns.50, 51

Physical fitness
Physical fitness is likely to be negatively affected by (the combination of) prolonged hospitalization and the consequences of the injury itself.52, 53 Even when bed rest is not prescribed the possibilities for physical activity are limited during hospitalization due to risk of infection, immobilization/positioning after skin grafting, medication, pain, fear of movement and/or fatigue. The consequences of burn injury can affect all components of physical fitness, which will be briefly described per component.

Body composition
Decreased values of bone mineral content, lean body mass (muscle) and fat mass were found up to three years after extensive burn injury, mainly due to persistent hypermetabolism and protein catabolism.36, 39 Regarding anthropometry, growth delays in both height and weight were observed in children even two to three years after extensive burns36, 54, as a consequence of the altered energy expenditure. In addition to the physiological impact, altered nutrition and activity patterns as a result of admission after burn injury could lead to changes in lean mass and fat mass proportions.

Muscular strength & muscular endurance
Great loss of muscular mass and muscular strength was demonstrated in people with extensive burns, under influence of both the persisting skeletal muscle catabolism and disuse.39 O’Neill et al
showed in mice that even burns of 8% TBSA significantly affect skeletal muscle, which implicates that this might be of serious concern after minor to moderate burns in humans as well. Recent studies also suggest impact of burns on muscle function in humans, even in skeletal muscle of a non-burned limb, due to reductions in mitochondrial content and function or gene expression, but comprehension of these processes is still incomplete. With respect to physical inactivity during hospitalization, note that skeletal muscle mass already declines substantially after only 5 days of disuse.

**Cardiorespiratory endurance**

Aerobic capacity can be affected by burn injury, for instance owing to decreased muscular strength and/or the higher absolute energy requirements. Also, note that the cardiopulmonary system itself can also be affected in patients with burns. Williams et al. found cardiac stress to persist for at least two years after pediatric burn injury >40% TBSA. For example, the significantly elevated heart rate could hasten exhaustion during physical activity and decrease aerobic capacity. Furthermore, lung tissue can be damaged by smoke inhalation injury or artificial respiration, hampering oxygen uptake. Abnormal lung function was detected in a majority of children with inhalation injury, provoking that a certain level of exercise puts a greater demand on the respiratory system.

**Flexibility**

In the acute phase, pain, edema and avoidance behavior can result in a diminished flexibility around joints involved in a burn injury. Later on, during the first two years post burn, there is the risk of development of scar contractures, which bring discomfort and limit the range of motion of joints, or even deform normal anatomical structures. Pediatric burn patients additionally risk late onset contractures due to bodily growth.

**Further consequences of burn injury**

**Psychosocial impact**

Burn injuries are deemed one of the most traumatic injuries, for instance due to the sudden occurrence of the injury, a hospitalization characterized by pain, isolation and uncertainties, plus the additional burden of permanent scarring, with altered appearance and potential functional limitations. Burns are known to cause long-term psychological problems, such as emotional distress, anxiety, depression and difficulties with social functioning. Further, as burns often result in disfigurements, dissatisfaction with appearance is common, especially when scars are in visible areas, and so are changes in body-image, sexuality and relationships. Psychological problems and physical problems after burns were reported to be related. This dissertation will not attend to the
matter of psychosocial issues any further than acknowledging that these can influence physical outcomes.

**Physical activity and participation barriers**

It is well-known that physical activity is essential to maintain and/or improve the level of physical fitness. After burns, physical activity might advance the restoration of physical fitness and functioning. This can be essential to retain a satisfactory quality of life, for instance by facilitating independency in daily living and reintegration into society. Indeed, results of implementation of physical activity during the rehabilitation process after extensive burn injury are promising: structured exercise programs starting at discharge led to significant improvements on all components of physical fitness and on pulmonary function after 12 weeks, and the number of surgical scar releases was reduced.66-68

Daily physical activity can be at least as important as a structured exercise program in the restoration of physical functioning after burns, especially in children who generally spend a large share of their time on participation in school, play, sports and other hobbies. However, burn injury can negatively affect the activity participation of children, as recently found by Grice et al. (2014).69 The decrease in physical activity participation in subjects with burns (3%-40% TBSA) could be attributed to multiple physical and psychosocial barriers.69 Parents perceived ‘attitudes of others’ and ‘self-consciousness about appearance’ as two primary factors that prevented their children from participation in activities.69 Lack of self-esteem and confidence was suggested as explanation for the fact that children engage less in ‘formal activities’, like organized sports, than in ‘informal activities’, which are mostly home-based.69 Baldwin et al. (2013) reported that barriers to exercise were experienced by 76% of adult burn survivors, with poor physical condition identified as a main barrier.70 In pediatric burn patients the negative experience of feeling physically weak and deconditioned after burns and a low body-esteem could be discouraging for activity participation as well. There have been a few more studies that reported reduced participation in hobbies or leisure-related physical activity, even after minor burns, in both short- and long-term64, 71, but conclusive evidence is lacking.71

**Health-related quality of life**

Health-related quality of life is a measure that combines experienced physical, psychological and social aspects of functioning and well-being.72, 73 Health-related quality of life is deemed a very relevant outcome after burns. Therefore, questionnaires on health-related quality of life are widely used in burn research, comprising subscales like pain, itch, appearance, emotional health and physical function and sports. Although international results are very diverse, Van Baar et al. (2011) reported that >50% of Dutch and Flemish children after burns experienced long-term limitations in health-related quality of life.74
Fatigue
Fatigue is a very common complaint after burn injury\textsuperscript{75}, but it is scarcely studied.\textsuperscript{76} Fatigue can be caused by and experienced in both physical as well as mental processes, and thus can seriously impact one’s daily functioning.\textsuperscript{77} A 3-year outcome study referred to by Helm, Hendron & deLateur\textsuperscript{5} revealed fatigue as major barrier to return to daily activities after major burns. Fatigue was also described by patients with minor burns.\textsuperscript{78} Causal processes for fatigue after burns are yet unknown, but hypermetabolism, sequelae of surgeries and sleep deprivation, that was found to persist for years after severe pediatric burns, might be related. Since sleep deprivation is also known to negatively impact exercise tolerance, it is suggested that sleep deprivation might also affect physical performance after burns.\textsuperscript{76}

Aim and outline of this dissertation
This dissertation aims to enlarge the knowledge on physical functioning after burns. More specifically, it aims to uncover current outcomes in Dutch pediatric burn patients in the domains of functional independence and physical fitness after burns. Transferred to clinical practice, knowledge could contribute to optimize outcomes with respect to functioning.

In Chapter 2 the focus is on functioning shortly after burns. How do the pediatric burn patients perform on tasks of daily living during the first six months post burn? In this chapter, the level of functional independency in the domains of self-care, mobility and cognition in pediatric burn patients aged 0.5-16 years as measured with the WeeFIM\textsuperscript{©} instrument, is described.

Then, the focus turns to longer term functioning for the next chapters, in which the central theme is physical fitness after burns. In Chapter 3, the literature on physical fitness after burns is reviewed systematically to examine and appraise findings of earlier studies. The primary aim of this review is to gain insight into the physical fitness of people after burn injury compared with healthy subjects. As the review shows that the current knowledge was incomplete and not generalizable to a burn population like the Dutch, our group sets up multidimensional research on physical fitness, also comprising physical activity, health-related quality of life and fatigue in children and adolescents after burns in the Netherlands. In Chapter 4 the rationale behind this cross-sectional study is explained by means of a conceptual model and the objectives and methods of the study are extensively described. Eligible subjects are children and adolescents aged 6-18 who had been admitted to a Dutch burn center with burns of at least 10% TBSA, between six months and five years ago. Physical fitness assessments take place in a mobile exercise lab. The results on aerobic capacity, muscular strength and body composition are described in Chapter 5. The final section, Chapter 6, comprises of a summary of the findings and a general discussion.
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How disabling are pediatric burns?
Functional independence in Dutch pediatric patients with burns.


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

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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.

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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
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, Tokikawa, 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 (Niemiejer, 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 (Niemiejer 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).
Dutch norm values for the WeeFIM® instrument are not available. American norm values, given as means and standard deviations, are provided with the clinical guide of the WeeFIM® instrument (UDSMR, 2006). These norm values are based on data of American children aged from 6 months till 83+ months (≈7 years) with no documented developmental delay or disability and provided per interval of 3 months.

2.3. Procedure

Demographic information was registered for each participant, as well as injury characteristics like the extent of the burn. The extent of a burn is expressed in percentage total body surface area (% TBSA) involved in the burn, estimated by a burn physician. Additionally, the number of surgeries and length of stay in hospital were registered. It was also registered whether the child wore pressure garments, since this can hamper independence in dressing.

The assessments of functional independence using the WeeFIM® instrument took place at approximately 2 weeks and at approximately 3 and 6 months post burn. The assessments were done by burn care professionals (nurses, nurse practitioners, child life specialists, occupational and physical therapists) or research staff (human movement and health scientists, physicians, research nurses) working at the burn center, depending on availability. For inpatients, the assessments were done through direct observation of the child or by interviewing the child’s primary care givers. For outpatients all WeeFIM® assessments were completed based on interviews taken at follow-up appointments with the nurse practitioner or burn physician. Depending on the communicative skills of the child, the information necessary for the WeeFIM® assessment was acquired from the child and/or from his/her parents.

2.4. Analyses

2.4.1. Identifying affected functional independence

To judge whether or not the functional independence of a Dutch pediatric patient with burn injury was affected, his/her score on the WeeFIM® instrument was equated to the American norm value specific for this child’s age (in months) at the time of assessment. First, the American norm values for mean scores and standard deviations, which showed big fluctuations, were manually adapted to smooth lines. Second, those norms were complemented, carrying through the maximum scores of the 7-year-olds (ceiling) to encompass the age of 16. Third, the norm means and standard deviations were jointly plotted with the collected data against age in months. Theoretically, the number of children scoring at or below the line that represents a score of one standard deviation below the mean norm score for age, is expected to be 16% of the population (‘p16’). Scores above this so-called 16th percentile line are considered as typical functional independence for age; scores at or below the 16th percentile line possibly indicate atypical performance on daily activities. Lastly, the standard error of measurement (SEM) of 3.7 points on the WeeFIM® total scores was taken into account to determine at which point functional independence was significantly deviant from the norm (1.96*SEM; Niemeijer et al., 2012). In the present study, a child’s functional independence was considered affected if his/her total score on the WeeFIM® scale (range: 18–126 points), was 8 points or more below the 16th percentile line.

2.4.2. Subgroups

Participants were firstly allocated to three age groups based on their age in months at first assessment. These age groups will be referred to as ‘Young’ (6–35 months), ‘Middle’ (36–83 months) and ‘Older’ (≥84 months). This grouping is related to the course of the norm values. From 6 to 35 months old the provided means show a strong rise and the standard deviations are mainly large and variable. Further, the provided norms stop at ‘83’ months of age; this equals the age of 7 years. From that point children are supposed to attain the maximum score on the WeeFIM® instrument (UDSMR, 2006). In addition to group for age, participants were divided into three groups based on the extent of their burn, i.e. burns involving ≤5% TBSA, 6–10% TBSA, or >10% TBSA.

2.4.3. Statistics

Wilcoxon signed rank tests were applied on group results to determine improvements in functioning over time. Since children were expected to get higher WeeFIM® total scores over time, due to development and/or recovery of the burn
injury, one-tailed tests were used with a significance level of 5%. Effect sizes ($r$) were calculated for improvement over time and interpreted according to Cohen’s benchmarks (Cohen, 1988): $r = .10$ represents a small change, $r = .30$ represents a medium change and $r = .50$ represents a large change. Effect size statistics have been widely recommended for use as indicators for responsiveness (Husted, Cook, Farewell & Gladman, 2000).

To determine individual change in functional independence over time the difference in WeeFIM® total score between two assessments was evaluated. The least detectable difference (LDD), calculated with the standard error of measurement and a significance level of 5%, is 11 points ($\sqrt{2} \times 1.96 \times \text{SEM}$; Niemeijer et al., 2012). A statistically significant change was therefore defined as a gain or decrease of at least 11 points ($\geq 1 \text{LDD}$) on the WeeFIM® total score (Niemeijer et al., 2012). The changes over time, compared to the LDD, would provide information on whether the WeeFIM® instrument is responsive in this specific setting and population.

IBM SPSS Statistics version 17 was used for analyses. Microsoft Excel was used to produce graphs. Outliers were not excluded from analyses, nor were regression or other analyses based on averaged scores used in order to preserve the information outliers could provide. Participants who were considered affected and/or who showed remarkable development over time were described.

3. Results

3.1. Participants

The age of the 119 participants at time of admission ranged from 0 to 16 years and 70 of them (58.8%) were boys. The age group ‘young’ included 61.3% of the population (54.8% boys), the group ‘middle’ 14.3% (47.1% boys) and the group ‘older’ included 24.4% (76% boys). The extent of the burns varied from 0.4% TBSA to 72% TBSA. The subgroups with extent of burn $\leq 5\%$ TBSA, 5–10% TBSA and $> 10\%$ TBSA comprised 63%, 23.5% and 13.4% of the participants, respectively. Length of stay in the hospital was less than a week for more than 50% of the patients. In total, 27 of the participants (22.7%) underwent surgery, of whom 22 participants (82.1% of this selection) underwent surgery once.

3.2. Evaluation of functional independence

3.2.1. Group evaluations

In total, 223 WeeFIM® assessments were done for the 119 participants in this study. Of all participants 98.3% were assessed 2 weeks post burn (Fig. 1); 57.1% at 3 months post burn (Fig. 2) and 31.9% at 6 months post burn (Fig. 3). For 31 participants (26.1%) assessments were available at all three time points.

![Fig. 1. The WeeFIM® total scores at 2 weeks post burn for each participant plotted against age, displayed against the American norm values and with indications of the different subgroups based on extent of burn and age. TBSA, total body surface area; Young, 6–35 months; Middle, 36–83 months; Older, $\geq 84$ months.](image-url)
Children of similar ages showed large differences in WeeFIM scores at 2 weeks post burn (Fig. 1). The performance of 22 children (18.5% of the total study population) was affected (Table 2). At 3 months post burn nine children (7.6% of the total study population) showed affected functional independence (Fig. 2 and Table 2). At 6 months post burn nine children (7.6% of the total study population) were affected (Fig. 3 and Table 2).

Fig. 2. The WeeFIM total scores at 3 months post burn for each participant plotted against age, displayed against the American norm values and with indications of the different subgroups based on extent of burn and age. TBSA, total body surface area; Young, 6–35 months; Middle, 36–83 months; Older, ≥84 months.

Fig. 3. The WeeFIM total scores at 6 months post burn for each participant plotted against age, displayed against the American norm values and with indications of the different subgroups based on extent of burn and age. TBSA, total body surface area; Young, 6–35 months; Middle, 36–83 months; Older, ≥84 months.
3.2.2. Evaluation per subgroup

The ‘young’ children formed the largest subgroup and the variability in scores in this group was large; at first assessment scores ranged from 18 to 101 points, though at 6 months post burn scores ranged from 26 to 68. This group included the highest number of affected children at each time of assessment. The age group ‘middle’ comprised few children and variability in scores was smaller; at first assessment scores ranged from 18 to 101 points, though at 6 months post burn scores ranged from 26 to 68. This group included the fewest affected children. In the group with burns 10% TBSA, eight children were affected in their functional independence at 2 weeks post burn, of which four were still hospitalized at the time of assessment (Table 2). At 3 and 6 months all ‘older’ children functioned within normal limits, except for one outlier: a boy with 72% TBSA who was still hospitalized (Table 2). Scores in the group ranged from 18–126 at first assessment to 92–126 at third assessment; the lowest values were scored by this outlier.

The group with burns ≤5% TBSA included by far the highest number of children, of which the majority were part of the youngest age group. The group with 6–10% TBSA comprised the fewest affected children. In the group of children with burns >10% TBSA, eight children were affected in their functional independence at 2 weeks post burn and four children were affected at 6 months post burn. Thus, this group had a relatively higher number of affected children than the other groups.

3.2.3. Evaluation of affected subjects

To gain information on factors influencing functional independence, the cases of the 31 children (41.9% boys) that were affected at least one assessment were analyzed in detail. Of this selection, 61.3% were from the ‘young’ age group and 61.3% had burns involving ≤5% TBSA; these percentages were equal to those in the total population. In the selection of affected children the percentages of children with burns >10% TBSA and of those who underwent surgery were 29% and 38.7%, respectively; in the total study population these percentages were 13.4% and 22.7%. The median for length of stay in the hospital was 12 days in the affected group, while in the total study population the median was 6 days.

Four children showed affected functional independence at all three assessments. Three of them had extensive burns located at the trunk (front and back), the arms and the legs. Their ages were 2, 2 and 16 years, the burns involved 28.5%, 29% and 72% TBSA and these children underwent 1, 2 and 15 surgeries, respectively. All three had to wear pressure garments after discharge. The fourth child was a 1-year old with superficial burns involving 4% TBSA. The child was hospitalized for 16 days and did not need surgery nor pressure garments after discharge. Misinterpretation of the level of independence is not likely since the assessments were done by three different raters. On the score form the raters wrote the following remarks: “This child is from an immigrant family and culture plays an important role in her functioning. Almost everything is taken care of by the care givers, so the child is not stimulated to function independently.” At the third assessment the mother told the assessor that the child functioned as he/she had done before the injury. The score for functional independence of this third assessment was significantly below the mean norm score for the child’s age.

3.3. Change over time

3.3.1. Group analyses

The total population showed significant improvements in WeeFIM® total scores for each time interval and so did the age groups ‘young’ and ‘older’ (Table 3). The effect sizes indicate medium to large changes in WeeFIM® total scores over time (Table 3).
3.3.2. Individual changes between 2 weeks and 3 months post burn

Of the 66 children who were assessed at 2 weeks post burn as well as at 3 months post burn, 56 had higher WeeFIM$^\text{1}\text{ total}$ scores on the second assessment (Table 4). For 20 of these 56 children (30.3%), this improvement in score was one LDD or more and therefore statistically significant. Ten children showed decreased scores at the second assessment. All ten had scored within norm values at the first assessment (Table 4). For three of these ten children the decrease was statistically significant. None of these three was hospitalized at any time of assessment, nor did they undergo surgery, nor did they wear pressure garments. Of these three, the first child – to describe here – was a 1-year old boy with burns involving 5% TBSA. He scored sufficiently at first assessment, then declined 15 points at second assessment, and returned to non-affected performance at third assessment. The second child was a 3-year old girl suffering burns of 3% TBSA. Her performance was non-affected at first assessment, but with a decrease of 33 points her performance was affected at second assessment. There were no remarks and the girl was not assessed at 6 months post burn. The third child was a 1-year old boy with a burn involving 1% TBSA who scored 13 points above his norm value at first assessment. Despite the fact that his score declined 20 points at second assessment, it remained within normal limits. He was not assessed at 6 months post burn. Overall, scores of most children changed less than one LDD. The majority of children maintained non-affected scores or changed to scoring within normal limits for age between 2 weeks and 3 months post burn.

<table>
<thead>
<tr>
<th></th>
<th>2 weeks–3 months</th>
<th>3 months–6 months</th>
<th>2 weeks – 6 months</th>
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<tr>
<td></td>
<td>$T$</td>
<td>$p$</td>
<td>$r$</td>
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<tr>
<td>Young</td>
<td>111.5</td>
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<td>–.38</td>
</tr>
<tr>
<td>Middle</td>
<td>9.5</td>
<td>.117</td>
<td>–.27</td>
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<tr>
<td>Older</td>
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<td>&lt;.001</td>
<td>–.56</td>
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<tr>
<td>Total</td>
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<td>&lt;.001</td>
<td>–.42</td>
</tr>
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</table>

$T$, test value for Wilcoxon Signed Rank Test; $p$, one-tailed significance value; $r$, effect size.

Table 4

<table>
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<tr>
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<th>Stays nonaffected</th>
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<th>Stays affected</th>
<th>Nonaffected to affected</th>
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<td>Improvement</td>
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<td>0</td>
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<td>3</td>
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<tr>
<td>Total</td>
<td>51</td>
<td>7</td>
<td>4</td>
<td>4</td>
<td>66</td>
</tr>
</tbody>
</table>

Affected, total score ≥ 8 points below 16th percentile line; LDD, least detectable difference (changes > 1 LDD are significant).

3.3.2. Individual changes between 2 weeks and 3 months post burn

Of the 66 children who were assessed at 2 weeks post burn as well as at 3 months post burn, 56 had higher WeeFIM$^\text{1}\text{ total}$ scores on the second assessment (Table 4). For 20 of these 56 children (30.3%), this improvement in score was one LDD or more and therefore statistically significant. Ten children showed decreased scores at the second assessment. All ten had scored within norm values at the first assessment (Table 4). For three of these ten children the decrease was statistically significant. None of these three was hospitalized at any time of assessment, nor did they undergo surgery, nor did they wear pressure garments. Of these three, the first child – to describe here – was a 1-year old boy with burns involving 5% TBSA. He scored sufficiently at first assessment, then declined 15 points at second assessment, and returned to non-affected performance at third assessment. The second child was a 3-year old girl suffering burns of 3% TBSA. Her performance was non-affected at first assessment, but with a decrease of 33 points her performance was affected at second assessment. There were no remarks and the girl was not assessed at 6 months post burn. The third child was a 1-year old boy with a burn involving 1% TBSA who scored 13 points above his norm value at first assessment. Despite the fact that his score declined 20 points at second assessment, it remained within normal limits. He was not assessed at 6 months post burn. Overall, scores of most children changed less than one LDD. The majority of children maintained non-affected scores or changed to scoring within normal limits for age between 2 weeks and 3 months post burn.

Individual changes between 3 months and 6 months post burn

Of the 33 children who were assessed at 3 months post burn as well as at 6 months post burn, 29 had higher scores on the last assessment, of which four (12.1%) improved one LDD or more (Table 5). None of the four decreases in scores was 1 LDD or more. Although individual scores changed over time, performance status did not change for most children: their scores remained either non-affected or affected.

4. Discussion

Burns impact the functional independence in Dutch pediatric patients with burns. At 2 weeks post burn about one-fifth of the participants showed affected functional independence, as measured by the WeeFIM$^\text{1}\text{ instrument}$ and compared to American norm values. Fortunately, the majority of the children returned to functional independence adequate for age...
within 3 months and only few children showed affected performance at 3 and 6 months post burn. This indicates recovery within 6 months post burn, which proves that 6 months is an appropriate time span for follow-up in this population. This is in line with findings by Serghiou et al. (2008), who reported that children from 6 to 16 years old with burns up to 15% TBSA attained maximum improvement in functional independence about 6 months post burn. Gorga et al. (1999) reported age-appropriate independence in self-care skills in children (aged 6 months–6 years; TBSA range 1–20%) at 1, 6 and 12 months post burn and found significant improvements in motor skills over time.

About one-third of the participants in the present study significantly improved on the WeeFIM® total score within 3 months post burn. This indicates that the WeeFIM® instrument is responsive enough to detect changes in Dutch children with burns, regardless of their age or extent of the burn. Furthermore, the effect sizes found in this study represent medium to large responsiveness (Husted et al., 2000).

The children younger than 3 years of age showed a lot of variability in scores and a higher rate of affected participants at follow-up assessments than older children. Note that this subgroup formed a big part of the total group of children admitted to Dutch burn centers and therefore strongly influenced the general results.

4.1. Utility of the WeeFIM® instrument

4.1.1. In a Dutch pediatric population

Overall, few participants were considered affected, according to the definition in this study. Nonetheless, many scores were below the mean norm scores, mainly for the young children. A first possible explanation for this is that American norm values would differ from Dutch standards. Next to personal, social and environmental factors, culture plays a role in differences in skill development. Differences in functional independence measured by the WeeFIM® instrument that are due to culture were mentioned before (Jongjit et al., 2006; Wong & Wong, 2007). Cross-cultural validation of the WeeFIM® instrument has not been done yet for northern European countries, but it was done for the Pediatric Evaluation of Disability Inventory (PEDI). The PEDI was developed as both an assessment and evaluative tool for children with disabilities from 6 months to 7.5 years of age. It measures ability related to self-care, mobility and social function and it is used to give functional descriptions. The PEDI shows a strong correlation with the WeeFIM® instrument, indicating that these instruments measure similar constructs (Ziviani et al., 2001). Berg, Aamodt, Stanghelle, Krumlinde-Sundholm, and Hussain (2008) showed that a randomized Norwegian population scored, for both functional skills and caregiver assistance scales, significantly worse than the American norm group in the domains of self-care and mobility and somewhat lower for social function. PEDI score profiles of Dutch children (n = 20; age range: 23–86 months) were also found not to be compatible with those of American children, although self-care and mobility seemed cross-culturally similar in this very small sample (Custers, Hoijtink, Van der Net, & Helders, 2000). For the WeeFIM® instrument, Dutch normative values for children younger than 3 years would probably be below American values.

Secondly, the large variability in scores and many below the norm values in the group of children younger than 3 years, could suggest that the WeeFIM® instrument might be less suitable to assess functional independence in children this young. In an informal evaluation our raters reported that they experienced difficulties in scoring children aged 2 and 3 years. Serghiou et al. (2008) had reported difficulties scoring young children with burns as well. They discovered that the levels of independence in the young age group in their study (6 months to 6 years) were misinterpreted by the raters, forcing them to disregard these data. This having happened had made us extra alert to this potential problem. The current data do not indicate misinterpretations as described by Serghiou et al. (2008). The inter-rater reliability between raters in the current study was good in children younger than 7 years (ICC = 0.989), although it was lower than in the total study sample that comprised children up to and including 16 years (ICC = 0.996; Niemeijer et al., 2012). To prevent scoring difficulties in young children, in future research the ‘WeeFIM® Instrument: 0–3 Module’ could be used (Niewczyk & Granger, 2010). This instrument, consisting of 36 items rated on a 3-level scale, was developed to measure precursors to basic daily living function in young infants, but was not yet available at the start of this study.

For children older than 3 years, on the other hand, the WeeFIM® scores found in this study were reasonably similar to the American norm values. This implies (1) that these children’s level of functional independence is adequate for their age and (2) that obtaining Dutch norm values would not be necessary. For older children with burns (7 years) however, the WeeFIM® instrument might have a ceiling effect. In this study all children over 7 are functioning well from 3 months post burn on, except for one outlier with 72% TBSA. The instrument measures if a child’s functional independence is sufficient for a 7-year old, but will not differentiate between different levels of independent functioning matching the individual age of the subject older than 7.

4.1.2. In children with burns

The WeeFIM® instrument has been proven to be a feasible and reliable measure for use in the Dutch burn centers and the population of children with burn injury. There are, however, also some drawbacks to the use of the WeeFIM® instrument and the interpretation of the results in this population and setting. Firstly, hospitalization could restrict WeeFIM® scores on each domain, because the WeeFIM® measures actual performance and not ability. For example, even if the child would have been capable of it, dressing could not be accomplished (domain self-care), walking stairs was impossible as there were no stairs in the burn center (domain mobility) and social interaction with peers was impossible because of isolated rooms or simply
4.2. Limitations in study design and conduct

A reasonable amount of participants was lost to follow-up at 3 months post burn and even more at 6 months post burn. The reason is that children who showed good recovery did not need follow-up visits at the outpatient clinic and therefore were not assessed anymore. This caused a slight selection bias at 3 and 6 months post burn; only the subjects that were still experiencing problems related to their burn injury returned for follow-up assessments. This might suggest that the population was doing even better than shown by the collected data. Besides this systematical bias, a small minority of children was randomly missed for assessment due to practical reasons (e.g. unavailability of rater, no follow-up visit planned at assessment time point).

4.3. Study strengths

First, this study is unique for its follow-up on functional independence in this large and special population. Second, as no selections were made on inclusion of participants, the study population forms a good representation of Dutch pediatric patients with burns. Third, all participants were assessed by certified raters. Fourth, the scores of each assessment were compared to norm scores determined for the participants' exact age at that assessment.

4.4. Functional independence; the end result

The majority of Dutch pediatric patients with burns returns to functional independence typical for age within 6 months post burn. At 6 months post burn only nine children showed affected functional independence, which is 7.6% of the total study population. In the light of issues discussed above, though, some remarks can be placed. Of those nine children, four were affected at all assessments. For one of those four it was reported that the deviance from typical functioning was not due to burn injury, but to cultural influence. The other three had extensive burns and underwent surgery. One of them was even experiencing problems related to their burn injury returned for follow-up assessments. This might suggest that the population was doing even better than shown by the collected data. Besides this systematical bias, a small minority of children was randomly missed for assessment due to practical reasons (e.g. unavailability of rater, no follow-up visit planned at assessment time point).

Of the other five from these nine affected participants at 6 months post burn, four had shown non-affected functional independence earlier. Their scores decreased between second and third assessment, but these decreases were not statistically significant. The fifth child had just not been assessed at 3 months post burn.

Furthermore, it must be noted that of the nine children, seven were from the youngest age group (<3 years). As mentioned before, children in this age were experienced as difficult to rate and furthermore the WeeFIM® instrument has not been implemented in standard care in the Dutch burn centers. If subsequent research is intended at a large scale, Dutch norm values should be obtained and the ‘WeeFIM: 0–3 Module’ should be applied for young infants.

The abovementioned remarks nuance our finding that nine children remain affected in their functional independence. Overall, we feel that functional independence is adequate in children 6 months after burn injury.

4.5. Future research

The WeeFIM® instrument has not been implemented in standard care in the Dutch burn centers. If subsequent research is intended at a large scale, Dutch norm values should be obtained and the ‘WeeFIM: 0–3 Module’ should be applied for young infants.

It was felt by the burn care professionals that psychosocial factors could play a role after discharge, e.g. the child could ask for more assistance than necessary or the parents could get overprotective as a result of the burn accident. For additional research it would be interesting to link the acquired WeeFIM® scores to data on the psychosocial functioning of the children and their parents, in order to explore relationships with the independence of the child.

5. Conclusions

The WeeFIM® instrument was found to be responsive enough to detect improvement over time in the functional independence of children with burns.

Functional independence was affected in 22 (out of 117) Dutch pediatric patients with burns at 2 weeks post burn, in nine children (out of 68) at 3 months post burn and in nine children (out of 38) at 6 months post burn. Concerning age, the group of
children younger than 3 years accounted for the most affected children at each time of assessment. Concerning the extent of burn, the subgroup of children with burns involving > 10% TBSA had a relatively higher number of affected children than the other groups.

Concluding, burn injury impacts children’s functional independence. Fortunately, after 3 months functional independence is adequate in most children with burns.

Disclaimer

The use of the WeeFIM® instrument to collect data for this research study was authorized and conducted in accordance with the terms of a special purpose license granted to Licensee by Uniform Data System for Medical Rehabilitation, a division of U B Foundation Activities, Inc. ("UDSMR"). Licensee has not been trained by UDSMR in the use of the WeeFIM® instrument, and the patient data collected during the course of this research study have not been submitted to or processed by UDSMR. No implication is intended that such data have been or will be subjected to UDSMR's standard data processing procedures or that it is otherwise comparable to data processed by UDSMR.

Conflict of interest

The authors declare that there are no conflicts of interest.

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References

Chapter 3

Physical fitness in people after burn injury: a systematic review.


*Archives of physical medicine and rehabilitation, 2011, 92*(9), 1501-1510.
Physical Fitness in People After Burn Injury: A Systematic Review

Laurien M. Disseldorp, BSc, Marianne K. Nieuwenhuis, PhD, Margriet E. Van Baar, PhD, Leonora J. Mouton, PhD

Objective: To gain insight into the physical fitness of people after burn injury compared with healthy subjects, and to present an overview of the effectiveness of exercise training programs in improving physical fitness in people after burn injury.

Data Sources: Electronic databases EMBASE, PubMed, and Web of Science were searched for relevant publications. Additionally, references from retrieved publications were checked.

Study Selection: The review includes studies that provide quantitative data from objective measures of physical fitness of both the intervention group and the control group.

Data Extraction: Characteristics of each study such as study design, institution, and intervention are reported, as well as mean ages and burn sizes of the subjects. Results are divided into 5 components of physical fitness—muscular strength, muscular endurance, body composition, cardiorespiratory endurance, and flexibility—and reported for each component separately.

Data Synthesis: Eleven studies met the inclusion criteria, and their methodological quality was assessed using the PEDro score and a modified Sackett scale. Six studies were used for the comparison of physical fitness in burned and nonburned subjects, and 9 studies for evaluating the effectiveness of exercise training programs.

Conclusions: Physical fitness is affected in people with extensive burns, and exercise training programs can bring on relevant improvements in all components. However, because of the great similarities in the subjects and protocols used in the included studies, the current knowledge is incomplete. Future research should include people of all ages with a broad range of burn sizes, for both short-term and long-term outcomes.

Key Words: Burns; Exercise; Outcomes assessment; Physical fitness; Rehabilitation; Review.

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METHODS

Data Sources

To identify relevant studies the electronic databases EMBASE (including Medline search), PubMed and Web of Sci-
study provides sufficient statistical information to make results interpretable. The PEDro assessment scale scores range from 1 to 10 points, where 10 indicates excellent methodological quality and 1 indicates very poor methodological quality. Third, the modified Sackett scale (table 1) as developed by Teasell et al was used to determine the strength of evidence. This is expressed as levels from 1, the strongest level of evidence, to 5, the weakest level of evidence.

**Data Extraction**

Information was collected on characteristics of each study, such as study design and intervention, as well as on characteristics of the subjects (eg, mean ages and burn sizes). To provide a structured overview, the 5 health-related components of physical fitness as originally described by Caspersen were used as a framework in this review. The framework comprises muscular strength, muscular endurance, body composition, cardiorespiratory endurance, and flexibility. Results were reported for each component separately.

**RESULTS**

Eleven relevant studies could be included (table 2), and 4 of these were used in both parts of this review. Six studies provided data for the first aim of this review, the comparison of the physical fitness in burned and nonburned subjects. One of these reports on 2 different study groups, which are discussed separately throughout this review, yielding a total of 7 study groups for this comparison. Nine studies were included for the second aim of this review, the evaluation of the effects of an exercise program on the physical fitness of people with burns.

**Methodological Quality of the Included Studies**

Eight studies were randomized controlled trials, of which 7 had PEDro scores of 6 points or more (see table 2), so were classified as level 1 evidence according to the modified Sackett scale. One randomized controlled trial, with a PEDro score of 5 points, and 1 nonrandomized controlled trial provided level 2 evidence. Two static group comparison studies, which were used to compare physical fitness in burned and nonburned people, were considered as level 3 evidence (see table 2).

**Physical Fitness of People After Burn Injury Compared With Nonburned Subjects**

The studies of Alloju and St.-Pierre and colleagues aimed to assess the physical consequences of burn injury and compare

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**Table 1: Classification of Levels of Evidence**

<table>
<thead>
<tr>
<th>Level of Evidence</th>
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<tbody>
<tr>
<td>1</td>
<td>RCTs with a PEDro score ≥ 6</td>
</tr>
<tr>
<td>2</td>
<td>RCTs with a PEDro score &lt; 6, cohort and non-RCTs</td>
</tr>
<tr>
<td>3</td>
<td>Case-control trials</td>
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<tr>
<td>4</td>
<td>Pre-post studies, posttest, and case series</td>
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<tr>
<td>5</td>
<td>Observational studies, clinical consensus, and single case reports</td>
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</table>

Abbreviation: RCTs, randomized controlled trials. *Adapted from Teasell et al.

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**Table 2: Quality Assessment of Included Studies**

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<thead>
<tr>
<th>Reference</th>
<th>Year</th>
<th>Institution</th>
<th>Design</th>
<th>PEDro Score</th>
<th>Level of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>St-Pierre et al</td>
<td>1998</td>
<td>MU</td>
<td>Static-group comparison</td>
<td>NA</td>
<td>3</td>
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<tr>
<td>Cucuzzo et al</td>
<td>2001</td>
<td>SHCG</td>
<td>RCT</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td>Suman et al</td>
<td>2001</td>
<td>SHCG</td>
<td>RCT</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Suman et al</td>
<td>2002</td>
<td>SHCG</td>
<td>RCT</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Suman et al</td>
<td>2003</td>
<td>SHCG</td>
<td>RCT</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Przkora et al</td>
<td>2007</td>
<td>SHCG</td>
<td>RCT</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Suman and Herndon</td>
<td>2007</td>
<td>SHCG</td>
<td>RCT</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>De Lateur et al</td>
<td>2007</td>
<td>JHU</td>
<td>RCT</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>Alloju et al</td>
<td>2008</td>
<td>SHCG</td>
<td>Static-group comparison</td>
<td>NA</td>
<td>3</td>
</tr>
<tr>
<td>Neugebauer et al</td>
<td>2008</td>
<td>SHCG</td>
<td>Nonrandomized controlled trial</td>
<td>NA</td>
<td>2</td>
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<tr>
<td>Al-Mousawi et al</td>
<td>2010</td>
<td>SHCG</td>
<td>RCT</td>
<td>6</td>
<td>1</td>
</tr>
</tbody>
</table>

Abbreviations: JHU, Johns Hopkins University School of Medicine Baltimore; MU, McGill University Quebec; NA, not applicable; RCT, randomized controlled trial; SHCG, Shriners Hospitals for Children Galveston.

*Levels of evidence are determined using a modified Sackett scale.
the physical fitness of burn patients with that of healthy control subjects. The other 4 studies\textsuperscript{18-21} aimed to evaluate the effect of a physical training program in burn patients, but hereby provided results of burned and nonburned subjects before the start of the program. Overall, most subjects were male, and the time of assessment varied from 0.5 to 12 months postburn (table 3).

Five of the 7 included study groups originated from Shriners Hospitals for Children in Galveston, Texas. Obviously, the participants of these 5 study groups were children (mean ages, 10.7–12.5y). Less obvious, but important for the results found in these studies was that all the studies were done with patients whose burns involved more than 40% TBSA, which is exceptionally large. In 3 of these 5 study groups the controls were matched for age, and in one of them, matched also for sex.

St-Pierre\textsuperscript{16} included adults aged 24 to 69 years with upper extremity burns involving at least 15% TBSA. The group of burned subjects was split into 2 study groups: patients with burns involving 30% TBSA or less, and patients with burns involving greater than 30% TBSA. Controls for both study groups were matched for age, sex, and physical activity level.

Muscular strength. Six study groups provided information about muscular strength, expressed as peak torque, measured with an isokinetic dynamometer. The 4 Shriners' studies measured peak torque in the dominant leg extensors, and all found less strength in burned subjects than in controls. Of these, Suman and Herndon\textsuperscript{21} and Alloju\textsuperscript{17} reported significant differences in the dominant leg extensors, and all found lower values in children with burns than in nonburned controls. In one of the studies,\textsuperscript{17} the differences were significant only for knee extension at 5.4 rad/s. The results did not show significant between-group differences for knee and elbow flexion during the performance of leg extension. The results did not show significant differences (\(P=.93\)) between burned and nonburned children.

Muscular endurance. In 3 study groups,\textsuperscript{16,17} the muscular endurance of patients with burns and healthy controls, expressed in terms of work and power, were compared (see table 4). The same methods were used as for muscular strength. The study group of St-Pierre,\textsuperscript{16} consisting of subjects with burns involving 30% TBSA or less, scored higher than the control group on both work and power in knee as well as elbow flexion and extension. No significant between-group differences were found. The study group with burns involving greater than 30% TBSA, however, showed lower values than controls on all measures of muscular endurance, though not all between-group differences were significant (see table 4). Alloju\textsuperscript{17} also reported significantly lower values (64.2% without a \(P\) value) of total work in burned subjects than in the control group.

Cardiorespiratory endurance. The cardiorespiratory endurance, expressed as peak oxygen consumption (\(V_{\text{O}}\text{peak}\)), is measured by treadmill testing in 3 study groups (see table 5). One study\textsuperscript{18} reported a significant between-group difference \((P<.05)\) in cardiorespiratory endurance, with the higher values on the side of nonburned subjects. The other 2 studies\textsuperscript{19,20} showed great differences in \(V_{\text{O}}\text{peak}\) between the groups, but withoutstatistical analyses.

Flexibility. Only 1 study\textsuperscript{17} measured flexibility (see table 5). Functional dynamic range of motion (ROM) was assessed during the performance of leg extension. The results did not show significant differences \((P=.93)\) between burned and nonburned children.

Effect of an Exercise Program on the Physical Fitness of People After Burn Injury

Nine controlled trials were included to evaluate the effectiveness of exercise training programs in improving physical fitness in people after burn injury (table 6). All but 1 trial were from Shriners Hospitals for Children (Galveston, Texas) and clearly involved just children. The mean TBSA involved in the burns of these children was greater than 50%, with a minimum of 40%. The subjects in the study by De Lateur et al\textsuperscript{22} were adults with burns involving a mean TBSA of 19.3%\textpm 15.7%.  

Table 3: Characteristics of Included Study Groups and Corresponding Subjects, Regarding Physical Fitness in Burned and Nonburned Subjects

<table>
<thead>
<tr>
<th>Study Group</th>
<th>Institution</th>
<th>n</th>
<th>% Male</th>
<th>Mean Age (y)</th>
<th>Mean TBSA (%)</th>
<th>Time PB (mo)</th>
<th>n</th>
<th>% Male</th>
<th>Mean Age (y)</th>
</tr>
</thead>
<tbody>
<tr>
<td>St-Pierre et al\textsuperscript{16} (&lt;30% TBSA)</td>
<td>MU</td>
<td>14</td>
<td>86</td>
<td>40.0</td>
<td>23.4</td>
<td>0.5-3 and 3.5-6*</td>
<td>14</td>
<td>86</td>
<td>40.6</td>
</tr>
<tr>
<td>St-Pierre et al\textsuperscript{16} (&gt;30% TBSA)</td>
<td>MU</td>
<td>16</td>
<td>75</td>
<td>39.8</td>
<td>46.1</td>
<td>0.5-3 and 3.5-6*</td>
<td>16</td>
<td>75</td>
<td>39.0</td>
</tr>
<tr>
<td>Suman et al\textsuperscript{19}</td>
<td>SHCG</td>
<td>31</td>
<td>77</td>
<td>10.7</td>
<td>58.6</td>
<td>6 and 9</td>
<td>21</td>
<td>94</td>
<td>13.5</td>
</tr>
<tr>
<td>Suman et al\textsuperscript{20}</td>
<td>SHCG</td>
<td>44</td>
<td>56</td>
<td>11</td>
<td>57.0</td>
<td>6 and 9</td>
<td>16</td>
<td>56</td>
<td>10.8</td>
</tr>
<tr>
<td>Przkora et al\textsuperscript{18}</td>
<td>SHCG</td>
<td>51</td>
<td>80</td>
<td>11.3</td>
<td>53.5</td>
<td>6 and 9</td>
<td>Unknown</td>
<td>85</td>
<td>12.2</td>
</tr>
<tr>
<td>Suman and Herndon\textsuperscript{21}</td>
<td>SHCG</td>
<td>20</td>
<td>85</td>
<td>12.5</td>
<td>58.8</td>
<td>6, 9, and 12</td>
<td>26</td>
<td>94</td>
<td>13.5</td>
</tr>
<tr>
<td>Alloju et al\textsuperscript{17}</td>
<td>SHCG</td>
<td>33</td>
<td>76</td>
<td>11.8</td>
<td>56.0</td>
<td>6</td>
<td>46</td>
<td>52</td>
<td>12.1</td>
</tr>
</tbody>
</table>

Abbreviations: mo, month; MU, McGill University Quebec; n, number of participants; SHCG, Shriners Hospitals for Children Galveston; Time PB, time postburn of assessment.

*Range, 15–92 days postburn.

†Matched with burned subjects.
# Table 4: Results for the Comparison of Muscular Strength and Muscular Endurance in Burned and Nonburned Subjects

<table>
<thead>
<tr>
<th>Study Group</th>
<th>Muscular Strength Parameters</th>
<th>Joints</th>
<th>Study Results</th>
<th>Statistics</th>
<th>Muscular Endurance Parameters</th>
<th>Joints</th>
<th>Study Results</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>St-Pierre et al(^{16}) ((\leq 30% \text{TBSA}))</td>
<td>Isokinetic peak torque*</td>
<td>Knee flexor</td>
<td>B&gt;B-NB</td>
<td>NS (All differences &lt;10%)</td>
<td>Isokinetic total work and average power*</td>
<td>Knee flexor</td>
<td>B&gt;B-NB</td>
<td>NS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Knee extensor</td>
<td>B&gt;B-NB and B&lt;NB</td>
<td></td>
<td></td>
<td>Knee extensor</td>
<td>B&gt;B-NB</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Elbow flexor</td>
<td>B&gt;B-NB and B&lt;NB</td>
<td></td>
<td></td>
<td>Elbow extensor</td>
<td>B&gt;B-NB</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Elbow extensor</td>
<td>B&lt;NB</td>
<td></td>
<td></td>
<td>Elbow extensor</td>
<td>B&gt;B-NB</td>
<td></td>
</tr>
<tr>
<td>St-Pierre et al(^{16}) ((&gt;30% \text{TBSA}))</td>
<td>Isokinetic peak torque*</td>
<td>Knee flexor</td>
<td>B&lt;NB</td>
<td>Knee extensor at 3.14rad/s</td>
<td>Isokinetic total work and average power*</td>
<td>Knee flexor</td>
<td>B&lt;NB</td>
<td>Knee extensor work:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Knee extensor</td>
<td>B&lt;NB</td>
<td>- Sign (16%)</td>
<td></td>
<td>Knee extensor</td>
<td>B&lt;NB</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Elbow flexor</td>
<td>B&lt;NB</td>
<td>Other measures - NS</td>
<td></td>
<td>Elbow flexor</td>
<td>B&lt;NB</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Elbow extensor</td>
<td>B&gt;B-NB</td>
<td></td>
<td></td>
<td>Elbow extensor</td>
<td>B&gt;B-NB</td>
<td></td>
</tr>
<tr>
<td>Suman et al(^{20})</td>
<td>Isokinetic peak torque*</td>
<td>Knee extensor (dominant side)</td>
<td>B&lt;NB</td>
<td>No statistical analyses</td>
<td>Knee extensor total work(^1)</td>
<td>Knee extensor (dominant side)</td>
<td>B&lt;NB</td>
<td>Sign (64.2%)</td>
</tr>
<tr>
<td>Przkora et al(^{18})</td>
<td>Isokinetic peak torque*</td>
<td>Knee extensor (dominant side)</td>
<td>B&lt;NB</td>
<td>No statistical analyses</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Suman and Herndon(^{21})</td>
<td>Isokinetic peak torque*</td>
<td>Knee extensor (dominant side)</td>
<td>B&lt;NB</td>
<td>Sign ((P=0.011))</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alloju et al(^{17})</td>
<td>Isokinetic peak torque*</td>
<td>Knee extensor (dominant side)</td>
<td>B&lt;NB</td>
<td>Sign (68.1%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: B, burned subjects; NB, nonburned subjects; NS, nonsignificant between-group differences; NT, not tested; Sign, significant between-group differences.

*Measured at 1.05 and 3.14rad/s.

\(^1\)Measured at 150°/s.
Table 5: Results for the Comparison of Body Composition, Cardiorespiratory Endurance, and Flexibility in Burned and Nonburned Subjects

<table>
<thead>
<tr>
<th>Study Group</th>
<th>Parameters</th>
<th>Results</th>
<th>Statistics</th>
<th>Results</th>
<th>Statistics</th>
<th>Results</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suman et al19</td>
<td>NT VO2 peak by treadmill test</td>
<td>B-NT</td>
<td>NS</td>
<td>NT</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Przkora et al18</td>
<td>TLBM by DEXA</td>
<td>B-NT</td>
<td>NS</td>
<td>NT</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Suman and Herndon17</td>
<td>TLBM and LLM by DEXA</td>
<td>B-NT</td>
<td>NS</td>
<td>NT</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Alloju et al16</td>
<td>TLBM by DEXA</td>
<td>B-NT</td>
<td>NS</td>
<td>NT</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
</tr>
</tbody>
</table>

Abbreviations: B, burned subjects; LAM, lean arm mass; LTM, lean trunk mass; NB, nonburned subjects; NS, nonsignificant between-group differences; NT, not tested; Sign, significant differences among groups.

All studies comprised an intervention with a duration of 12 weeks. In the Shriners’ studies, the control group participated in a home-based rehabilitation program without exercise prescriptions. For the intervention groups, this rehabilitation program was supplemented with hospital-based, individualized and supervised exercise training programs consisting of aerobic as well as resistance training. Most of these interventions involved 3 training sessions per week, of which 20 to 40 minutes was aerobic exercise (for exceptions see table 6). The study by Neugebauer et al23 is an exception in the Shriners’ studies; this intervention for young children was not individualized but comprised group sessions. The intervention group received, in addition to 3h/wk of rehabilitation therapy, 3 sessions of an exercise and music program per week, each lasting 60 minutes. The control group was heterogeneous in the number of sessions and the location of therapy, as participants were trained and given a home-based rehabilitation program or received outpatient therapy at the hospital.

In the study of De Lateur22 all participants received the standardized, tailored burn rehabilitation protocol of the John Hopkins Burn Center. For the intervention groups, this was supplemented with 30 minutes of aerobic treadmill exercise 3 times a week. For the “work-to-quota” group, this exercise was intensified throughout the 12 weeks by increasing the target exercise heart rate and time according to preset quotas. The “work-to-tolerance” group was instructed to tolerate the exercise at the individual target heart rate for as long as possible.

The time postburn at the start of the intervention varied between studies. In all but 2 studies, the exercise program started at 6 months postburn (see table 6). Subjects in the study by Neugebauer23 joined the exercise and music groups as soon as they were medically ready, which is not further specified. Subjects in the study by De Lateur22 started at a mean of 37.5 days postburn. It was unclear on which criteria this was based.

Two studies of Shriners Hospitals investigated the effect of additional drugs (oxandrolone18 and growth hormone20), but only results of the relevant (nondrugged) groups were used in this review. However, in 2 other studies of Shiners Hospitals used here19,24 subjects who received growth hormone were included in both the intervention and control groups.

Muscular strength. Information about the changes in muscular strength as a result of the exercise training program of 12 weeks was given in 5 studies8,18,20,21,24,25 (table 7). A dynamometer was used to measure isokinetic peak torque in the knee extensors of the dominant leg. All studies reported averaged increases in strength of more than 40% in the intervention group, all significantly greater than increases of the control group. Significant differences persisted when increases in strength were normalized to individual changes in TLBM.24,25 However, note that SDs were very large in the studies by Przkora18 and Al-Mousawi25 and colleagues (see table 7). One of the studies17 applied a follow-up measure after another 12 weeks with home-based exercise prescriptions, but this did not cause significant changes in both groups.

Muscular endurance. Two studies reported data on muscular endurance (see table 7). Suman et al24 measured total work and average power in the leg extensors, while Cucuzzo et al8 used the calculated total volume of work produced by the biceps, triceps, forearms, quadriceps, and hamstrings. Significant between-group differences in the improvement of muscular endurance over 12 weeks were found on all 3 variables.

Body composition. Body composition, measured by DEXA and expressed as lean mass in kilograms, was mentioned in 5 effect studies8,18,20,21,24,25 (see table 7). All studies reported significantly greater increases in the intervention group than in the control group over 12 weeks. Al-Mousawi25 normalized the
measurements to height and found that this significant difference persisted. A follow-up measure in one of the studies did not show significant changes from another 12 weeks of home-based exercise prescriptions.

**Cardiorespiratory endurance.** In 6 studies (table 8), cardiorespiratory endurance was measured. Five studies used treadmill exercise testing following the modified Bruce protocol, and these outcomes were expressed in VO2peak for children and maximum oxygen consumption (VO2max) for adults. In 1 study, functional cardiorespiratory endurance was assessed with the 6-minute walk test. Five studies included children with burns involving greater than 40% TBSA. Four of these used treadmill tests and found increases greater than 20% in VO2peak in the intervention group, which differed significantly from increases in the control group. The fifth study used the 6-minute walk test and reported that the performance of both the intervention and control group increased, but with a significantly larger increase for the intervention group.

The 1 study including adults (mean TBSA, 19.3%) reported significant increases in VO2max for both the work-to-quota and work-to-tolerance intervention groups. The control group did not improve significantly, and both between-group differences were significant.

**Flexibility.** Only 1 study (see table 8) included flexibility, which was measured in the elbow and knee joints by goniometry and expressed as passive and active ROM. The change in passive ROM after 12 weeks of intervention in the intervention group was not significantly different from the change in passive ROM in the control group. Active ROM increased significantly more in the intervention group than in controls for the left elbow and the right knee. On the contrary, for the right elbow and left knee, between-group differences appeared nonsignificant, despite significant increases in active ROM over the intervention.

**DISCUSSION**

This review included 11 high-quality studies, which reported on 12 study groups, to provide an overview of (1) the physical fitness of people after burn injury, and (2) the effectiveness of exercise training programs in improving physical fitness in people after burn injury. It showed that (1) children and adults with extensive burns score worse than nonburned controls on measures of all 5 components of physical fitness, and (2) burn patients participating in a 12-week exercise training program improve more on all parameters than burn patients without this specific training.

**Physical Fitness in People After Burn Injury**

This review brings to light important insights on the physical fitness of people after burn injury compared with that of nonburned controls. However, the included studies show great similarity in subjects on the domains of age, burn size, and time postburn. Therefore, the included population in this review is a remarkable one—that is, a selection of the patients generally admitted to burn centers. Only 2 of the 7 included study groups concern adults; the other 5 involve only children. Moreover, these children have exceptionally extensive burns. In the Netherlands, on average, only 1.3% of burn patients younger than 18 years have burns involving more than 40% TBSA. Recent American data show that patients with a total burn size of more than 40% TBSA have burns involving more than 40% TBSA.26

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**Table 6: Characteristics of Included Studies and Corresponding Subjects, Regarding Effectiveness of an Exercise Program on Physical Fitness**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Institution</th>
<th>Study</th>
<th>Control</th>
<th>Mean TBSA (%)</th>
<th>Time PB (mo)</th>
<th>Sessions/wk</th>
<th>Content per Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cucuzzo et al*</td>
<td>SHCG</td>
<td>11</td>
<td>10</td>
<td>10.6</td>
<td>3</td>
<td>6 and 9</td>
<td>Resistance and aerobic exercise</td>
</tr>
<tr>
<td>Suman et al**</td>
<td>SHCG</td>
<td>19</td>
<td>16</td>
<td>10.7</td>
<td>3</td>
<td>6 and 9</td>
<td>Aerobic exercise 20–40min + resistance training</td>
</tr>
<tr>
<td>Suman et al**</td>
<td>SHCG</td>
<td>17</td>
<td>14</td>
<td>10.7</td>
<td>3</td>
<td>6 and 9</td>
<td>Aerobic exercise 20–40min + resistance training</td>
</tr>
<tr>
<td>Suman et al**</td>
<td>SHCG</td>
<td>13*</td>
<td>11*</td>
<td>10.6</td>
<td>3</td>
<td>6 and 9</td>
<td>Aerobic exercise 20–40min + resistance training</td>
</tr>
<tr>
<td>Przkora et al**</td>
<td>SHCG</td>
<td>17†</td>
<td>11†</td>
<td>11.3</td>
<td>5</td>
<td>6 and 9</td>
<td>Aerobic exercise 20–40min + resistance training</td>
</tr>
<tr>
<td>Suman and Herndon</td>
<td>SHCG</td>
<td>11</td>
<td>9</td>
<td>12.5</td>
<td>3</td>
<td>6, 9, and 12</td>
<td>Aerobic exercise 20–40min + resistance training</td>
</tr>
<tr>
<td>De Lateur et al**</td>
<td>JHU</td>
<td>15</td>
<td>9</td>
<td>38.0</td>
<td>3</td>
<td>1, 2, and 4.2†</td>
<td>Exercise-based music activities to promote ROM, endurance, and functional movement; 60min</td>
</tr>
<tr>
<td>Neugebauer et al**</td>
<td>SHCG</td>
<td>15</td>
<td>9</td>
<td>3.5</td>
<td>5</td>
<td>Recently discharged from intensive care unit and medically ready (not specified)</td>
<td></td>
</tr>
<tr>
<td>Al-Mousawi et al**</td>
<td>SHCG</td>
<td>11</td>
<td>10</td>
<td>12.6</td>
<td>3</td>
<td>6 and 9</td>
<td>Aerobic exercise 30min + resistance training</td>
</tr>
</tbody>
</table>

Abbreviations: JHU, Johns Hopkins University School of Medicine Baltimore; mo, month; n, number of participants; SHCG, Shriners Hospitals for Children Galveston; Time PB, time postburn of assessment.

*This is a selection of the participants. The rest of the participants received growth hormone, and are excluded in this review.

†Range, 9 to 122 days postburn; mean, 37.5 days.
than 40% TBSA accounted for only 4.6% of all cases, whereas 71% had a TBSA of less than 10%. Not only the low prevalence but also the physiologic consequences of such extensive burns make this group exceptional. After extensive burns, the metabolic and catabolic disturbances are significant relative to burns involving less than 40% TBSA and can persist up to 12 months postburn. Therefore, the included populations are not truly representative of the general burn population.

For both muscular strength and endurance, children and adults with extensive burns scored lower than their controls on all parameters. For the knee extensor the differences were significant; for other joints the differences were nonsignificant. On the other hand, adults with burns involving less than 30% TBSA scored higher than their controls, who were matched for age, sex, and activity level, but these differences were not significant. Concerning the methods of measurement, it is remarkable that in all reviewed studies, muscular strength and muscular endurance were measured in the knee extensor of the dominant side. Only in the adult groups were the knee flexors and elbow extensors and flexors also assessed. It can be questioned whether measuring only knee extension is a good indication of the overall muscular capacity, especially since the precise location of the burns and their possible influence on leg or arm function are not taken into account. A much longer lasting deficit in strength was reported in another study related to the Shriners Hospital, but this study by Baker et al was excluded from the review because a control group was lacking. Baker found that 35% of 83 young adult survivors of burns sustained in childhood (mean time postburn, 14 ± 5 y; TBSA range, 30%–99%) had deficits in strength in any part of the body, compared with normative values. Overall, the subjects with a higher percentage of TBSA involved had lower mean strength.

In all studies that measured body composition, the children with extensive burns had lower mean values of lean body mass than their controls. Hypermetabolism might play a role, but taking into account that the severely burned children were only 6 months postburn and will just have had a long period of (bed) rest, this finding also does not seem very surprising. Moreover, in this age span, healthy children are in the period of the most rapid gain in lean body mass, with the skeleton showing the highest responsiveness to physical activity. The pediatric burn patients might miss a part of this rapid gain because of metabolic responses and the sedentary period postburn, but whether they catch up later is yet unknown.

Cardiorespiratory endurance is affected in severely burned children compared with controls. This finding lies within expectations, considering the relatively short period postburn and the inactivity in this period. It is interesting that a similar conclusion was drawn for adults with smaller burn sizes at a relatively longer period postburn. This follow-up study by Jarrett et al did not measure a control group and was therefore not included in the review. They assessed 86 adult burn patients (mean age, 38 y; mean TBSA, 11.2%) and reported that functional exercise capacity, measured by a shuttle walk test, did not return to baseline levels at 6 months after discharge from the hospital.

Flexibility, in terms of the functional dynamic ROM in leg extension, was somewhat decreased in children with extensive burns compared with controls. Because scars subsequent to burn injury can cause contractures in the affected joint, the question arises whether ROM in the leg is a sufficient parameter for the overall flexibility. Schneider et al reported that 38.7% of adult burn patients (n = 985) have developed at least 1 contracture at discharge, with an average of 3 contractures...
per person. Given this, it is remarkable that only 1 study could be included that measured flexibility. In a study by Gorga et al,35 not included in the review because of lack of a control group, flexibility around multiple joints (ie, head/neck, upper extremity, hand, and lower extremity) was tested in very young children with relatively small burns (mean age, 27 mo; mean TBSA, 6%). They concluded that at 1, 6, and 12 months postburn, most of the children had ROMs within normal limits, according to normative values.35 In the study by Moore et al,14 which was also not included because of lack of a control group, ROM of both upper and lower extremities was measured to calculate physical impairment in older children with extremely extensive burns (>80% TBSA). Their outcomes varied from no measurable physical impairment to more than 90% impairment, with an average of 52%.14 So whereas ROM seemed an easy and appropriate parameter for flexibility in people after burn injury, it proves difficult to interpret. Furthermore, the location of the burn is essential for flexibility and should be reported with the results. Since measurements are done at a certain time point postburn, the possible recent surgical interventions should also be taken into account.

**Effectiveness of Exercise Training Programs in People After Burn Injury**

Exercise training programs have shown very positive effects on the physical fitness of patients after burn injury; however, the critical remarks on the included study population and assessments as discussed above should be kept in mind. In addition, specific to this review question, the mentioned similarity in studies caused a lack of variation in applied protocols and exercise interventions. Eight of the 9 included studies in this part of the review originated from Shriners Hospitals for Children, and 7 of these tested similar interventions. Therefore, fewer different training protocols are evaluated in this review than one would like.

This review shows that because of a 12-week exercise training program, starting 6 months postburn, children’s muscular strength, muscular endurance, and lean body mass strongly increased. Likewise, exercise has also been proven effective in improving the cardiorespiratory endurance in adults as well as children. Passive and active ROM increased in very young children with extensive burns due to participation in exercise and music groups as part of the rehabilitation. Additional literature36-38 suggests that ROM in people with burns could also be increased by massages, virtual reality treatment, and motor imagery, but for none of these is there indisputable evidence yet.

Besides effects on the components muscular strength, muscular endurance, body composition, cardiorespiratory endurance, and flexibility, more beneficial effects of exercise on physical outcomes are known. Exercise can significantly reduce the number of surgical scar releases39 and has been proven effective in improving pulmonary function in children with severe burns,19 according to randomized controlled trials from the Shriners Hospitals.

Whereas apparently significant improvements in physical fitness can be made with exercise training programs, the question is whether the physical fitness of burn patients returns to fitness levels from before the injury (normal values). Only Suman and Herndon11 made a comparison and reported that after completion of the exercise program, the values of patients with burns remained below those of nonburned subjects for lean mass and muscular strength. As all studies compared people with burns in exercise groups and noneexercise groups, the comparison of burn patients in exercise groups with groups of matched healthy controls is lacking.

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**Table 8: Results for Effectiveness of an Exercise Program on Cardiorespiratory Endurance and Flexibility in People With Burn Injury**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Cardiorespiratory Endurance</th>
<th>Flexibility</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parameters</td>
<td>Results</td>
</tr>
<tr>
<td>Cucuzzo et al16</td>
<td>VO₂peak by treadmill test</td>
<td>I: 47.3% †</td>
</tr>
<tr>
<td>Suman et al14</td>
<td>VO₂peak by treadmill test</td>
<td>I: 22.7% †</td>
</tr>
<tr>
<td>Suman et al19</td>
<td>VO₂peak by treadmill test</td>
<td>I: 24.3% ± 4.7% †</td>
</tr>
<tr>
<td>Suman et al20</td>
<td>VO₂peak by treadmill test</td>
<td>I: 23.1% †</td>
</tr>
<tr>
<td>Przkora et al18</td>
<td>VO₂peak by treadmill test</td>
<td>I: 23.2% ± 16.6% †</td>
</tr>
<tr>
<td>De Lateur et al22</td>
<td>VO₂max by treadmill test</td>
<td>-I-WTT: †</td>
</tr>
<tr>
<td>Neugebauer et al23</td>
<td></td>
<td>-I-WTT: †</td>
</tr>
</tbody>
</table>

**NOTE.** Values are mean ± SD or as otherwise indicated. † indicates improvement on this parameter. Abbreviations: C, control group; I, intervention group; I-WTT, intervention group exercising by target heart rate and time intensified according to preset quotas; I-WTQ, intervention group exercising as long as possible at individual target heart rate; NS, between-groups difference not significant; NT, not tested; Sign, significant between-group difference († † † † C).
Study Limitations

The present review is the first to emphasize the hiatus in knowledge about physical fitness in patients after burn injury. The main strength of this review is that it reports on the level of physical fitness and improvements in the fitness level resulting from exercise programs, in a highly structured way, using the 5 health-related components of physical fitness: muscular strength, muscular endurance, body composition, cardiorespiratory endurance, and flexibility.

This review is mainly limited by the quantity, quality, and similarity of the available studies. Only 11 studies could be included. Three of those were not randomized controlled trials, and none of the 8 randomized controlled trials received the maximum PEDro score. Since 9 studies were from the same institute and showed great similarities in study populations, applied exercise programs, and research protocols, the generalizability of the results is not optimal.

Practical Implications

We feel that physical fitness and exercise definitely deserve a lot more attention in burn care. Furthermore, to maintain and further improve the fitness levels achieved by exercise in the rehabilitation phase, promotion of an active lifestyle is very important. Physical fitness is essential in the performance of activities of daily living. By improving fitness, the independent functioning and self-care in burn patients could get better. Furthermore, it can hasten reintegration into occupational and social activities and increase participation after burn injury. Because improved physical fitness might have a positive impact on several areas of life, it is assumed to improve the perceived quality of life.

CONCLUSIONS

This review of 11 high-quality studies showed that physical fitness is affected in people after extensive burn injury, and that exercise training programs can bring on meaningful improvements in all components of physical fitness. However, the number of appropriate studies on physical fitness is limited, and the number of burn centers publishing on this topic is even smaller. Because of the great similarities of the subjects and protocols used in the included studies, many questions remain unanswered. Controlled studies including both children and adults with minor and moderate burns, aimed at both short-term and long-term physical fitness outcomes, are necessary to fill the hiatus in the current knowledge. Preferably, future studies would include assessment of all 5 components of physical fitness. Furthermore, intervention studies should investigate varying duration, intensity, and frequency of exercise, to enable optimization of the effectiveness of exercise training protocols for individual patients. In this decade of increasing attention to physical fitness, exercise, and healthy aging, the burn (research) community should take advantage of this trend, which brings new opportunities and growing knowledge. Thereby, they should intensify and increase its efforts to limit the physical burden of burn injury as much as possible.

References


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42


Design of a cross-sectional study on physical fitness and physical activity in children and adolescents after burn injury.


Study Protocol

Design of a cross-sectional study on physical fitness and physical activity in children and adolescents after burn injury

Laurien M Disseldorp1*, Leonora J Mouton1, Tim Takken2, Marco Van Brussel2, Gerard IJM Beerthuizen3, Lucas HV Van der Woude1,4 and Marianne K Nieuwenhuis3

Abstract

Background: Burn injuries have a major impact on the patient’s physical and psychological functioning. The consequences can, especially in pediatric burns, persist long after the injury. A decrease in physical fitness seems logical as people survive burn injuries after an often extensive period of decreased activity and an increased demand of proteins leading to catabolism, especially of muscle mass. However, knowledge on the possibly affected levels of physical fitness in children and adolescents after burn injury is limited and pertains only to children with major burns. The current multidimensional study aims to determine the level of physical fitness, the level of physical activity, health-related quality of life and perceived fatigue in children after a burn injury. Furthermore, interrelations between those levels will be explored, as well as associations with burn characteristics.

Methods/design: Children and adolescents in the age range of 6 up to and including 18 years are invited to participate in this cross-sectional descriptive study if they have been admitted to one of the three Dutch burn centers between 6 months and 5 years ago with a burn injury involving at least 10% of the total body surface area and/or were hospitalized ≥ 6 weeks. Physical fitness assessments will take place in a mobile exercise lab. Quantitative measures of cardiorespiratory endurance, muscular strength, body composition and flexibility will be obtained. Outcomes will be compared with Dutch reference values. Physical activity, health-related quality of life and fatigue will be assessed using accelerometry and age-specific questionnaires.

Discussion: The findings of the current study will contribute to a better understanding of the long-term consequences of burn injury in children and adolescents after burns. The results can guide rehabilitation to facilitate a timely and optimal physical recovery.

Trial registration: The study is registered in the National Academic Research and Collaborations Information System of the Netherlands (OND1348800).

Keywords: Burns, Outcome assessment, Child, Fatigue, Quality of Life

Background

Worldwide, millions of people suffer from burn-related disabilities and disfigurements. In the Netherlands, each year about 550–750 people are admitted to a dedicated burn center, of which approximately 40% is younger than 18 years [1]. The survival rate in patients with – even very extensive- burn injuries increased over the last decades. As a result, attention in international burn care and research has shifted from mortality towards the life after burns. Nowadays, dedicated burn centers provide multidisciplinary care and rehabilitation programs, generally starting at admission, in order to optimize patient’s outcomes. Nevertheless, a relevant part of the burn population still shows long-term declined physical and/or psychological functioning and/or suboptimal quality of life after burns [2-7]. Especially consequences of pediatric burns may persist from childhood through adolescence into adulthood. As in burn care, burn
research nowadays intends to optimize the clinical process and patients’ outcomes on both short and long term post burn. Hence, our research group recently initiated multidimensional research on outcomes after burns comprising physical fitness, physical activity, health-related quality of life (HRQoL) and fatigue. The current study in children and adolescents is part of this research line.

Physical fitness as well as physical activity in children and adolescents are nowadays widely publicised topics due to the increasing awareness of their importance for health and well-being and, on the other hand, to prevent disability and morbidity throughout life. In children after a severe burn injury physical fitness is diminished (see Disseldorp, Nieuwenhuis, Van Baar, & Mouton, 2011 for review [8]). This decrease in physical fitness seems logical as people survive burn injuries after an often extensive period of physiological assault, decreased physical activity and an increased demand of proteins leading to catabolism, especially of muscle mass. However, the findings of diminished physical fitness are primarily based on children with severe burns involving >40% total body surface area [TBSA], representing only <5% of all pediatric burn patients [1,9]. Knowledge regarding physical fitness for the general population of children and adolescents after burns is lacking.

Physical activity, e.g. in the form of exercise programs, can significantly contribute to the restoration of physical fitness in children and adolescents after severe burn injury (among others [10-13]. Furthermore, physical activity is associated with improvements in health-related quality of life [14]. Despite its known positive effects, physical activity in this population might be diminished. This could be due to the loss of physical fitness, but other barriers may play a role as well, such as disfigurement and socioeconomic factors. However, physical activity levels in daily life after pediatric burns have been overlooked in burn research thus far.

Concerning health-related quality of life (HRQoL) research showed that long-term limitations in HRQoL are experienced by >50% of Dutch and Flemish children after burns [3]. The impact on HRQoL is not surprising, as both the burn accident and the persisting consequences of the burns can impact one’s appearance and functioning on several domains (e.g. the physical, psychological and social domain). Associations between HRQoL and both physical fitness and activity are plausible, though not yet examined in this population.

Another factor that impacts an individual’s daily functioning as well as activities and HRQoL, is fatigue [15]. Fatigue is often experienced in the long-term after burn injury, according to communication with the Dutch Association of Burn Survivors [personal communications]. Until now no studies on fatigue after pediatric burn injury, nor on its probable associations with physical fitness, activity or HRQoL after burns have been published.

The conceptual model that depicts the rationale of this study is shown in Figure 1. This model is partly based

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**Figure 1** Conceptual model depicting the rationale of this multidimensional study.
on the ideas of Bouchard et al. (1994), who emphasized the interrelations between physical activity, physical fitness and health (wellness) [16]. Also, concepts of the International Classification of Functioning, Disability and Health are taken into account [17]. Furthermore, both burn characteristics and individual characteristics are highlighted in the model, as we assume those to substantially influence the central aspects of this study, i.e. physical fitness, physical activity, HRQoL and fatigue.

The objective of the current paper is to describe the rationale and design of a cross-sectional study in children and adolescents after burn injury. The study aims to 1) determine the levels of physical fitness and physical activity in this group, also in comparison to reference values; 2) assess HRQoL and fatigue; and 3) explore what associations exist between fitness, activity, HRQoL and fatigue, taking individual (burn-related) characteristics into account. The results of the study will enlarge our understanding of the physical consequences of burn injury. Subsequently, this can lead to an adaptation of rehabilitation protocols to facilitate a timely and optimal recovery of future pediatric burn patients.

**Methods**

**Design**
In this cross-sectional descriptive study the levels of physical fitness and physical activity in children and adolescents after burn injury will be determined and compared with Dutch reference values. This design is chosen to gain insight in the physical consequences of burn injury in a group of subjects varying in extent of burn, time post burn and age, accomplished within a study period of one year.

**Setting**
This study is a collaboration between the Association of Dutch Burn Centers (Epidemiology & Registration; Clinical Research), Wilhelmina Children’s Hospital (Child Development and Exercise Center) and the University Medical Center Groningen (Center for Human Movement Sciences, University of Groningen).

To keep the inconvenience of participation low and enlarge the feasibility of the study, assessments will take place on personal arrangement. The use of a mobile exercise lab enables us to meet the subjects and his/her parents at any date and time that is convenient for them, near the subject’s home (or other location of choice). The mobile exercise lab is a specially equipped truck in which equipment for cardiopulmonary exercise testing is installed, e.g. a cycle ergometer and a mobile gas analysis system, as well as other testing equipment. This truck has been in use for several years for (clinical) exercise testing [18].

**Subjects**
Eligible for this study are all children and adolescents aged from 6 up to and including 18 years with healed burns that had been admitted to one of the Dutch burn centers with 10% TBSA or more involved in the burn and/or had a length of stay of more than 6 weeks, see Table 1. The source population will be restricted to children and adolescents for whom the time post burn is between 6 months and 5 years, and discharge and/or reconstructive surgeries are at least 2 months ago at the time of the assessment. Extensive (pre-existing) comorbidity or (mental) disabilities and insufficient Dutch language proficiency are criteria for exclusion, see Table 1. Informed consent must be provided by all parents (or legal representatives) as well as by subjects up from 12 years of age before enrolment in this study; only for subjects aged 18 parental informed consent is not requested. Contra-indications for exercise testing, based on the Exercise Preparticipation Screening questionnaire or from consultation with the burn physician, may lead to exclusion on the cardiopulmonary exercise test. The Medical Ethical Committee of the University Medical Center Groningen approved this study (NL40183.042.12).

**Sample size**
A precise sample size calculation is not possible as no data are available on a similar population, as this study is the first to assess physical fitness, physical activity, HRQoL and fatigue in such a population. Nevertheless, we made an estimation of the expected sample size. At the first inclusion date, August 1st, 2012, 56 children met the inclusion criteria as identified in the Dutch Burn Repository [1]. At the second inclusion date in the spring of 2013, it is estimated that 10 more children will be eligible. However, it is probable that not all eligible children can be included and, secondly, not all included children will be reached and/or will agree to participate. We expect to be able to assess about 30 subjects.

**Procedure**
Inclusion and study procedures are depicted in Figure 2. Demographic and burn (treatment) characteristics, e.g. age, sex, extent of burn, location of burn, time post burn, discharge and/or reconstructive surgeries are at least 2 months ago at the time of the assessment. Extensive (pre-existing) comorbidity or (mental) disabilities and insufficient Dutch language proficiency are criteria for exclusion, see Table 1. Informed consent must be provided by all parents (or legal representatives) as well as by subjects up from 12 years of age before enrolment in this study; only for subjects aged 18 parental informed consent is not requested. Contra-indications for exercise testing, based on the Exercise Preparticipation Screening questionnaire or from consultation with the burn physician, may lead to exclusion on the cardiopulmonary exercise test. The Medical Ethical Committee of the University Medical Center Groningen approved this study (NL40183.042.12).

Table 1 Criteria for eligibility and exclusion of subjects

<table>
<thead>
<tr>
<th>Eligibility</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admitted to Dutch burn center</td>
<td>Time post burn &lt; 0.5 year or &gt; 5 years</td>
</tr>
<tr>
<td>Burns ≥ 10% TBSA; or hospitalization ≥ 6 weeks</td>
<td>(Pre-existing) comorbidity or (mental) disabilities</td>
</tr>
<tr>
<td>Aged 6 up to and including 18 years</td>
<td>Insufficient Dutch language proficiency</td>
</tr>
<tr>
<td></td>
<td>No signed informed consent</td>
</tr>
</tbody>
</table>

47
presence of inhalation injury and the number of surgeries, will be documented for each subject. Further, subjects will be assessed once on physical fitness, as described below and shown in Table 2 and Figure 2. Estimated duration of the physical fitness assessment session is 1.5 h, including introduction, explanations and social talk. For the assessments of physical activity, HRQoL and fatigue the accelerometer and questionnaires, including instructions, will be handed out on the day of physical fitness assessment and taken home by the subjects, see Table 2 and Figure 2. The subjects are requested to wear the accelerometer for seven consecutive days, preferably starting the day after the fitness assessments, and return the questionnaires and accelerometer by mail (pre-paid postage) after this week.

Physical fitness
Physical fitness will be objectively and quantitatively assessed, measuring four components of health-related
physical fitness [19], i.e. muscular strength, cardiorespiratory endurance, body composition and flexibility, see Table 3. All measurements will be performed by the first author and using the same instruments to prevent bias.

- **Cardiorespiratory endurance**

  Aerobic exercise capacity will be measured using an incremental maximal exercise test on an electronically braked cycle ergometer (Lode Corrival, Lode, ProCare BV, Groningen, The Netherlands). The subjects will start with a three minute warming-up of unloaded cycling, after which the work rate (WR [W]) will increase according to the Godfrey protocol [20]. While cycling the subject will breathe through a small face mask with low dead space, adapted to his/her face, which is connected to a calibrated mobile metabolic cart (Cortex Metamax, Cortex Medical, Leipzig, Germany). From the expired gas, minute ventilation (V\(_E\)), oxygen uptake (V\(_O2\)), carbon dioxide output (V\(_{CO2}\)) and RER (respiratory exchange ratio= V\(_{CO2}\)/V\(_O2\)) will be calculated (corrected for dead space of the mask) by a computer connected to the gas analysis system. Additionally, saturation of the blood and heart rate (in beats per minute: bpm) will be monitored continuously during the exercise test, using pulse-oximetry and a heart rate monitor, respectively. A heart rate (HR\(_{peak}\)) above 180 bpm and/or a RER\(_{peak}\) above 1.01 will be regarded as criteria for maximal effort [21,22].

  The outcomes will be compared with age- and sex-matched Dutch reference values [22].

- **Muscular strength**

  Maximal isometric muscle strength (in Newtons: N) will be quantified with a calibrated hand-held dynamometer (Citec, type CT 3001, CIT Techniques, Groningen, The Netherlands). The shoulder abductors, knee flexors and extensors, elbow flexors and extensors and grip strength will be tested three times with at least 30s interval, at the dominant side of the body. The test protocols are adopted from Beenakker et al. (2001) and for grip strength from Wind et al. (2009) to enable comparison with age- and sex-matched Dutch reference values from those studies [23-24]. The highest force generated will be taken as the final score. In case of burn scars over or close to a joint, the involved muscle groups will be tested at both sides of the body, so that scores of the burned and non-burned side can be compared.

- **Body composition**

  The outcome variables for body composition are height, weight, body mass index (BMI), waist circumference and skinfold thicknesses (Table 3). Body height will be measured to the nearest centimeter with a “wall”-mounted stadiometer, and body weight will be measured with an electronic scale, to the nearest 100 gram. Calculated BMI values (kg/m\(^2\)) \(\frac{\text{weight (kg)}}{\text{height (m)^2}}\) will be compared with age- and sex-matched reference values from TNO [25].
<table>
<thead>
<tr>
<th>Construct</th>
<th>Component</th>
<th>Variable (Instrument)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical fitness</td>
<td>Cardiorespiratory endurance</td>
<td><strong>Aerobic exercise capacity</strong> (Cycle ergometer + gas analyzer)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$\text{VO}_2\text{peak} \ [\text{ml\cdot min}^{-1}]$</td>
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<tr>
<td></td>
<td></td>
<td>$\text{VO}_2\text{peak relative for weight} \ [\text{ml\cdot kg}^{-1\cdot \text{min}}]$</td>
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<td></td>
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<td>$%\text{HR}_01 \ [%]$</td>
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<td></td>
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<td>$%\text{HR}_02 \ [%]$</td>
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<td></td>
<td>$WR_{\text{peak}} \ [\text{W}]$</td>
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<tr>
<td></td>
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<td>$DE \ [\text{ml\cdot min}^{-1}/WR_{\text{peak}}]$</td>
</tr>
<tr>
<td>Muscular strength</td>
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<td><strong>Maximal force</strong> (Hand-held dynamometer)</td>
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<td></td>
<td></td>
<td>$\text{Grip strength} \ [\text{N}]$</td>
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<tr>
<td></td>
<td></td>
<td>$\text{Elbow flexors &amp; extensors} \ [\text{N}]$</td>
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<td></td>
<td></td>
<td>$\text{Shoulder abductors} \ [\text{N}]$</td>
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<tr>
<td></td>
<td></td>
<td>$\text{Knee flexors &amp; extensors} \ [\text{N}]$</td>
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<tr>
<td>Body composition</td>
<td></td>
<td><strong>Height</strong> (Stadiometer)</td>
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<tr>
<td></td>
<td></td>
<td><strong>Weight</strong> (Electronic scale)</td>
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<tr>
<td></td>
<td></td>
<td><strong>Waist circumference</strong> [cm] (Measuring tape)</td>
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<tr>
<td></td>
<td></td>
<td><strong>Skinfold thickness</strong> sum of four thicknesses [mm] (Caliper)</td>
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<tr>
<td>Flexibility</td>
<td></td>
<td><strong>Range of motion</strong> (Goniometer)</td>
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<tr>
<td></td>
<td></td>
<td>$\text{Wrist dorsal &amp; palmar extension} \ [\text{degrees}]$</td>
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<tr>
<td></td>
<td></td>
<td>$\text{Elbow flexion &amp; extension} \ [\text{degrees}]$</td>
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<tr>
<td></td>
<td></td>
<td>$\text{Shoulder anteflexion} \ [\text{degrees}]$</td>
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<td></td>
<td></td>
<td>$\text{Knee flexion &amp; extension} \ [\text{degrees}]$</td>
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<tr>
<td></td>
<td></td>
<td>$\text{Ankle plantar &amp; dorsal extension} \ [\text{degrees}]$</td>
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<tr>
<td>Physical activity</td>
<td></td>
<td><strong>Objectively assessed physical activity</strong> (Accelerometer)</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Self-reported physical activity</strong> (Activity questionnaire, 16 items)</td>
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<tr>
<td></td>
<td></td>
<td>Subscale Dutch Standard Questionnaire for Activity (12 items)</td>
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<td>Subscale FIT Norm (2 items)</td>
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<td></td>
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<td>Subscale Dutch Activity Norm (2 items)</td>
</tr>
<tr>
<td>Health-related quality of life</td>
<td></td>
<td><strong>Health-related quality of life</strong> (Burn Outcomes Questionnaire, 53 items)</td>
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<tr>
<td></td>
<td></td>
<td>Subscale upper extremity function (7 items)</td>
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<td>Subscale physical function and sports (6 items)</td>
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<tr>
<td></td>
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<td>Subscale transfers and mobility (5 items)</td>
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<td></td>
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<td>Subscale pain (2 items)</td>
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<td></td>
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<td>Subscale itch (2 items)</td>
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<td>Subscale appearance (4 items)</td>
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<td>Subscale compliance (5 items)</td>
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<td>Subscale satisfaction with current state (7 items)</td>
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<td></td>
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<td>Subscale emotional health (4 items)</td>
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<tr>
<td></td>
<td></td>
<td>Subscale family disruption (5 items)</td>
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</tbody>
</table>
Waist circumference will be measured with a tape (measure tape 201, Seca, Hamburg, Germany), at the smallest area between the lowest rib and the hip-bone. Scores will be compared to Dutch values obtained from TNO [26].

Skinfold thicknesses will be assessed using a Harpenden skinfold caliper (Baty International, West Sussex, England) according to the protocol by Gerver & De Bruin (1996) which enables comparison with the age- and sex-matched reference values presented in that study [27]. At each site three measures will be taken, from which an average score will be calculated and used as the final score. When a site of measurement is scarred skinfold measurement will be not performed at that site.

- **Flexibility**

  Passive joint range of motion (in degrees) will be measured around wrist, elbow, shoulder, knee and ankle on the dominant side of the body with a goniometer (Gollehon extendable goniometer 01135, Lafayette Instrument, Lafayette, U.S.A.), see Table 3. In case of burn scars over or surrounding a specific joint, this joint will be measured at both sides of the body to enable comparison. Standardized measurement protocols and, for comparison, Dutch reference values will be used [28; personal communications].

### Physical activity

Physical activity will be monitored using objective, quantitative assessment as well as self-report (Table 3). For the objective measure of daily physical activity accelerometry will be applied. The ActiGraph accelerometer (GT3X+, ActiGraph, Pensacola, Florida, U.S.A.) will be worn on the right hip for seven consecutive days to monitor physical activity and gives activity counts as output [29]. Additionally, subjects will briefly report their activities as well as for which period during the day the accelerometer is worn.

To gain insight in the habitual physical activity and participation in sports of children after burns an activity questionnaire is used. The questions covering the Dutch physical activity guidelines (‘Dutch Norm for Healthy Activity’ and ‘Fit’-norm [30,31]) are put together with the ‘Standard Questionnaire for Activity’ [31,32] (Table 3). The first two enable comparisons with Dutch norms, while the latter includes questions about transfer activities, sport participation and sedentary behavior (TV, gaming). A parental version for parents of children aged 6 to 11 and a version for children up from the age of 12 will be used.

### Health-related quality of life

As HRQoL is an experienced state, it will be subjectively measured using a child- and burn-specific questionnaire: the Dutch version of the American Burn Association/Shriners’ Hospital for Children Burn Outcomes Questionnaire (BOQ) is used, which had proven to be a feasible, reliable and valid instrument, also in the Dutch population of children with burns [33]. The BOQ assesses 12 functional and psychosocial domain scales and, for example, includes items on comorbidity, functioning at school and participation in leisure time activities, see Table 3. The parental proxy version will be applied for children up to and including 11 years of age and the adolescent version will be used for children aged 12 and older.

### Fatigue

Perceived fatigue will be measured with the Dutch version of the 18-item PedsQL Multidimensional Fatigue Scale [34]. This scale, designed to measure fatigue in pediatric patients, comprises three subscales: the General Fatigue, Sleep/Rest Fatigue and Cognitive Fatigue (Table 3). The Dutch version has recently demonstrated adequate feasibility, reliability and validity [35]. Age-specific versions of both child and parent reports will be used for the age groups 6–7 years, 8–12 years and 13–18 years.

### Data analyses

Descriptive statistics will be used to present subjects’ demographic and burn characteristics and also for quantitative data attained from fitness tests and physical activity monitoring. To find out whether differences in physical fitness exist between children after burn injury and the general population of Dutch children, data from the fitness assessments will be compared to reference values from the literature. To this end, data will be transformed into Z-scores.
based on the reference values and independent t-tests will be used.

To determine associations between the physical fitness (primary outcome parameter: VO2peak) and the amount of physical activity (total activity counts), Pearson correlation coefficients will be calculated. Associations between the individual characteristics and the outcome parameters for fitness, activity, HRQoL and fatigue will be calculated by Pearson or Spearman’s correlation coefficients, depending on the scale of measurement and on the distribution of the data. Regression and/or modeling may additionally be used. IBM SPSS Statistics version 20 will be used for analyses.

**Discussion**

The current paper describes the rationale, design and methods of a cross-sectional study concerning physical fitness and physical activity in children after burn injury. The study aims to determine the levels of physical fitness and physical activity in children after a burn injury and to place these findings in a multidimensional context, taking into account the experienced HRQoL and fatigue after burns, as well as several demographic and burn characteristics.

As objective measurements are chosen where possible and as the study procedures are standardized and adopted from the studies of which Dutch reference values will be used, we feel that the presented design and methods are strong. All physical fitness assessments will be done by the same rater, using the same instruments and will take place at the same location. Moreover, the use of the mobile exercise lab strongly minimizes the inconvenience of participation and with that is expected to maximize the participation rate. The study population is expected to form a good representation of the general population of children and adolescents with burns.

New insights gained from this study can stimulate and guide the improvement of rehabilitation protocols to facilitate a timely and optimal functional recovery of children after burns. As the study is done in close collaboration with the Association of Dutch Burn Centers knowledge transfer is evident and chances of implementation are promising. Overall, this unique study will contribute to a better understanding of the consequences of pediatric burn injury on physical functioning on the long term and to improvement of outcomes for people after burn injury in future.

**Abbreviations**

BOQ: Burns Outcomes Questionnaire; Bpm: Heartbeats per minute; VO2: Carbon dioxide output; DE: Delta efficiency; HRPO1: HR-PO2; Recovery of heart rate during the second minute in rest after the test; HRpeak: Peak heart rate; HRQoL: Health-related quality of life; PedsQL-MFS: PedsQL Multidimensional Fatigue Scale; TBSA: Total body surface area; VE: Minute ventilation; VO2peak: Peak volume oxygen uptake; WRpeak: Peak work rate on cycle ergometer.

**Competing interests**
The authors declare that they have no competing interests.

**Authors’ contribution**
MKN and LMD developed the study design, for which GJUMB, TT and MVB used their expertise to advice on the measures chosen in the protocol. LHVVDW and LJM substantially contributed to the realization of this paper. All authors have critically revised the manuscript. They all read and approved the final version for publication.

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**References**


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Chapter 5

**Anthropometry, muscular strength and aerobic capacity up to 5 years after moderate to severe pediatric burns: a cross-sectional study.**

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Anthropometry, muscular strength and aerobic capacity up to 5 years after moderate to severe pediatric burns: a cross-sectional study

Abstract

Objective: To describe anthropometry, muscular strength and aerobic capacity in children and adolescents up to 5 years after moderate to severe burns.

Design: Cross-sectional descriptive study

Setting: A mobile exercise lab, The Netherlands

Subjects: Children and adolescents aged 6-18 years were invited to participate if admitted to one of the three dedicated Dutch burn centers between 0.5-5 years ago with burns involving at least 10% of the total body surface area (% TBSA) or with a length of stay of more than 6 weeks. Inclusion rate was 56.8%. Assessments were completed by 24 subjects (58.3% male; 6-18 years; 10-41% TBSA; 1-5 years post burn).

Main measures: Demographics, burn characteristics and anthropometrics were recorded. Muscular strength in six muscle groups and aerobic capacity were measured using hand-held dynamometry and a graded cardiopulmonary exercise test, respectively. Subjects’ scores were compared with Dutch age- and sex-matched norm values and converted to Z-scores.

Results: On group level, no significant differences between the subjects’ scores and norm values were found. Individually, eight subjects (33.3%), mostly aged 6 or 7, showed significantly low performance on at least one variable: seven for strength, one for aerobic capacity and one for both. No trends were seen indicating an effect of extent of burn or time post burn.

Conclusion: Anthropometry, muscular strength and aerobic capacity are adequate in the majority of Dutch children and adolescents 1-5 years after moderate to severe burns.
Introduction

Children form a large risk group for burn injury; they account for approximately one-third of all admissions in Dutch burn centers. Burn injuries can have a major impact on physical functioning, for example due to scarring, in both the short and long term. Patients with burns are at risk of getting into the so-called negative spiral of deconditioning, where a condition leads consecutively to inactivity, ongoing deconditioning, deterioration of functioning and, finally, to possible disability. This is highly undesirable considering functioning and participation in daily life, especially in pediatric burn survivors since childhood is a critical life period for development during which also a basis is laid to prevent deficits and disease throughout life.

Deconditioning after pediatric burns is a serious concern, as physical fitness was shown to be significantly affected in children with extensive injuries (for review see Disseldorp et al., 2011). Deconditioning after burns is assumed to be induced by (the combination of) prolonged hospitalization and the consequences of the injury itself. Hospitalization (i.e. prolonged bed rest, immobilization, inactivity) after burns can result in a decrease in heart and lung capacity and in peripheral effects like muscle atrophy, osteoporosis and contractures. Furthermore, extensive burn injuries result in a severe state of disease, provoked by the stress-induced release of inflammatory mediators and stress hormones. This pathophysiologic response is characterized by hypermetabolism, increased catabolism (e.g. of muscle and bone minerals) and insulin resistance.

The current paper is specifically focused on components of physical fitness that the combination of inactivity and pathophysiological consequences of burn injury interfere with. Firstly, several pediatric studies indicated growth delays in both height and weight up to 3 years after extensive burn injury, due to altered energy expenditure, indicating that anthropometry is affected. Secondly, muscular strength is affected after burns as the increased protein demand leads to catabolism and results in loss of muscle mass. Recent studies additionally suggest impact on mitochondrial function and gene expression in skeletal muscle in a non-burned limb, but full comprehension of
these processes is still lacking. Aerobic capacity, lastly, can be affected by a combination of, for example metabolic, muscular and cardiorespiratory, effects.\(^4, 13, 17, 18\)

However, the current knowledge on physical outcomes is limited and can therefore hardly be generalized.\(^8\) Firstly, all this information is based on children with extensive burn injuries, whereas the impact of less extensive burns on physical outcomes is hitherto neglected in the literature. The studies on pediatric burns solely included children with burn injuries covering >40% of the total body surface area (%TBSA). Such major pediatric burn injuries are rare in the Netherlands and the US\(^1, 19\), i.e. represent <5% of cases, and this will probably also apply for other developed countries. Since the current knowledge is based on a selection with respect to extent of burn, it is not representative for the general pediatric burn population. Secondly, the assessments were performed relatively short post burn, considering the severity of the injuries plus long hospitalization. Hence, the results are not necessarily representative for longer term outcomes. Furthermore, the physical outcomes after pediatric burns depend on more factors than burn characteristics only.\(^20\)

All in all, it is yet unknown whether physical fitness is affected in pediatric burn patients with less extensive burns and/or at a longer period post burn. The current paper therefore aims to describe anthropometry, muscular strength and aerobic capacity in Dutch children and adolescents with a wide range of burn characteristics, also in comparison to norm values of non-burned peers.

**Methods**

**Subjects**

Between August and December 2012, children and adolescents aged 6 - 18 years were invited to participate if they had been admitted to one of the three Dutch burn centers between 0.5 and 5 years ago with burn injuries of at least 10% TBSA and/or had a length of stay of more than 6 weeks. Extensive (pre-existing) comorbidity or (mental) disabilities and insufficient Dutch language proficiency were criteria for exclusion. Informed consent, signed by the participant aged 18 years or
by parents / legal representatives and children 12 years and older, was required for participation, as well as a signed pediatric Exercise Pre-participation Screening questionnaire\textsuperscript{21}. The Medical Ethical Committee of the University Medical Center Groningen approved this study (NL40183.042.12).

Data collection
The protocols for data collection were described in detail previously \textsuperscript{22}. Anthropometry, muscular strength and aerobic capacity were assessed in a mobile exercise lab and all data collection has been done by the same researcher.

Subject characteristics Age, sex, 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 for all subjects. These data were also obtained, anonymously, for non-participants to enable a non-response analysis.

Anthropometry Body height and weight were assessed using a “wall”-mounted stadiometer (Seca 206, Seca, Hamburg, Germany) and an electronic scale (Seca 803, Seca, Hamburg, Germany), respectively. Waist circumference was measured in centimeters with a tape (measure tape 201, Seca, Hamburg, Germany) between the lowest rib and the hip-bone \textsuperscript{23}. Skinfold thicknesses were measured in millimeters with a Harpenden skinfold caliper (Baty International, West Sussex, England) at the triceps, biceps, subscapular and supra-iliacal site \textsuperscript{24}.

Muscular strength A hand-held dynamometer (Citec, type CT 3001, CIT Techniques, Groningen, The Netherlands) was used to assess muscular strength [N] in shoulder abductors, knee flexors and extensors, elbow flexors and extensors and grip strength \textsuperscript{25}. For grip strength assessment, a special full-fist applicator was used \textsuperscript{26}.

Aerobic capacity Aerobic capacity was assessed with a graded cardiopulmonary exercise test on an electronically braked cycle ergometer (Lode Corrival, Lode, ProCare BV, Groningen, The Netherlands)\textsuperscript{27}. During the exercise test, subjects breathed through a face mask connected to a
calibrated mobile metabolic cart (Cortex Metamax, Cortex Medical, Leipzig, Germany), used for breath-by-breath analyses. Additionally, a pulse-oximeter and a coded heart rate sensor (Polar T31™ transmitter, Polar, Kempele, Finland) were used to continuously monitor saturation of the blood and heart rate (in beats per minute), respectively. The instrumented participants started with three minutes sitting in rest, followed by a three minutes warming-up of unloaded cycling. Thereafter, the work rate (WR [W]) increased with 10, 15 or 20 W*min⁻¹, dependent on body height according to the Godfrey protocol 27, 28. Participants were instructed to maintain a pedaling rate of 60-80 revolutions·min⁻¹ and verbal encouragement was given during the test. The MetaSoft software (Cortex Medical, Leipzig, Germany) provided output for analyses of the exercise test values. Peak exercise oxygen uptake (VO₂peak) was calculated by averaging the values taken from the last 30 seconds of the test. Only tests in which the participant reached maximal level of effort were analyzed; the criteria for maximal effort were a heart rate ≥ 180 and/or a respiratory exchange ratio (RER) ≥ 1.0 at peak exercise 29. Main outcome variables were VO₂peak [ml·min⁻¹], VO₂peak/kg [ml·kg⁻¹·min⁻¹], WR [W] and WR/kg [W·kg⁻¹].

Data processing

Subject characteristics. For the non-response analysis participating subjects and the non-participants were compared on age, gender, extent of burn, time post burn, the number of surgeries and length of stay, using a Mann-Whitney U test.

Outcome analyses. To evaluate whether the subjects displayed affected anthropometry, muscular strength and/or aerobic capacity, their outcomes were compared to the most recently published age- and sex-matched Dutch norm values 23-27, 30, 31 (table 1), which had been obtained using the same protocols and instruments. As for some variables the norm values were not available for all ages, additional data were obtained from original authors 26, 27 and/or extrapolation or supplement data 32 were used based on expert opinion, see Table 1. Using the norm values, results were converted into Z-scores to report individual performance and to equalize influence of all participants on the group.
mean. Based on the $\alpha = .05$ level, Z-scores < -1.96 or > 1.96 represent scores significantly deviant from the norm. For strength scores an individual mean Z-score was calculated, based on the individual Z-scores on all strength variables. No subgroup analyses were performed due to the small sample size. Scatter plots with $R^2$-values were used to indicate possible associations between outcomes and burn characteristics. IBM SPSS Statistics 20 was used for general data analyses and Microsoft Excel 2010 for the extrapolations.

**Results**

**Inclusion**

In total 56 children and adolescents were identified in the Dutch Burn Repository whom met the eligibility criteria. Of those, eight were excluded (one deceased; two had (mental) disabilities; two lived abroad; three turned 19 before assessment would take place). Another four could not be contacted. Therefore, 44 children and adolescents were invited to participate. Of these 44, seven sent back the form that he/she would not participate and 12 did not respond to the postings. Signed informed consent(s) were obtained from 25 subjects; the inclusion rate was 56.8%. Results are given for 24 subjects instead of 25 however, as one subject (> 40% TBSA) was anatomically and functionally not able to execute the assessments of the current study, as a consequence of the burn accident. A non-response analyses was performed based on 23 non-participants: the 4 that could not be contacted, the 7 non-participating responders and the 12 non-responders.

**Subject characteristics**

Among the 24 subjects (58.3% boys) included in the data analyses, the average extent of burn was 18.1% TBSA (Table 2). Seven subjects displayed burns of more than 20% TBSA. Average time post burn was 3.0 years (Table 2). Length of stay at the burn center varied between 5 and 78 days, with 77.3% (17 subjects) discharged within four weeks post burn. Three subjects had no surgery at all.
during initial hospitalization and nobody had suffered inhalation injury. None of the subjects underwent surgery for (at least two) months before assessments.

The distribution of sex ($p = .861$), age ($p = .766$), age at the time of the burn injury ($p = .949$), extent of burn ($p = .462$), time post burn ($p = .101$), number of surgeries ($p = .475$) and length of stay ($p = .297$) were the same across the group of subjects’ and the group of non-participants’. The high average of extent of burn and the wide range of number of surgeries and of the length of stay in the non-participants group, Table 2, is explained by three exceptionally extensively burned non-participants (55% -65% TBSA).

**Anthropometry**

No significant deviations from the norm were observed in the group means for all anthropometric variables (Table 3). Generally, the subjects tended to be slightly and non-significantly shorter and ‘rounder’ (height, BMI, waist circumference) than the Dutch norm populations$^{23, 30, 31}$. Three children showed significantly high values on body-fat related variables. Note that analyses on the sum of four skinfold thicknesses were based on 22 subjects instead of 24, due to severe scarring on measurement sites impeding assessment.

**Muscular strength**

None of the muscular strength variables group means was significantly different from the norm values$^{25}$ (Table 3). The performances on grip strength measures, which is considered to represent overall muscular strength$^{26}$, were within normal ranges with one exception: a significantly high score (Z-score=2.0). The individual mean Z-score for strength, which is based on the individual Z-scores on all strength variables, was significantly low for one subject (7 years old, about 2.5 years post-burn). In the majority of subjects, strength values for shoulder abduction, knee extension and knee flexion were below the norm but not statistically significantly. In total, seven subjects (30.4%) showed significantly low strength in at least one muscle group (there were nine significantly low
scores on a total of 136 strength measurements). Five out of these seven subjects were aged 6 or 7. No trend indicating an effect of the extent of burn or time post burn on muscular strength outcomes was observed in the data (Figure 2).

**Aerobic capacity**

All 24 subjects completed the CPET without complications. Nevertheless, aerobic capacity analyses are based on 22 subjects (Table 3), as data of two 7-year-olds (10% TBSA and 37% TBSA) had to be excluded because criteria for maximal effort (HR ≥ 180 and/or RER ≥ 1.0) were not met. The 22 subjects did not differ from the norm population of Bongers et al. (2012)27 in terms of height and weight.

No significant deviations from the norm were observed in the group means for VO$_{2peak}$, VO$_{2peak}$/kg, WR$_{peak}$ and WR$_{peak}$/kg (Table 3). For VO$_{2peak}$ Z-scores ranged from -2.0 to 1.12. 11 subjects scored higher than the matched norm value and 11 scored equal to or lower than the norm; one subject (10% TBSA) scored significantly below the norm (Table 3 and Figure 3). For VO$_{2peak}$/kg two subjects scored significantly above the norm, whereas one subject (41% TBSA) scored significantly below the norm. No trend indicating an effect of the extent of burn or time post burn on VO$_{2peak}$ was seen in the data (Figure 3). For work rate all subjects scored within normal ranges (Table 3).
Discussion

On group level no significant differences in anthropometry, muscular strength and aerobic capacity were found between children and adolescents 1-5 years after moderate and severe burns (10-41% TBSA) and matched Dutch norm values. Furthermore, no trends indicating an effect of extent of burn or time post burn on muscular strength or aerobic capacity were found. On individual level, seven subjects showed a significantly low score on one or more strength variables and two on an aerobic capacity variable.

Regarding the subjects with lower scores on strength, it should be noted that five out of these seven subjects were only 6 or 7 years old. It is likely that for these young children their performance was also influenced by motivation and/or comprehension. Furthermore, regarding the strength data as a whole, we must remark that the norm values fluctuate strongly with age. This might relate to the measurement of choice, as the reliability of hand-held dynamometry is dubious. Nevertheless, hand-held dynamometry is definitely the most feasible measurement available and the most widely used in the clinic.

Comparison with the literature

Other recent studies on physical capacity on pediatric burns all originate from the same research group at Shriners Hospitals for Children (Galveston, Texas) and indicated that subjects with pediatric burns had low lean body mass, knee extensor strength and peak oxygen uptake. Our results, however, should not be compared to these results because of two essential population differences, namely in extent of burn and time of assessments post burn. Firstly, in our population the average extent of burn was 18.1%, compared to an average of around 55% TBSA in Shriners’ studies. It can be assumed that our subjects deconditioned less, possibly owing to less severe hypermetabolism and catabolism and shorter periods of bed rest and inactivity. Secondly, time of assessment in our study population was 1 to 5 years post burn, compared to 1 year post burn in the Shriners’ studies.
This longer period post burn offered more time for recovery of disturbed physiological processes as well as time to resume daily activities and/or training to (re)gain, for example, muscular strength. In the study of Baker et al.\textsuperscript{9}, with also a longer period between injury and assessment, results showed that at 14±5 years post burn 35% of the 83 included subjects had deficits in muscular strength in any part of the body. However, again only subjects with very extensive burns were involved (52%±20% TBSA).

Though comparable long-term studies in children after burns are not available, the study from Ganio et al. (2013)\textsuperscript{36} on adult burn survivors is interesting for comparison. Ganio and colleagues measured aerobic capacity in 25 adults after burns (17-75% TBSA split-thickness grafts; 1-51 years post burn) and reported that aerobic capacity was disproportionally lower than the age-matched norm values in at least 80% of the adults. Interestingly, the decrements in aerobic capacity were found to be unrelated to the extent of burn or time post burn. The authors emphasized that the mechanisms by which these burn survivors have such low aerobic capacities remain unclear, though they suggested substantial influence of (low) physical activity levels after full recovery of burn injury\textsuperscript{36}. We endorse this suggestion.

A possible explanation for the different findings in children and adults might then be that children are both more resilient and more active naturally, which enhances physical outcomes. Pediatric burn survivors appear to cope better than adults\textsuperscript{37} and whereas adult burn patients tend to pull away from activities\textsuperscript{38}, for children the time to reintegration in school is short\textsuperscript{39}. However, these explanations are still speculative as conclusive evidence is lacking. All in all, the current results are novel and provide an interesting addition to the previously published literature.

\textit{Study population}

We consider our study population convenient for this pediatric burn study and the outcomes representative for the majority of moderate to severe pediatric burn patients in the Netherlands. Firstly, we found the inclusion rate of 56.8% satisfactory, also taking into account what the children and parents had already been through due to the burns. We assume that the use of the mobile
exercise lab has contributed to this inclusion rate, as participants did not have to invest time or
effort in traveling for the assessments. Furthermore, the mobile exercise lab might have made the
study more appealing and it has definitely improved the feasibility of the study. The use of Z-scores
and exhaustive description of the results compensate the statistical limitations of the sample size of
24. Secondly, the study population showed wide ranges in demographics and burn characteristics, as
was intended for this study. For time post burn, our subjects showed a nice distribution between the
limits of 0.5 to 5 years, supported by the average of 3.0 years post burn. With inclusion up from 10%
TBSA, the subjects had moderate to severe burns ranging from 10% to 41% TBSA, of which most
were less than 20% TBSA. The non-response analyses underlined that, in terms of demographics and
burn characteristics, our study population was a representative sample. However, it must be pointed
out that of all eligible children, the four with the most extensive burns did not participate in the
assessments of the current study. Furthermore, a possible selection bias could be that children and
adolescents who were more interested in sports and an active, healthy lifestyle, or have parents
who were thus inclined, were more likely to participate than those who were not. An active lifestyle
is reflected in better physical performance and, moreover, in children after burns structured exercise
has proven to significantly increase the aerobic capacity. Inclusion of the more physically active
children in the population would create a positively distorted perspective about the aerobic exercise
capacity after burns.

Future research

The current study has made a start in filling the hiatus in knowledge on physical fitness after
pediatric burns and has set a standard for interpretation of future results. We hope to encourage
others around the world to address this theme in the near future and that the knowledge that long-
term outcomes can be positive, inspires to aim for an early recovery of physical fitness after burns.

The current results on physical fitness are part of a larger multidimensional study which also
comprised physical activity measures and questionnaires on health-related quality of life and fatigue,
which are currently being analyzed. It will be very interesting to see how subjects’ fitness levels relate to activity levels, health-related quality of life and feelings of fatigue. We are well aware that this paper focuses only on the physical aspects, while psychological and social issues can influence functioning and participation after burns as well. The barriers and motivation to perform physical activity and exercise after pediatric burns are another interesting topic for further research. Lastly, the evolution of physical fitness and activity after burns in (Dutch) adults deserves attention as well.

Clinical message

- Anthropometry, muscular strength and aerobic exercise capacity are on group level adequate in Dutch children and adolescents on the long term after moderate to severe burns, despite individual deficits.
- Trends indicating an effect of extent of burn or of time post burn on muscular strength or aerobic capacity were not seen in the current data.
- For long-term clinical outcome studies we recommend the use of a mobile exercise lab to improve feasibility and inclusion rate.

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<table>
<thead>
<tr>
<th>Variable</th>
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<tbody>
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<tr>
<td>- Height</td>
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<tr>
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<td>17-18 yr. extrapolation</td>
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<td>- Shoulder abduction</td>
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<td>17-18 yr. extrapolation</td>
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<td>- Grip strength *</td>
<td>Wind et al. (2009)</td>
<td>6-8 yr. extrapolation</td>
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<td><strong>Aerobic capacity</strong></td>
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<td>&lt;7.5 yr. Binkhorst et al.</td>
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</table>

NA, not applied; yr, years of age; *Data was published only in graphs, upon request data were provided by the authors of the source publication to enable Z-score calculation.
<table>
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<th>Subjects</th>
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<th>Age at incident (yr)</th>
<th>% TBSA</th>
<th># ≤ 20%</th>
<th># &gt; 40%</th>
<th>Years post burn</th>
<th>Surgeries (#)</th>
<th>Length of stay (days)</th>
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<td>13 (56.5)</td>
<td>8.58</td>
<td>2-17</td>
<td>24.2</td>
<td>10-65</td>
<td>15</td>
<td>4</td>
</tr>
</tbody>
</table>

#, number; %, percentage; yr, years; % TBSA, percentage of total body surface area involved in burn injury
Table 3. Observed values, Z-scores and additional comparisons with the norm values for all measured variables

<table>
<thead>
<tr>
<th>Metric</th>
<th>n</th>
<th>Observed values</th>
<th>Z-scores</th>
<th>Comparison with norm</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Min</td>
</tr>
<tr>
<td><strong>Anthropometry</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Height [cm]</td>
<td>24</td>
<td>146.77</td>
<td>23.49</td>
<td>119.50</td>
</tr>
<tr>
<td>Weight [kg]</td>
<td>24</td>
<td>41.59</td>
<td>18.63</td>
<td>22.10</td>
</tr>
<tr>
<td>BMI [kg/m²]</td>
<td>24</td>
<td>18.27</td>
<td>2.90</td>
<td>14.10</td>
</tr>
<tr>
<td>Waist circumference [cm]</td>
<td>24</td>
<td>63.02</td>
<td>8.19</td>
<td>51.00</td>
</tr>
<tr>
<td>Skinfold thickness [mm]</td>
<td>22</td>
<td>27.54</td>
<td>6.58</td>
<td>20.95</td>
</tr>
<tr>
<td><strong>Muscular strength [Newton]</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elbow flexion</td>
<td>23</td>
<td>173.61</td>
<td>90.59</td>
<td>71</td>
</tr>
<tr>
<td>Elbow extension</td>
<td>22</td>
<td>122.91</td>
<td>62.69</td>
<td>44</td>
</tr>
<tr>
<td>Shoulder abduction</td>
<td>22</td>
<td>115.63</td>
<td>58.48</td>
<td>38</td>
</tr>
<tr>
<td>Knee flexion</td>
<td>23</td>
<td>194.09</td>
<td>91.67</td>
<td>76</td>
</tr>
<tr>
<td>Knee extension</td>
<td>23</td>
<td>255.78</td>
<td>111.84</td>
<td>106</td>
</tr>
<tr>
<td>Grip strength</td>
<td>22</td>
<td>93.05</td>
<td>58.61</td>
<td>29</td>
</tr>
<tr>
<td>Individual mean Z-score</td>
<td>23</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Aerobic capacity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VO₂peak [L/min⁻¹]</td>
<td>22</td>
<td>1.91</td>
<td>.86</td>
<td>.84</td>
</tr>
<tr>
<td>VO₂peak per kg [mLkg⁻¹min⁻¹]</td>
<td>22</td>
<td>44.49</td>
<td>7.6</td>
<td>28.20</td>
</tr>
<tr>
<td>WRpeak [W]</td>
<td>22</td>
<td>151.41</td>
<td>81.4</td>
<td>55</td>
</tr>
<tr>
<td>WRpeak per kg [Wkg⁻¹]</td>
<td>22</td>
<td>3.37</td>
<td>.68</td>
<td>2.20</td>
</tr>
</tbody>
</table>

SD, standard deviation; #, number; VO₂peak = oxygen uptake at peak exercise; WRpeak = peak work rate
Figure 1. Muscular strength outcomes, i.e. the individual mean of Z-scores for all strength variables, including trendline-based associations ($R^2$) to the extent of burn and time post burn.

- For age [years], $R^2 = .004$
- For % TBSA, $R^2 = .030$
- For time post burn [years], $R^2 = .030$
Figure 2. Aerobic capacity outcomes, given in Z-scores for VO$_2$peak and VO$_2$peak/kg, including trendline-based associations ($R^2$) to extent of burn and time post burn.


Chapter 6. Summary and general discussion

Summary

Objectives

The overall aim of this dissertation is to gain insight into physical functioning after pediatric burns in the Netherlands. Beyond that, as part of a broader line of research, it is intended to support clinical practice in its efforts to assist patients in a timely and optimal physical recovery. This dissertation provides a compilation of results of studies on functional independence and physical fitness in children and adolescents after burn injury in the Netherlands.

The most important aims of the separate chapters were to:

- Determine functional independence throughout the first six months after pediatric burn injury
- Review the international literature in order to provide insight into physical fitness in people after burn injury and the effects of exercise programs
- Introduce the rationale and methods of a multidimensional study on physical fitness, physical activity, health-related quality of life and fatigue in children and adolescents after pediatric burns in the Netherlands
- Present the results on anthropometry, muscular strength and aerobic capacity up to five years after pediatric burns

Main findings

CHAPTER 2 focused on the level of functional independence, i.e. the performance of tasks of daily living without help/assistance from a person or device, in children with burns in the short term. More specifically, functional independence was determined on 18 items in the domains of self-care, mobility and cognition using the WeeFIM© instrument. Assessment took place at approximately two weeks, three months and six months post burn during either hospitalization or an already planned follow-up appointment. Subjects in this study were 119 pediatric patients (0.5-16 years) who had been admitted to a Dutch burn center for at least 24 hours. Inclusion rate was 86%, but in the course of the study subjects were lost to follow-up. At two weeks post burn 117 children were assessed, 22 of which showed affected functional independence in comparison to American norm values. 68 children were assessed at three months post burn and 38 at six months post burn. At both these time
points, nine children (7.6% of the total study population) showed affected functional independence. Four children showed affected functional independence at all three assessments. Three of them had extensive burns; the other child’s low level of independence, however, was not due to burn injury but to cultural influence. The subgroup with burns >10% TBSA relatively accounted for the most affected children at each time of assessment. The study population showed significant improvement in WeeFIM© scores between two weeks post burn and six months post burn. The WeeFIM© instrument was found to be a feasible measure and sensitive to change in this study; nevertheless there were drawbacks to its use in this specific setting and population. To conclude, burn injury impacts functional independence in the short term, but at three months post burn the majority of children demonstrate adequate functional independence for their age. It is, however, important to keep an eye on those who tend to fall behind to prevent difficulties later in life.

The next chapters, i.e. chapters 3, 4 and 5, focused on longer term outcomes and on capacity rather than daily life performance. The central theme in these chapters is physical fitness. Physical fitness is considered an important measure of health, as a good level of fitness is related to lower risk of illness and an improved quality of life.  

CHAPTER 3 comprised a systematic review of the burn literature on physical fitness, aiming 1) to gain insight into physical fitness in both children and adults after burn injury and 2) to present an overview of the effectiveness of exercise training programs in improving physical fitness after burns. Inclusion criteria were objective measurements and quantitative data on both the study population and the control group. Eleven studies were included and assessed on methodological quality: six studies for the first aim and nine for the second, as four studies were included in both parts of the review. The five components of health-related physical fitness as defined by Caspersen, i.e. body composition, muscular strength, muscular endurance, cardiorespiratory endurance and flexibility, were used as a framework to structure results. Three main conclusions were drawn: 1) children and adults with extensive burns score worse than non-burned controls on all five components of physical fitness; 2) burn patients who participated in an exercise training program improved more on all components than burn patients without this specific training; and 3) although this knowledge is highly relevant, it is also very incomplete. The number of studies was limited and the number of institutes that had published on this topic was even smaller, as nine out of the eleven studies originated from the same institute. But above all, the incompleteness was due to great similarities in the included studies. In the comparison of physical fitness between burned and non-burned subjects, five out of six studies included children, all with very extensive burns (mean % TBSA range: 53.5-58.8). This is an exceptional selection of pediatric burn patients, considering both the low prevalence and the associated physiological consequences of such extensive burns, which makes the findings of the review not generalizable to the general, and in
this case: Dutch, pediatric burn population. Besides the extent of burn, time post burn was a factor: all measures were done at six and nine (and in one study: twelve) months post burn, which is relatively short-term considering the severe physiological impact plus the long period of bed rest following such extensive burns.

To fill the hiatus in current knowledge that was uncovered in the review and to put physical fitness in context, a cross-sectional study was set up. **CHAPTER 4** described the rationale, design and methods of this study, which in addition to multiple physical fitness measures also comprised measures of physical activity, health-related quality of life (HRQoL) and fatigue. The multidimensional design was chosen because it provides a more comprehensive view on physical functioning after pediatric burns. This was illustrated in a conceptual model with physical fitness, physical activity, HRQoL and fatigue as the central themes, also including personal and environmental factors and burn characteristics. An overview of how these constructs are operationalized in the study was presented in chapter 4. The outcomes of the study would enable an exploration of both interrelations between the central themes and associations with burn characteristics. The study aimed at longer term outcomes in Dutch pediatric burn patients and the design paper emphasized that inclusion of children and adolescents with a great diversity in age (6-18 years), extent of burn (≥10% TBSA) and time post burn (0.5-5 years) was aimed for, in order to obtain a fair representation of the population. Furthermore, the design paper introduced the use of a mobile exercise lab for data collection, to increase the feasibility of the study and to minimize inconvenience for participation.

The study as described in chapter 4 has been completed and **CHAPTER 5** described a selection of the results of physical fitness variables: anthropometrics, muscular strength and aerobic capacity. 24 subjects were included, with an inclusion rate of 56.8%. The subjects varied in age from 6 to 18 years, in extent of burn from 10% to 41% TBSA and in time post burn from 1 to 5 years. Subjects’ scores were compared with Dutch age- and sex-matched norm values and calculated to Z-scores for all variables. For anthropometry, body height and weight, waist circumference and skinfold thickness were measured and, subsequently, BMI values and total skinfold thickness were calculated. No differences between subjects and norm values were seen in the data. Muscular strength was measured with a hand-held dynamometer, applied in elbow and knee flexion and extension, shoulder abduction and grip strength. On none of these variables were group means significantly different from the norm but, regarding individual scores, seven subjects scored significantly low on at least one strength variable. Lastly, aerobic capacity was measured using a graded exercise test, with VO_{2peak} [mL*min^{-1}] and VO_{2peak/kg} [mL*kg^{-1}*min^{-1}] as primary outcome parameters. All subjects completed the test without complications, but two subjects were excluded from analyses because criteria for maximal effort were not reached. The mean results of the 22 subjects did not significantly
differ from the norm, but one subject scored significantly below the norm on VO$_{2\text{peak}}$ and one other subject scored significantly below the norm on VO$_{2\text{peak/kg}}$.

Despite some individual deficits, our data showed adequate group levels of anthropometric measures, muscular strength and aerobic capacity for children and adolescents at 1-5 years after burns. Our data did not show trends indicating that either extent of burn or time post burn was associated to muscular strength or aerobic capacity outcomes.

The finding that moderate to severe pediatric burns do not necessarily affect physical fitness in the long term is a relevant addition to the knowledge on physical fitness after pediatric burns, since earlier studies had all concluded that physical fitness was affected during the first year after extensive burns. We suggested that these differences can be largely attributed to the fact that in our population more time had elapsed between burn injury and assessments, i.e. more time for physical recovery. Moreover, we like to emphasize the important role physical activity can play in the restoration of fitness after burns. Note that it is possible that specifically children interested in sports and an active, healthy lifestyle were inclined to participate in this study. Altogether, the results emphasize the strong resilience that many children show after burns.

In conclusion, this dissertation showed that children’s functional independence mostly returns to norm levels within 6 months post burn and that their physical fitness, measured between 1 and 5 years post burn, is quite similar to non-burned peers. Although these outcomes were adequate for the majority of Dutch children and adolescents after burns, there is an important minority that displays affected physical functioning that we may not overlook.
General discussion

In this final section of the dissertation the included studies and findings will be discussed. Methodological considerations, a broad clinical message and subsequent directions for future research will be addressed.

Challenges in burns research

Although burn research on functional outcome is highly clinically relevant, it is still in its infancy and often hampered by, for example, small sample sizes and heterogeneous groups. In the Netherlands, too, we encounter several complications to set up large and high quality studies to provide conclusive evidence. Primarily, the sample sizes are generally small, because in this small and highly developed country, we see a relatively small number of burn patients. This is amplified by low inclusion rates, since a part of these burn patients cannot participate due to comorbidity or mental issues, they may not participate in a study because they participate in another study, or they do not want to participate in research as they have been through enough already.

Secondly, possibilities for statistical analyses are limited because (the already small sample of) burn patients form a very heterogeneous group, for instance in age, etiology and extent of burn. Together this hampers conclusive statements on the effect of a burn injury. Besides, each individual responds differently to a certain thermal impact and, when studying physical outcomes after burns, one should keep in mind that those are also influenced by psychological issues, social concerns and subjective experiences.

The potential problem of small sample sizes was dealt with in the planning of the clinical studies (chapters 2 and 5), and this resulted in satisfactory inclusion rates and sample sizes. The issue was partly tackled through organizing multicenter studies, including all Dutch burn centers. In case of the WeeFIM© study inclusion took place within the burn center and a long inclusion period was chosen to optimize sample size. Further, the WeeFIM© study had as main advantage that assessments were done during already planned appointments. The fact that participation did not take extra effort and could improve the monitoring of the child’s functioning, probably contributed to the inclusion rate of 86.6%. On the contrary, the cross-sectional fitness-study (chapters 4 and 5) did require extra effort from participants and parents, and therefore we were content with the inclusion rate of 56.8%. The use of a mobile exercise lab has almost certainly contributed positively to this inclusion rate, as was aimed at. The main advantages were that participants did not have to invest effort, time or money in travelling (to the burn center in Groningen, for example) for the measurements. Together with the factor that the assessments would take place at home at a convenient date and time for the participant, this was expected to reduce the threshold to participation and thus increase inclusion rate. Further, use of the mobile exercise lab added a unique element to the study. Lastly, potential
participants were contacted first by members of the burn center staff, which may have contributed to their trust and the notion of the importance of the study.

Figure 1. The mobile exercise lab in which all physical fitness assessments took place

Another challenge in burn research is that it seems susceptible to selection bias. In chapter 5 the possibility was mentioned that in particular the fittest children felt inclined to participate in the fitness study. Regarding all burn studies, it would be imaginable that the most heavily burned patients either refused to participate for they had been through enough already, or otherwise felt inclined to participate to gain a possible benefit or to find out whether something is ‘still wrong’. Information on selection bias is critical to indicate whether the study sample represents the population of interest, and should be taken into account when drawing conclusions on the findings. Non-response analyses is a tool to uncover selection bias on included subject characteristics like age, extent of burn or time post burn. Therefore, a non-response analysis was performed in chapter 5. Furthermore, it is remarkable that, as pointed out in chapter 3, a large part of international burn research so far had focused on a small part of the population: people with exceptionally extensive burns. On the one hand, this seems tenable since more extensive burns have a larger and longer persisting impact, and thus knowledge and clinical support are very much needed to overcome difficulties in these patients. On the other hand, the remarkable fact that little is published about the recovery of patients with minor burns, gives the odd impression that the largest part of the burn population receives the least attention. Oppositely, Finlay et al. described that minor burn patients are being studied, but are often lost to follow-up. They proved that in their sample (16-66 years, <1-10% TBSA) the non-attendance at follow-up was not random, but most likely in younger people and related to a good recovery. The same ‘loss to follow-up’ was encountered in the WeeFIM©-study (chapter 2), mainly in the subgroups with burns <10%, because children who showed good recovery did not need follow-up visits and were, consequently, not assessed anymore. This ‘missingness’
hampers analysis of recovery after minor burns worldwide. The results of this dissertation contribute to current knowledge on outcomes after minor and moderate pediatric burns, and hopefully encourage other institutes to publish data on this large but under-published group of patients.

**Methodological considerations**

Besides the abovementioned population-related challenges in burn research, there are general methodological considerations about the clinical studies. Firstly, the designs will be discussed. Whereas the prospective cohort design used in the WeeFIM©-study (chapter 2) is quite strong, the cross-sectional design of the fitness-study (chapter 5) has some features that should be kept in mind in the interpretation of the results. Primarily, in a cross-sectional study the measurement is a snapshot: you measure only once at a certain time point that can be influenced by environmental and personal factors on that day. Further, the outcomes do not tell us anything about how the subject got to this level of functioning, or what he/she does in daily life. Was functioning ever affected? Has functioning improved due to time or due to training? Do these subjects need and use their physical capacities in daily life? Measures for physical activity, HrQoL and fatigue were included in the study to provide a more comprehensive view of the current situation. The abovementioned questions pointed at shortcomings of capacity assessment, yet measuring actual performance has its limitations as well. An illustrative example from the WeeFIM©-study: there was a risk of underestimation of functional independence during hospitalization, because inpatients could not accomplish several tasks, regardless of their physical capability, due to environmental restrictions in the burn center. However, note that these issues are inherent to clinical outcome research rather than limitations of the studies.

Secondly, considering data analyses, the use of norm values is subject to discussion. In both chapter 2 and chapter 5 no control group was measured for comparison between burned and non-burned peers. It might however seem somewhat ironical, since the inclusion and assessment of a control group was a requirement for inclusion of studies in the review (chapter 3). Instead, we deliberately used norm values from the literature and collected our data according to the same protocols and instruments. This was considered the most reliable and representative option since the used norm values were based on a larger group of children of each age than we could possibly have included and assessed ourselves. Apart from the use of norm values, there are some remarks to the norm values that were used for comparison. Firstly, in the norm values for both muscular strength and the WeeFIM©, strong fluctuations exist between age categories, despite the fact that they were based on many subjects. For example, the strength norm for knee flexors for 12 year old girls is 221N and for 13 year olds 301N, for 15 year old girls 282N and for 16 year olds 336N.³ The WeeFIM© norms were smoothed out before use. Secondly, while in the fitness-study only up-to-date and matched Dutch
norm values were used, for the WeeFIM©-study Dutch norms were not available. Instead, the USA-norms as supplied with the instrument were used, risking influence of cross-cultural differences. Altogether, this emphasizes the importance of reliable norm values to enable a meaningful comparison of populations in clinical research. There is thus a need for reliable and widely accessible national norm data on many clinical outcome measures.

**Restoration of physical functioning after burns**

A certain decrease in physical functioning is inevitable after burns, but for this to persist in the long term is highly undesirable. Physical functioning is namely of major individual importance after burn injury in many areas of life. In addition, it is of societal and economic importance that burn patients optimally recover and achieve a full level of functioning, in order to enhance their societal contributions, for example by occupational activities, and to prevent health problems later in life. It is thus of great importance to restore physical fitness and functioning after burn injury to avoid long-term difficulties, especially so for pediatric patients since they have a whole life ahead of them.

For all people, physical activity is essential to acquire and maintain an adequate level of physical functioning. However, increasing levels of physical inactivity are seen worldwide. To illustrate this point: the World Health Organization reported that 80% of the world's adolescent population is insufficiently physically active.6 As a consequence, promotion of physical fitness and physical activity in daily life has expanded considerably over the past years.7, 8 Also in health care, physical activity is increasingly applied under the slogan ‘exercise is medicine’ and active rehabilitation has become widely accepted.9-11

In burn care and rehabilitation ‘exercise is medicine’ indeed, as physical activity proved to improve physical fitness in patients with burns.12-15 Although the approach is gaining ground, physical activity should be applied more widely in burn rehabilitation than it currently is.16-18 Figure 2 shows three hypothetical scenarios of the evolution of physical functioning in burn patients, compared to a non-burn scenario, and depicts possible gains through physical activity in the restoration of physical functioning after burns. Note that all burn-scenarios show a sudden decline in physical functioning, due to (the combination of) the pathophysiological consequences of the injury and the prolonged inactivity. If no effort is made to prevent the decline or to restore physical functioning later on, physical functioning decreases further following the negative spiral of deconditioning, or in the case of pediatric burns, the natural development is disturbed and a catch-up never occurs. Such is depicted in scenario 1, the lower line in Figure 2: the burn patient waits for the wound to heal and pulls away from activities in order not to put any more burden on the body and/or scars (which has an adverse effect). This might result in disability.
In *scenario 2* there is no special attention for physical activity, though the burn patient reintegrates in society quite well. By resuming daily activities like school, play, hobbies, household, walking and cycling for transport, etc., the body is somewhat challenged and trained. Physical functioning improves gradually to a level that is sufficient for, but also limited by, this person’s daily activities. This results in suboptimal outcome in terms of health and future perspectives, as physical functioning is thus restricted by the inactive, more sedentary lifestyle as currently predominant in highly developed countries.

Figure 2: Hypothetical scenarios of physical functioning after burns, depicting a threefold gain of physical activity. 
*Scenario 1:* Patient remains inactive after burns, pulls away from activities. *Scenario 2:* Patient fully reintegrates; functioning is sufficient for, but limited by daily activities. *Scenario 3:* The physically active patient shows faster restoration of functioning, an optimal end result, and the level of functioning is better maintained/preserved with aging.

To keep the emphasis on the essence of the concept and for clearness, the figure is kept simple; e.g. only three out of many possible scenarios are depicted, the development of physical functioning is drawn as a smooth curve and the proportions of the time frames are not realistic.

In *scenario 3*, in contrast, there is a focus on physical activity after burns, through which restoration of functioning is both accelerated and optimized. Presumably, the positive effects are threefold as physical activity could be effective to A) limit the deterioration of physical functioning shortly after burns; B) advance the restoration of functioning; and C) maintain the level of physical functioning on the longer term. These stages correspond with the frames in Figure 2.

Frame A shows that the deterioration of physical functioning has come to a halt much earlier in *scenario 3* than in the other scenarios. Deconditioning is limited by early intervention, i.e. mobilization and activation initiated already during hospitalization (before wound closure is complete) as soon as the patient is able to manage.
Frame B shows that physical activity after burns increases the slope of the improvement in physical functioning as well as the end result. Furthermore, the sooner one starts, the sooner a certain rehabilitation goal can be attained.

Frame C emphasizes the long-term importance of an optimal recovery of (pediatric) burns, hence it contains the ‘healthy aging’-perspective of this dissertation. This part of the figure is based on a similar figure from the WHO-report by Kalache & Kickbush.\textsuperscript{19} They suggested that a good level of functional capacity, a term synonymous with fitness\textsuperscript{20}, during early life can contribute to maintaining function and independence and prevents disability later in life.\textsuperscript{19} Thus, in \textit{scenario 3} the solid physical basis has made the system more robust which slows down the rate of deterioration of functioning at older age, whereas in the other scenarios a suboptimal level resulted in faster-than-general decline at older age that departed from an already lower level of functioning.

On top of all the physical benefits, it is likely that the psychosocial domain gains from physical activity as well. Physical activity is known to positively effect HrQoL and mental well-being\textsuperscript{21,22}, and the experience of improving physical functioning could improve the patients self-esteem, body-esteem and faith in future perspectives.

Besides the plead for the importance of physical functioning and physical activity, it must be mentioned that physical functioning is not the only relevant outcome after burns and that physical activity is not a holy grail. Yet, these issues deserve to be highlighted, as this is the first dissertation in this research line and because the perspective is gaining ground in both (international) research and clinical practice.

\textbf{Clinical implications}

Implications for clinical practice from this dissertation are mostly indirect yet recognizable. The used outcome measures have not (yet) been implemented into clinical practice in the Dutch burn centers. The WeeFIM\textsuperscript{©} instrument is not used anymore, whereas the set of fitness assessments is currently applied in a longitudinal study and time will tell whether (some of) these assessments will find their place in clinical practice after that.

Regardless of permanent clinical implementation, both studies are deemed to have enlarged awareness of functional independence and physical fitness among clinicians. This is an important step, for the studies and results in this dissertation then serve as a stepping stone for further development in this field in both research and clinical practice. The multidisciplinary functional approach is not standard practice, since burns were originally a surgical specialty, but it is evidently upcoming. Over the last years, these developments have moved towards a comprehensive approach incorporating the ICF-model: the International Classification of Functioning, Disability and Health.\textsuperscript{23}
The ICF conceptualizes functioning using the components ‘body functions and structures’, ‘activity’, and ‘participation’, that are in a complex, dynamic interaction with health status and contextual factors (both environmental and personal). Principles from the ICF-model are fundamental for the current research line, and thus for this dissertation. The ICF has recently been applied in other burn outcome research as well.\textsuperscript{3, 24-26} In clinical practice in the Netherlands, the ICF-principles currently are increasingly applied, providing a framework directing acute care, rehabilitation and after care for patients with burns towards functional goals.

Likewise, protocols are increasingly changing towards early intervention in the Dutch burn centers, in order to prevent deconditioning and improve and accelerate the restoration of functioning. For example, there is attention for early mobilization of burn (even ICU) patients and an increased use of exercise machines (e.g. a bedside-cycle ergometer, rowing machine) and other means like the Kinect to promote and facilitate physical activity during hospitalization.

In the Netherlands, current burn rehabilitation protocols do not comprise (the widely pleaded for) structured in-hospital exercise programs.\textsuperscript{17, 18} Yet, if we interpret the results of chapters 2 and 5 as indirect feedback on rehabilitation after burns, this indicates that the current Dutch protocols suffice to restore an important part of physical functioning in children and adolescents with burns, without a structured exercise program. The positive findings in physical functioning might, besides excellent multidisciplinary care, be attributed to the support and stimulation towards a full reintegration and participation in society after burns and the strong resilience that children show after burns. Our findings encourage clinicians and researchers to look beyond the negative physical outcomes of pediatric burns demonstrated in previous studies.

Furthermore, the results in this dissertation indicate that fitness outcomes are not associated with extent of burn in the Dutch population. For example, one of the two subjects that scored significantly low on an aerobic capacity variable had suffered 10% TBSA burns, whereas the other had 41% TBSA. Ganio et al. and Baker et al. have also reported that outcomes were not related to the extent of burn in patients with burns <50%.\textsuperscript{27, 28} Likewise, Ryan et al. (2015) showed that in young adults recovery levels for a.o. ‘social function limited by physical function’ and ‘fine motor function’ tracked toward the non-burned group regardless of the extent of burn.\textsuperscript{29} Tyack & Ziviani (2003) found that injury factors had no significant impact on functional outcomes after pediatric burns <35%, whereas pre-morbid factors and parent factors had.\textsuperscript{26} As physical prospects after burns are optimistic nowadays rehabilitation goals should not be limited by reserve, but instead focus on current functioning and optimistic future goals.

Although the current findings on physical functioning were mainly positive, in burn rehabilitation less decline, earlier recovery and better outcomes are always to be strived for. Likewise, the findings that
a selection of patients shows long-term deficits in physical functioning should not be overlooked. As soon as this is detected in clinical practice, individual intervention should be initiated. The intervention may be targeted to overcome the patient’s physical and/or psychosocial experienced limitations and barriers to participation or could, for example, comprise an exercise program. Furthermore, it should be kept in mind that individual rehabilitation goals are not addressed in research, even though they are of utmost importance to the patient. For example, imagine a violinist who scores within normal values on all tests, but even so he cannot play the violin because of the scars on his fingers. Each individual values other capabilities for his/her well-being\textsuperscript{30} and those specific functions are not picked up by general outcome assessments. This emphasizes that personal care, instead of test outcomes, should always remain leading in clinical rehabilitation.

**Directions for future research**

This dissertation underscored that, as physical functioning is a novel topic in burn research, the current knowledge is just a fragment of what we want and need to know. A part of what we further want to know, is already (being) addressed. Firstly, chapter 5 reported only on a small selection of the data collected in the study described in chapter 4. This provided info on physical capacities without establishing a link to daily life performance. The collected data on physical activity, HRQoL and fatigue will be analyzed soon to put the findings in context, for example to explore a possible association between physical fitness and activities in daily life, as well as to provide their own unique information on a pediatric burn population. Secondly, as a selection of the subjects showed deficits in longer term physical fitness (chapter 5), it is important to indicate potential risk factors for diminished physical fitness in Dutch pediatric burn survivors. A longitudinal study, similar to chapter 4, was recently initiated to this end, as well as to gain insight in the evolution of physical fitness after burns, which could guide future interventions.

Another interesting follow-up study, not yet initiated, would include adult burn patients. Our clinical experience is that adults show less resilience than children after burns, which is somewhat supported by literature. Jarrett et al. found that adult burn patients tend to pull away from activities after burns\textsuperscript{31} and Rowley-Conwy stated that adults have more difficulties coping with burns than children\textsuperscript{32}. Therefore, a study on physical fitness, physical activity, HRQoL and fatigue in our adult burn population would be interesting.

In the Netherlands our line of research on physical fitness and physical activity is expanding rapidly, and it would be great if this work inspires others around the world to also address this issue. The burn centers in Perth (Australia) and Galveston (Texas, USA) used to be the only other institutes with
a similar line of research. It seems promising that, over the past months, the number of related publications from other countries slightly increased.\textsuperscript{33-36} 

The primary recommendation for future studies applies to a standard core set of burn outcome assessments, preserving the multidisciplinary approach. This has previously been advocated\textsuperscript{37, 38}, but so far outcome assessment in burn care and research has been very inconsistent and different methods were used.\textsuperscript{17} A standard core set of burn outcome assessments would enable reliable comparison of outcomes between burn- or study populations and thus enlarge knowledge. Hopefully our set of assessments contributes to its development. 

Ideally, a certain routine of regular assessments would be implemented as well, so that functioning in patients with burns is repeatedly measured at predetermined time points in both the short and long term using the standard core set of burn outcome assessments. Additionally, international collaboration would expand so that such a routine could be implemented in multiple burn centers worldwide. From the originating consented cohort, a large study population can be selected for each specific research aim, as suggested by Relton et al..\textsuperscript{39} Possibilities for statistical analyses expand and comparisons of outcomes could easily be made within and between populations based on, for example, treatment characteristics, location of the injury or social support. Although this kind of design is a long way off, it could solve a lot of the challenges encountered in burn research. 

When the same outcome measures are used, studies in similar pediatric populations would be valuable to support our findings on physical fitness and to strengthen evidence on physical consequences of pediatric burns (including minor to moderate burns). Of course, similar studies in different pediatric and adult burn populations are valuable as well. 

Another recommendation is the use of a mobile exercise lab for follow-up of outpatients. A mobile exercise lab provides a standardized setting, despite its spatial limitations, plus is deemed to improve the feasibility and the inclusion rate in research. A similar setup could work as well for follow-up care and monitoring, especially when aimed at adults, with their many occupations. 

However, the abovementioned ideas account to a large extent for highly developed countries like the Netherlands. In less developed countries burn populations are different, clinical needs and treatment possibilities are different and outcomes are probably worse. Yet, to be able to determine needs in a certain population, specific knowledge is necessary and research could contribute to such population-specific knowledge. Hopefully, our work encourages other institutes around the world to more systematically monitor outcomes after burns, desirably not restricted to functional independence, physical fitness or certain populations, and to share their findings. Common knowledge will thereby expand and can subsequently be transferred to and applied in clinical practice.
References


