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Return to Work and Health-related Quality of Life after Severe Burn

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Dissertation presented at Uppsala University to be publicly examined in Enghoffslalen, Entrance 50, Akademiska sjukhuset, Uppsala, Friday, December 10, 2010 at 13:15 for the degree of Doctor of Philosophy (Faculty of Medicine). The examination will be conducted in Swedish.

Abstract

A major burn is one of the most severe traumas a person can experience, and recovery can be a protracted process. The principal aim was to increase the knowledge base regarding factors related to return to work and health-related quality of life (HRQoL) after burns. Patients treated at the Uppsala Burn Center between 2000 and 2007 were included on a consecutive basis. Assessments were made at hospitalization, and thereafter and included a home visit 2 to 7 years after injury.

The psychometric properties of the generic HRQoL instrument EQ-5D were investigated. The results support the use of EQ-5D as an adjunct to burn-specific assessments of HRQoL. Most former patients exhibited a good HRQoL at 2 to 7 years postburn. Not working at the time of injury and having PTSD at 12 months, as well as having low scores on the EQ VAS at 12 months, were related to a worse EQ VAS score at 2 to 7 years after injury.

The majority of former patients had returned to work 2 to 7 years postburn. Time to return to work was predicted by length of hospital stay and a personality disorder diagnosis. Predictors for not returning to work were length of stay and having any anxiety or substance use disorder prior to injury. Those who were not back at work reported lower generic and burn-specific health, and exhibited more psychiatric morbidity at follow-up than those who were working. The latter group exhibited HRQoL that was comparable to that of the general population. Participants emphasized their own psychological resources and capabilities as facilitators in the process of returning to active work.

The findings suggest that an early and systematic approach for assessing recognized risk factors enhances the possibility of discovering patients at risk of developing problems during postburn adaptation.

Keywords: Burn, Return to work, Health-related quality of life, Outcome assessment, Rehabilitation, Injuries, Psychiatric Disorders, Personality Disorder

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“Health is not only to be well, but to be able to use well every power we have to use”

Florence Nightingale
List of Publications

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.


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Introduction

The explosion came from out of nowhere. Flames surround me. I couldn’t see through the glowing white light of burning magnesium. Instinctively, I back away from the flames. Smoke permeating the room and although I can hardly see, I noticed that my T-shirt has caught fire. As if in a dream, I used my hands to put it out. Time slows down. I am thinking what to do next. Someone calling from the other side of the room is trying to guide me toward an exit. Realizing I am trapped, the flames bursting between the door and me, I decided to run through the fire in order to escape. When I reach the other side, my clothes once again in flames. I remove my shoes, what remain of my T-shirt, and my trousers – all still burning – and make my way to the exit. There, standing in partially charred socks and underwear, I drop down to the safety of the cold stone floor and look down at my hands. The right one is black, but it still has the shape of a hand with which I am familiar, and thus it seem generally fine. But, my left hand had large pieces of skin hanging loosely from it, as white as the stone floor beneath me, with particles of chemicals and ash showing clearly against the white skin. Only then does the unbearable pain in my arms and legs overcome me. Trying to minimize my pain, I moved as little as possible and breathed small breaths. Soon the medical team arrives and carries me away.

Dan Ariely [17]

Burn injury

A major burn is one of the most severe traumas a person can experience and a life threatening state in which all of the main integrating systems in the body are affected. Depending on the location affected and the degree of severity, an injured person may experience a large number of potentially fatal complications including shock, infection, electrolyte imbalance and respiratory distress. The phrase “one accident seldom comes alone” is particularly relevant for burns. There are often devastating social consequences such as injured relatives, or even loss of family members. Furthermore, property damage and house fires with loss of residential properties can be socially and economically arduous.

The severity of a burn is a function of the cause of the burn, the extent, depth and localization of the injury, age at injury, presence of related injuries and co-existing illnesses. A burn injury may be caused by heat, cold, electricity, chemicals, light, radiation, or friction. The extent is defined as the percentage of the Total Body Surface Area (TBSA) that is affected, and is dependent on the degree of exposure and length of time exposed. The depth is characterized by the extent to which layers of the skin are damaged. It is commonly described in terms of “epidermal”, “dermal” or “full thickness”
injury. A superficial burn heals spontaneously in less than three weeks but a full thickness burn requires surgical excision and skin coverage [56, 77].

Epidemiology of burns

Global perspective

Burns are a major cause of premature mortality and years lived with disability in a global perspective. According to WHO data, approximately 10% of all deaths from unintentional injury are a result of fire-related burns [118]. Global data on non-fatal outcomes from burns are not readily available, but fire-related burns are among the leading causes of disability-adjusted life years (DALYs) lost in developing countries [188]. The incidence varies between countries and is strongly related to cultural practices regarding cooking, sub-standard electrical wiring and exposure to fire and liquids. Those at greatest risk for burn injuries are women in Southeast Asia and the Eastern Mediterranean, children, the elderly, men working in heavy industries and people who are economically underprivileged [40, 118]. Many burn-related accidents in high-income countries occur as a result of workplace accidents. In a review, 23% of injuries in adult samples were work-related [54], and in a Swedish study 39% of burn injuries were work-related [46].

In Sweden

In 2009, 118 persons died of burn injuries in Sweden. More than half of the burns occurred in the home. A 30% reduction in patients with burns who were admitted to Swedish hospitals during the period 1987 to 2004 has been reported [10]. In 2008, 1100 burn patients, or approximately 11/100 000 inhabitants, needed hospital care [4]. About two thirds were males.

Risk factors

Socioeconomic factors associated with an increased risk for burns include poverty, lack of education, unemployment, as well as substandard housing, including the lack of running water, and crowding [48].

Smoking is an individual risk factor for cigarette-caused fires and burns [132, 166]. Intake of alcohol represents an independent risk factor for burn injury. Alcohol and drugs reduce risk assessment ability and their intoxicating effects delay reaction [75]. Data indicate that in the United States, more than half of the burn patients test positive for ethanol in the blood at the time of hospital admission [13] and inhalation injuries associated with smoking, alcohol and drug abuse are an increasing problem [21].
There is a disproportionately high occurrence of burn injuries among vulnerable populations, and behavioral and psychiatric risk factors for burn injuries have been discussed in recent years. Pre-injury psychiatric morbidity has been found to increase the risk of being burned and of having a preventable injury [144], although it is nearly impossible to establish the contributory effect of such morbidity [116]. There are indications that individuals exhibiting higher levels of impulsiveness are predisposed to a greater risk for burn [141]. Furthermore, persons with personality traits such as high neuroticism and extroversion scores are more likely than others to be exposed to traumatic events [25], and neuroticism-related personality traits are exhibited to a greater extent in individuals afflicted by burn than in normative samples [59, 192].

Preburn psychopathology

A number of previous studies suggest that there is an over-representation of individuals with a history of psychopathology among burn patients [139]. However, there are few epidemiological studies that use validated interviews for psychiatric assessment. In a study by Fauerbach and colleagues, 64% of burn-injured individuals were diagnosed with at least one lifetime psychiatric disorder prior to the burn, 51% were diagnosed with a disorder during the year before the burn, and the prevalence of alcohol abuse or dependence was 41% [61]. In a Swedish study, 66% of burn patients were diagnosed with a lifetime disorder, 52% had a disorder during the year before the burn, and the prevalence of substance abuse or dependence was 32% [47]. In a recent Finnish study, 60% of the patients in burn care were diagnosed with a lifetime psychiatric disorder [137]. These figures are higher than those obtained in population based studies from the United States and Norway. The lifetime prevalence for any psychiatric disorder was reported to be 47% in the United States [87], 52% in a Norwegian urban area [96] and 31% in a rural area [97].

Powers and colleagues reported that 22% of burn patients met the criteria for a personality disorder [144], and in a recent Finnish study 23% of burn patients were diagnosed with a personality disorder [137]. These figures are higher than those obtained in population based studies, which regularly report prevalences of personality disorders between 9 and 16% with a mean of 11% [100].

Self-inflicted burn injuries are rare in the developed world and account for about 4% of burns [81, 113, 136]. However, there are great variations in prevalence, with deliberate self-burning responsible for a high proportion of suicide attempts in certain cultural, racial and religious groups [9, 133].

Preexisting psychopathology has an impact on both physical and psychological aspects of recovery. Patients with preburn alcohol abuse have a
greater risk of in-hospital mortality, and patients with preburn psychiatric disorders including substance use disorders require longer hospital stays [180]. Other studies have identified a longer hospital stay together with poor wound healing [176, 198] in patients with preburn psychiatric morbidity. Finally, a psychiatric history prior to burn is associated with a higher risk of post-burn psychiatric morbidity [47, 61].

**Burn care**

Advances in surgery and critical care have improved survival following large burns [10, 26]. Today a young person with a burn of about 80 % of body surface area has a 50 % chance to survive, whereas the same survival rate was reported for persons with 40 % of body surface area burned in the early 1970s [186].

Burn care aims to ensure survival with minimal loss of function. The acute care commences with a period of specialized intensive care when wound care and surgical treatment are carried out in parallel. The care focuses on infection control, wound care, wound closure, circulation and nutritional support, elimination, pain management, and physical therapy [56, 77].

Management of pain and anxiety related to care procedures is a challenge during the acute phase of care [77, 173]. A major proportion of burn patients in acute care suffer severe or excruciating pain, 100 % suffer daily pain [124], and patients’ experiences of pain make a strong impression on their memories [178].

**Long-term health outcome**

Burn patients constitute a heterogeneous population with wide variation in age, mechanism of injury, depth and site of burn and with a high level of comorbidity. The outcome therefore varies considerably, with various types of impact on all aspects of a person’s life and sometimes with permanent impairments [52, 54].

One of the most frequent impairments postburn is scar contracture, which limits movement and deforms normal anatomical structures [54, 57, 186]. Deep burn injuries sometimes heal with hypertrophic scarring, and surgical reconstruction may be required [54, 57]. In a review, one fifth of the patients reported restricted range of motion as long after injury as five years [182]. Amputations are sometimes necessary after deep limb injuries, particularly when they are caused by high voltage electricity [54]. Another consequence of severe burn is loss of muscle mass, resulting in reduced strength [57].

Pruritus, or itch, is one of the most disturbing issues for patients postburn, and the pathophysiology is not well known [72]. Although the severity of
pruritus tends to diminish with time in most patients, it can remain a problem for a long time after severe burn [54, 57, 112]. Pruritus was reported in 67% of burned patients 24 months postburn [184], and in 59% on average nine years after burn injury [195]. Seventy-two percent of individuals surviving severe burns reported problems with pruritus on average 17 years postburn [78].

Peripheral sensations such as pruritus, tingling, numbness and cold sensations have been reported in frequencies of 40 to 82% postburn [14, 32, 112, 126]. There is some evidence that touch, cold and warmth thresholds and magnitude estimations do not return to normal levels after skin grafting in burns [126].

Burn-related pain is experienced not only in the acute stage of injury but also in the longer term [54, 159]. Pain is also one of the greatest obstacles to successful burn rehabilitation [147]. A high prevalence of burn-related pain (52%) on average 11 years postburn was identified in a study, and pain was reported to interfere with both rehabilitation and daily life [38].

Psychiatric morbidity after burns

Psychiatric symptoms, as part of the multifaceted response to burn injuries, are frequent. Reported prevalences of psychiatric disorders vary greatly between studies, probably due to differences in the methodology employed and the time since burn. It seems, however, that the first year after a burn injury is the most vulnerable period, and many patients suffer from psychological symptoms during this time. Forty-five percent of burn patients reported psychological distress at some time during the first two years after burn, and 34% had clinically significant psychological distress at 24 months postburn [64].

A common psychiatric diagnosis postburn is major depression. In a review, a point prevalence of clinician-diagnosed major depression was reported to be 7 to 10%, and symptoms suggestive of major depression were reported in 2 to 28% postburn [179]. A recent Swedish study using the Structured Clinical Interview for DSM-IV disorders found that 17% of previous patients had major depression 12 months after burn [47].

Posttraumatic stress disorder (PTSD) is a not infrequent consequence of a traumatic event. Nightmares and an altered sleep pattern are common early symptoms noted after being exposed to a burn [105]. In a review, the prevalence rates for PTSD ranged from 20 to 45% up to 12 months after burn [54], and in another study 25% of the participants met PTSD criteria 24 months postburn, [115]. In the study by Dyster-Aas et al., 9% fulfilled criteria for PTSD 12 months after burn [47]. There is a high comorbidity between PTSD and depression, which is demonstrated both in burn patients [47] and other trauma populations [165].
Rehabilitation

Rehabilitation starts as early as during acute, specialist care, with active surgical treatment of wounds and scars, and measures such as physiotherapy, and occupational therapy to allow the patient to regain functional capacity to the greatest extent possible. The ultimate long-term goal of rehabilitation after burn is return to previous work, school, recreational and community activities. The process of rehabilitation often continues for many years after the burn and involves physical, psychological and social demands [88]. The diversity and complexity of the issues that influence long-term adjustments among burn patients require a multifaceted rehabilitation process within a multidisciplinary context. The multidisciplinary team therefore consists of surgeons, nurses, occupational therapists, physiotherapists, dieticians, clinical psychologists and other allied health specialists [186].

Many of the factors that affect the success of rehabilitation are not known. It is generally agreed, though that an optimal rehabilitation never goes beyond the patient’s own ability to contribute.

Nursing in rehabilitation

Nurses, in cooperation with physiotherapists and occupational therapists, often give individual rehabilitation care on a daily basis in the acute situation. In order to prevent complications and restore functioning, nurses’ responsibilities, in addition to technical management, include providing emotional support to the patient and the patient’s family and ensuring that the milieu is supportive for recovery. Recovery after burn is a protracted process, and intensive care nursing is often combined with aspects of psychiatric nursing [71].

Rehabilitation must be regarded as a continuum of care, with changing points of emphasis, rather than as an isolated phase [148]. Nursing functions based on caring competence can be accomplished during the process of rehabilitation, irrespective of workplace. The competence of the nurse encompasses assessing and managing pain and anxiety so the patient can be in balance between participating successfully in exercises and being comfortable enough to rest and sleep. An essential part of nursing is burn wound management and education of the patient and family regarding wound care [71]. Furthermore, the nurse must provide information about normal psychological reactions such as symptoms of depression and posttraumatic stress, as well as information about resources in the home community to which the patients and families have access [127]. It is important to enable a patient with changes in body image due to disfigurement to find support and meaning in life despite changes in appearance [7]. It can sometimes be of value to initiate peer support if that is available [169]. The patient and the family often need help in finding ways to return to a normal life despite the pa-
tient’s changed functions and perceived disability. One way of providing support is to coordinate cooperation between the patient, different caregivers, and the family. The nurse can also be observant regarding the need for vocational training in order to facilitate a return to work [71].

Outcome following burns

The concept of “Health-related quality of life”

The World Health Organization defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" in its constitution of 1948 [1]. This definition offered a new view - namely that health is a multidimensional concept that captures several domains of well-being simultaneously and not merely the absence of pathology. The base of this definition is the biopsychosocial model originated by V.M. Bekhterev in the late 19th century [11], which was later revitalized and advocated by Engel [51]. The biopsychosocial model considers that illness behaviors and recovery are influenced by the physical nature of the illness or injury (bio), which in turn is affected by the beliefs and understanding of the condition, and the state of mind of the person (psycho). All of them are affected by the influence of family, friends, community and work context (social). Thus all of these factors are taken into account in the biopsychosocial model.

One common concept of well-being is Quality of life (QoL). QoL can be defined as an individual’s perception of his or her position in life in the context of the culture and value systems in which he or she is living and in relation to his or her goals, expectations, standards and concerns [2]. The need for focus on aspects of the individual’s subjective experience of health and the consequences of illness, and not on issues relating to life in the broader sense and factors outside the person, was the origin for development of health-related quality of life (HRQoL) [68].

HRQoL focuses on the impact an injury or illness has on quality of life, including the individual’s perception of his or her injury or illness, and how this interferes with the individual’s ability to live a fulfilling life [68]. HRQoL is a subjective measure of well-being, and can be defined as the individual’s perception of physical, mental and social health over time [138].

The issues comprising HRQoL are particularly relevant in clinical areas in which the impact of interventions is not directly measurable using traditional measures such as morbidity or survival. Rehabilitation is such an area, with physical, psychological and social measures within a multidisciplinary context. While knowledge about factors influencing long-term HRQoL among burn patients is scarce, it is of essential importance in developing more suit-
able clinical, counseling, and social support programs to improve treatment outcomes.

Assessments of health-related quality of life
A balanced measure of HRQoL captures three fundamental domains: biological functioning, psychological functioning, and social functioning, and summarizes them in a single metric [168].

There is an increasing variety of instruments for measuring HRQoL. Two basic approaches are available: generic instruments that are broadly applicable, often include health profiles, and therefore can be used in comparisons across patient populations; and specific instruments that focus on problems associated with single diseases, patient groups or domains of function. Generic instruments sometimes generate health utilities useful in health economic evaluations and in policy decisions [74, 171]. Generic and disease specific measures capture somewhat different health aspects and their combined use has therefore been recommended in the evaluation of health outcome [35].

In studies reporting individuals’ perceived health after burn, several concepts have been used: perceived health, quality of life (QoL) and/or health-related quality of life (HRQoL).

Health-related quality of life after burn

Burn-specific health-related quality of life
Many individuals recover during the years after burn, but on average 9.3 years after injury a subgroup reported impaired burn-specific HRQoL [90]. The most frequent problems were reported in the domains of heat sensitivity, work and body image. In other studies, associations have been reported between injury-related factors such as burn size [22, 129, 175], burn depth [35, 43, 90, 103, 175], length of hospital stay [103, 154] and the number of surgical interventions [154], and reduced disease-specific HRQoL. Less pain and emotional distress during the first year postburn predicted better burn-specific health, whereas less emotional distress and better community reentry was predictive at 12 months [37].

Early studies revealed that preburn psychological disorders were associated with impaired burn-specific health [125], and concurrent pain, anxiety and depression correlated with reduced scores in all domains of burn-specific health [22]. There is evidence in recent studies of associations between personality traits [91, 197], coping strategies [92], and dysfunctional beliefs [192] and impaired burn-specific health. Finally, unemployment has previously been associated with impaired burn-specific health [22], and consequently better burn-specific health is reported in those employed after burn [45, 46, 90, 103, 125].
Generic health-related quality of life

Reduced generic HRQoL at hospital discharge, and slower recovery during the first year after burn were found in a group with a large physical burden or psychological stress during hospitalization [63]. In some long-term studies after burn, generic HRQoL has been reported to be comparable to that in the general population [15, 164], and not statistically different from healthy controls [14], whereas other studies have reported reduced HRQoL up to six years postburn [45, 122, 142]. In a study 2 to 20 years postburn of individuals with a total burned area of ≥ 50 %, impaired physical HRQoL was related to full thickness injury together with poor hand function, while older age at follow-up and perceived poor social support were related to impaired psychological HRQoL [15]. Diminished physical ability [135], as well as joint contractures and full thickness injury [99], influenced HRQoL negatively. Furthermore, full thickness injury, current psychopathology, living alone, pain, and being unemployed, were factors associated with poor outcomes in HRQoL on average 4.7 months postburn [122]. In a group of burn injured individuals employed at the time of injury, the subgroup that did not work on average 3.8 years after injury had considerably lower HRQoL than the subgroup that had returned to work [45]. In a recent study with repeated measures after burn, concurrent pain and the trajectory of PTSD severity after burn affected various dimensions of generic HRQoL up to two years after burn [36].

Sick-leave and work disability

There is considerable variation in social insurance schemes between countries and in the mode of assessment for compensation due to sickness and work disability [123].

The Swedish Social Insurance Act states that an individual is to be granted financial security when his or her work capacity is reduced by at least one-quarter due to disease or injury. The employer is responsible for sick pay during the first 14-day sick pay period, thereafter sick pay is paid by the Social Insurance Agency. If work capacity is still reduced after one year of sick leave, extended or continued sickness benefits can be applied for. Before July 1, 2008, it was possible to apply for a disability pension, without any time limitation, if work capacity was permanently reduced, i.e. for the foreseeable future [3].

The Work Environment Act defines obligations for the employer regarding individual work accommodation. This is mandatory when employees have been afflicted by injuries or illness [5].
Return to work after burn

Most individuals return to work (RTW) after burn injury, even though the rehabilitation period is sometimes a prolonged process [88]. For individuals employed at the time of the burn injury, return to work was reported to be the most vital, and at the same time demanding, treatment goal [33]. There are factors with considerable influence on the working situation after a burn injury, and work related problems are reported by 21-50 % of former burn patients [182].

Factors influencing RTW after burn show an inconsistent pattern [29]. This could be explained by different study designs: differences in follow-up time, retrospective data-collection, high dropout rates and inclusion of participants employed and not employed before burn. There is evidence that preinjury employment is one of the most influential factors regarding RTW after burn [58, 62, 83, 174, 199].

Time to return to work

In a recent review, time taken to RTW after burn ranged from 4.7 weeks to 24 months [146]. Factors related to time to RTW in individuals employed before burn were found in an early study to be the size of the burn (TBSA burned), the amount of stress during the year prior to the burn, the amount of responsibility patients accept for their health, and support from powerful others [8]. Studies have previously reported that the size and depth of the burn as well as the presence of hand burns [23, 76], age at injury and type of job [23], and length of hospital stay [76] are all associated with a delayed RTW. In a two-center study with 279 former burn patients, burn size was correlated with time to RTW [27], and in another study length of stay tended toward having significant impact on time to RTW [53]. In addition to size and depth of the burn, length of stay and number of surgical procedures, Saffle and colleagues reported that patients’ subjective assessment of function, of scars and of ability to stand were predictive of time to RTW [153]. Finally, in a review of patient records, pain was one of the most frequent barriers to return to work during the first year after burn [159].

No return to work

Some studies have revealed that 10 % of individuals with burn injuries do not RTW within two years after injury [27], and that 1–15 % have a permanent incapacity for work [182], whereas another study reported that 31 % of individuals were not working by 24 months postburn [93]. A review including 21 studies reported that an average of 33 % of individuals, range 9 % to 86 %, did not return to work following their burn [146].

There is not a given timeframe for the definition of recovery and RTW, and there are few long-time follow-up studies focusing on RTW after burn. In a Swedish study on average 9.3 years after injury, 42 % of the men and 65
% of the women were not working [90], and in a subgroup with work injuries, 17% had not returned to work [46].

In an earlier study, ethnicity, not being married, blaming oneself, and not receiving workers compensation were predictive factors for not returning to work at 12 months after hospital discharge [199]. In another study, length of stay, inpatient rehabilitation, having an electric burn or a work injury were associated with no RTW 12 months postburn [159]. Furthermore, in a study on average 34 months after injury, individuals without medical insurance who were involved in injury related lawsuits were less likely to return to work after burn [153]. One study 24 months postburn reported that burn size, extremity burns and a preburn psychiatric history were factors associated with no RTW [27]. A study from our research group found that burn depth, time since injury and dysfunctional beliefs were predictive for not returning to work 3.6 years postburn [45]. However, in a recent study physical and wound issues continued to be a significant barrier to RTW up to one year after burn, whereas working conditions and psychological factors were important barriers for those who did not RTW within 12 months [53].

From what has been reported above it is quite obvious that long-time follow-up studies focusing on RTW after burn are scarce. With few exceptions, RTW is reported before or at 24 months. It is therefore not clear to what extent those who are not at work at that time period actually return to work later. Nor is there any clear information on which factors are associated with the risk of not having returned to work many years after injury.

**Patients’ perspectives**

In an early interview study focusing on occupational role performance during the first year after burn, physical impairments were in focus for functional changes in the working situation [30]. In another interview study with the aim of exploring experiences of return to work after burn, five typologies were presented with different incentives for and outcomes of employment. The employment consequences of burns were related to physical and psychological problems, socio-economic background, treatment characteristics and employment factors [111].

In a review of the qualitative literature on RTW after injury, MacEachen and colleagues confirmed that RTW extends beyond concerns about managing physical function to the complexities related to the beliefs, roles and perceptions of many players [108]. After stroke, residual disabilities such as physical and cognitive impairments were perceived as barriers to RTW, whereas a flexible working environment and a supportive social network were perceived as facilitators [12, 117]. Furthermore, barriers and enablers to work after stroke were identified in the rehabilitation system, in the employer agencies, in the social structure and in the characteristics of the individual [104]. Individuals injured at work and in vocational rehabilitation perceived facilitators of employment continuation after return to work to be
appropriate work, supportive workplace relationships, and a sense of participation and satisfaction with being at work [200].

There are few studies focusing on patients’ perspectives regarding the RTW process after burn. Knowledge concerning these individuals’ perceptions of both barriers and facilitators to return to work after burn may contribute to a more in-depth understanding of the process.
Background and aims of the study

The present thesis is part of a larger multidisciplinary research program concerning different factors of importance for the final results of adaptation and recovery after a severe life-threatening trauma. The research started in 1998 and was implemented as a joint project with collaboration between the Uppsala Burn Center, the Department of Surgical Sciences, Plastic Surgery, and the Department of Neuroscience, Psychiatry, at Uppsala University. The Uppsala Burn Center is one of two national centers for treatment of severe burns in Sweden. At the time of the study the catchment area included the middle and northern parts of Sweden with a population of approximately three million inhabitants. This has now increased due to an expanded mandate, and is approximately 5 million, i.e. about half of the Swedish population.

The research program aims to acquire more in-depth knowledge about how different physical, psychological, injury and care-related aspects influence the outcome after severe burns. The project is based on the hypothesis that genetic and environmental factors, reflected by psychiatric and somatic health, cognitive processes, personality traits and coping strategies, as well as social situation, interact and, to a great extent, shape and determine the outcome. This occurs in interplay with characteristics of the injury itself and the additional stress during the long hospital treatment, and also later during the rehabilitation phase (Figure 1).

Figure 1. A presentation of the working hypothesis underlying the present thesis.
In previous work from the research group, on which doctoral theses have been based, improved instruments for assessing burn-specific health and the contribution of personality factors and coping on perceived long-term outcomes have been studied [88]. Furthermore, coping, personality and cognitive processes in short and long-term adaptation were evaluated [190], as was the impact of psychological factors and psychiatric morbidity in short and long-term adaptation [44]. In addition, the occurrence of physical and psychological problems and the consequences of such problems for clinical management [106] and care utilization, care experiences and patient satisfaction [189] were assessed.

The present thesis is based on previous studies by the research group and is a continuation of the research trail concerning social and work-related adaptation after burn injury. The principal aim of the present work was to increase the knowledge-base regarding factors related to return to work and health-related quality of life after burns.

The specific aims were:

- to analyze the psychometric properties of the generic instrument EQ-5D in the assessment of HRQoL after burns (paper I)
- to prospectively assess HRQoL after burns with EQ-5D and to investigate early identifiable predictors of HRQoL 2 to 7 years after burns (paper II)
- to explore predictors associated with time to return to work, assessed several years after injury, as well as predictors associated with not returning to work, and to identify what differentiates the group that has not returned to work from the group that has in terms of general and burn-specific HRQoL and current psychiatric morbidity (paper III)
- to gain knowledge about burn injured individuals’ perceptions of factors seen as facilitators and barriers in the process of RTW after burns (paper IV)
Methodology

Design, participants and procedures

The present thesis is based on an ongoing prospective longitudinal study concerning physical and psychological outcome after burn trauma. Consecutive burn patients admitted to the Intensive Care Unit at the Uppsala Burn Center starting in March 2000 were included if they were 1) 18 years of age or older, 2) Swedish speaking, 3) without documented mental retardation or dementia, and 4) had \( \geq 5 \% \) TBSA burned or a length of stay (LOS) at the Burn Center of more than one day. Patients admitted on a temporary basis and who had their main care provided elsewhere were not included.

In paper I, with inclusion up until March 2006, 95 patients fulfilled the study criteria and 78 participants were included. Two patients were missed due to administrative reasons and 15 declined participation. There were no significant differences between the 78 participants and the 17 non-participants with respect to age, sex, burn size, or length of hospital stay. During acute care, a member of the research team administered a generic HRQoL questionnaire. At three, six and 12 months postburn, data were collected by postal questionnaires. At six and 12 months postburn an additional generic HRQoL questionnaire and a burn specific HRQoL questionnaire were also included. Non-responders received one reminder letter and relevant questionnaires. In the psychiatric assessment that was carried out during hospitalization, a semistructured psychiatric interview was utilized.

In March 2007, a follow-up study was planned. In addition to the cohort from March 2006, 17 patients were eligible for inclusion; four of them were missed due to administrative reasons and two declined participation. Thus, 11 patients were added and the cohort now comprised 89 patients.

Paper II is based on 82 eligible former patients out of the total of 89, since four patients had died, two had emigrated and one had dropped out of the study. Seventy-six out of these 82 former patients (five were not located and one was excluded for other reasons) were contacted 2-7 years after burn and received information about the follow-up study by post. Consent was obtained by telephone; nine former patients declined participation. Thus interviews were conducted with 67 participants. Assessments were carried out during the period from April 2007 to August 2008, in a place chosen by the participant, mainly in the participant’s home, and comprised generic
HRQoL, everyday pain and socio-demographic variables. Psychiatric assessment for ongoing disorders was performed with a psychiatric interview.

The study sample in paper III constituted a sub-group of 58 patients from the above-mentioned sample who were employed or involved in full-time studies at the time of the burn and under the common retirement age of 65 years. The assessments used for paper II were supplemented with questionnaires for burn-specific health.

Participants in paper IV were selected by a maximum variation sampling procedure [140] from those in paper III. The sampling method was chosen taking into consideration the heterogeneous population of burn injured individuals and the fact that factors affecting RTW after burn are not well known. The variations for constructing the sample population in this study were: sex, age, burn size, cause of injury, living environment, social situation, type of preburn employment and time after burn. Based on these criteria 40 patients were selected and contacted by telephone. One man declined participation, which is why interviews were conducted with 39 participants. Socio-demographic and burn-related characteristics are presented in Table 1.

Assessments and measures

Health-related quality of life

The EQ-5D, a generic HRQoL instrument, is used in papers I, II and III and provides three different measures: a descriptive health profile, a summarized index and a self-rated health status using a Visual Analogue Scale (VAS) [55].

The EQ-5D descriptive system encompasses five questions covering five dimensions: mobility, self-care, usual activities, pain and anxiety/depression. For each dimension, respondents value their health by reporting whether they are experiencing 1 = “none”, 2 = “moderate” or 3 = “extreme problems”. The EQ VAS is a vertical 20-cm line, graded from 0 = “worst possible health state” to 100 = “best possible health state”, on which the respondent is asked to mark his or her own current state of health. The EQ-5D health state can also be converted into a weighted index. The conversion into the index is based on norm values obtained in population-based enquiries [41]. The EQ-5D index ranges from -0.594 = “death or worse than death” to 1 = “full health”.

The Short-Form 36 Health Survey (SF-36) used in paper I is another generic HRQoL instrument [187]. The questionnaire consists of 36 items divided into eight subscales: Physical functioning, Role-Physical, Bodily pain, General health, Vitality, Social functioning, Role-Emotional and Mental health. The raw scores of the eight subscales are transformed and the final
Table 1. Socio-demographic and burn-related characteristics of the participants in papers I-IV.

<table>
<thead>
<tr>
<th>Paper</th>
<th>Sample</th>
<th>Eligible/ included</th>
<th>Investigated sample</th>
<th>Response rate (%)</th>
<th>M/F</th>
<th>Age at injury</th>
<th>TBSA burned</th>
<th>TBSA-FT</th>
<th>LOS</th>
<th>Years since injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>2000-2006</td>
<td>95</td>
<td>78</td>
<td>82</td>
<td>61/17</td>
<td>43.6 (15.1)</td>
<td>24.3 (19.7)</td>
<td>10.3 (14.0)</td>
<td>26 (31)</td>
<td>na</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>19.2-89.5</td>
<td>0.5-80.0</td>
<td>0-63.5</td>
<td>1-230</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>2000-2007</td>
<td>Eligible for follow-up</td>
<td>89</td>
<td>67</td>
<td>75</td>
<td>52/15</td>
<td>42.6 (14.8)</td>
<td>25.4 (20.4)</td>
<td>10.8 (14.8)</td>
<td>27 (34)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>19.0-86.0</td>
<td>1.5-80.0</td>
<td>0-63.5</td>
<td>1-230</td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>Occupationally active prior to burn</td>
<td>70</td>
<td>58</td>
<td>83</td>
<td>48/10</td>
<td>39.0 (10.7)</td>
<td>27.8 (20.9)</td>
<td>11.3 (15.8)</td>
<td>28 (35)</td>
<td>4.5 (1.9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>19.0-60.5</td>
<td>1.5-80.0</td>
<td>0-63.5</td>
<td>1-230</td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>Occupationally active prior to burn</td>
<td>40</td>
<td>39</td>
<td>na</td>
<td>29/10</td>
<td>39.7 (10.3)</td>
<td>29.0 (21.0)</td>
<td>12.9 (15.6)</td>
<td>29 (38)</td>
<td>4.6 (1.9)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>19.0-60.5</td>
<td>1.5-80.0</td>
<td>0-63.5</td>
<td>1-230</td>
<td></td>
</tr>
</tbody>
</table>

Values are means (SD) and range. M/F = males/females. TBSA = total body surface area in percent, TBSA-FT = TBSA full-thickness burn in percent, LOS = length of stay at the Burn Center in days, na = not applicable.
scores for each category range from 0 (lowest) to 100 (highest). The SF-36 has demonstrated acceptable validity in a Swedish population [172] and was recently validated and found adequate in a burn patient population [49].

The Burn Specific Health Scale-Brief (BSHS-B) used in papers I and III is a disease-specific HRQoL instrument [89]. The 40-item questionnaire has nine subscales: Simple abilities, Hand function, Heat sensitivity, Treatment regimens, Body image, Affect, Interpersonal relationships, Sexuality and Work. Responses to the items are made on a five-point scale ranging from 0 = All the time/great difficulty to 4 = Never/no difficulty. Mean scores are calculated for each subscale and high scores indicate a good perceived health status. Recently, a factor analysis of BSHS-B derived three separated domains: affect and relations, function and skin involvement [193, 194].

Psychiatric assessment

The Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I) was used in papers I to III to assess the presence of psychiatric illness [67]. The first SCID-I interview was carried out during hospitalization, as soon as the patient’s medical condition allowed and when the patient was devoid of cognitive dysfunction. A preburn psychiatric history was considered if the participant met criteria for a DSM-IV diagnosis at any time in his or her life prior to and including the time of the burn. A second SCID-I interview, covering only major depression and PTSD, was carried out at a clinical follow-up offered routinely 12 months after the burn, and finally, the third SCID-I interview was performed at a follow-up visit in the participant’s home 2 to 7 years after the burn.

The Structured Clinical Interview for DSM-IV Axis II Disorders (SCID-II) was used in paper III to assess the presence of any personality disorder [66]. The interview was carried out during hospitalization together with the first SCID-I interview.

The SCID interviews were conducted by three trained interviewers who were not a part of the regular staff at the Burn Center and were therefore not involved in treatment decisions. Fourteen SCID interviews were independently rated for interrater reliability. Complete interrater agreement for diagnoses was obtained (kappa = 1).

Pain

One question in the Brief Pain Inventory-Short Form (BPI-SF) [34] was utilized for the assessment of pain at the 2 to 7-year follow-up.
Socio-demographic and burn-related variables
Age, sex and variables related to injury severity were obtained from medical records, while marital status and length of education were collected by questionnaires. Work-related information was obtained from medical records and from the follow-up interview.

Qualitative interview
The interviews were performed in a place chosen by the participant, most frequently in the participant’s home. In addition, four interviews were conducted in cafés, three in reception rooms at the hospital, one at a workplace and one in a park. One interview took place with a married couple who were burned in the same accident.

The semi-structured interview [98] included three guiding questions: What have you experienced as facilitators in the RTW process? What have you experienced as barriers in the RTW process? What could have been facilitators or barriers in the RTW process? In order to enhance the participants’ recalls of their RTW process, a life chart [150] was used during the interview to help them remember, but this was not used later in the analysis.

A confidential atmosphere was striven for by encouraging the participants to speak freely and by closely following their narratives and asking probing questions such as: What do you mean? Can you develop your answer a little more? Is there anything else you want to add? Adding follow-up questions made it possible to get more in-depth responses from the interviewees [140].

Many methodological decisions have to be made on the spot during interviews, since there are few pre-structured procedures for conducting this form of data collection [98].

The interview sessions were tape-recorded and lasted for 70-100 minutes including the narrative interviews that lasted on average 20 minutes. The narrative interviews were later transcribed verbatim.

Data analysis
Statistical analyses
Statistical analyses were performed using SPSS 17.0 in paper I, and SPSS 18.0 in papers II and III. Group comparisons were studied by means of Student’s independent t-test for two groups. Nonparametric analyses were used when data were not normally distributed, and included the Mann-Whitney U test and the Kruskal-Wallis test. Categorical data were analyzed using the chi-square test, and Fisher’s exact test when the expected number of observations was less than 5 in each cell. For continuous data, associations were assessed by means of the Pearson correlation coefficient or, in the case of non-normality,
the Spearman rank correlation coefficient. Associations were also studied by use of multiple regressions in the case of continuous dependent variables, and by logistic regressions when the dependent variables were dichotomous.

Qualitative analysis
The transcribed texts from the interviews were analyzed using qualitative content analysis to explore the content and the meaning of the texts and to identify patterns [140]. An analysis inspired by Graneheim & Lundman was performed [73]. The interviews were listened to and read through several times by the first author, bearing in mind the aim of the study. This was done in order to get a sense of the content. The content and understanding of the text were then discussed in relation to the aim by all three authors. Sentences or paragraphs related through content and context were identified as meaning units. The meaning units were condensed, abstracted and labeled with a code. The codes were grouped into mutually exclusive categories reflecting central messages in the interviews. Codes in the same category were presumed to have a similar meaning, either based on the precise meaning of words or on words sharing similar connotations. The categories were then divided into subcategories on the basis of dissimilarities within the categories.

To increase the rigor of the analysis, the interview texts were read again and the subcategories and categories were compared and validated against the whole text. The co-authors categorized meaning units from eleven randomly chosen interviews to validate subcategories and categories that had been identified. The themes and categorization were discussed among the authors until consensus was achieved. Quotations were chosen from the interviews to illustrate the results, and they have been de-identified to ensure confidentially.

Ethics
Participation was voluntary, informed consent was obtained from all participants, and assurances were given that all information would be handled confidentially. Before the participants gave their consent to participate, they were given easily understandable information about the study. The presumptive participants were informed about methods for gathering data, and that it was possible to withdraw from the study at any time, without having to explain why. Data are presented and quotations are used in such a way that individual participants cannot be identified. The study was approved by the Regional Ethical Review Board, Uppsala University. Ethical guidelines for nursing research proposed by the Northern Nurses Federation [131] and the principles of the Helsinki declaration [6] were also considered.
Results

Validation of the EQ-5D questionnaire in burn injured adults (Paper I)

The aim of paper I was to analyze the psychometric properties of the generic instrument EQ-5D in the assessment of HRQoL after burns. At baseline all 78 patients filled in the EQ-5D questionnaire and at three, six and 12 months the response rates were 96 %, 94 % and 89 %, respectively. A high response rate and a low proportion of missing or invalid answers demonstrated high feasibility of the EQ-5D.

Construct validity was demonstrated through good differentiation between health states and good discrimination of health states over time. At baseline in acute care a high proportion of individuals reported an EQ-5D index below zero (“death or worse than death”), but the mean index values and the VAS scores improved in an expected manner during the first year postburn. Severe problems in almost all five dimensions in the EQ-5D were reported at the first assessment in acute care. At 12 months only a small group of participants reported problems in the dimensions mobility, self-care and usual activities, whereas almost half of them still perceived problems in the dimensions pain and anxiety/depression (Figure 2).

Construct validity was also demonstrated through improvement in the mean index values and the VAS scores in an expected manner between the first and last assessments. Furthermore, the floor effects, i.e. the proportion of participants who scored the worst possible health state, and the ceiling effects, i.e. the proportion of participants who scored the best health state, were small at every time point. At baseline, for example, 2.6 % of the patients exhibited a floor effect for the EQ-index and 4.0 % showed a floor effect for the EQ VAS. At 12 months, 19.1 % of the patients exhibited a ceiling effect for the EQ-index and 4.5 % showed a ceiling effect for the EQ VAS. Expected associations of response levels in the EQ-5D with burn severity and between clinical subgroups also provide evidence for construct validity.

Criterion validity was demonstrated through significant associations between different response levels in the EQ-5D dimensions and median scores in the comparable subscales of SF-36 and BSHS-B at 12 months. For the EQ-5D index and EQ VAS scores, correspondence was assessed in rank
correlation analyses with the subscale scores of the SF-36 and BSHS-B at six and 12 months. The correlation coefficients between the EQ-5D index

![Figure 2. Distribution of participants’ responses to items on the EQ-5D questionnaire at baseline, 3, 6 and 12 months and responses of a Swedish general population [28], n = 65 (all participants who answered the questionnaire at all assessment time points).](image)

and the SF-36 subscales were in the range of 0.55 to 0.78, and the correlations with the BSHS-B subscales ranged from 0.26 to 0.69. The correlation coefficients between the EQ VAS scores and the SF-36 and BSHS-B subscales ranged from 0.32 to 0.77. All coefficients were significantly different from zero.
Health-related quality of life 2 to 7 years after burn injury (Paper II)

The aims of paper II were to assess the trajectory of HRQoL after burn measured by the EQ-5D, and to discover early identifiable predictors of HRQoL several years postburn.

There was a gradual improvement over time in HRQoL in the EQ-5D index, the EQ VAS, and in the different EQ-5D dimensions. At follow-up 4.6 years (range 2-7 years) on average after injury, the EQ VAS, but not the EQ-5D index, was still significantly lower than that of the Swedish general population. For the dimension mobility most of the improvement occurred between baseline and the 3-month assessment, after which no significant improvement occurred. Self-care, usual activities and pain/discomfort improved gradually up to the 2 to 7-year follow-up. The dimension anxiety/depression demonstrated no improvement during the first 12 months, but slowly improved up to the 2 to 7-year follow-up, when the proportion that reported moderate or severe problems was comparable to the general population. In agreement with our hypothesis, the EQ-5D index and the EQ VAS improved over time, although improvement was more pronounced during the first year (Table 2).

Table 2. The EQ-5D index and the EQ VAS at different assessment time points postburn.

<table>
<thead>
<tr>
<th></th>
<th>EQ-5D index</th>
<th></th>
<th>EQ VAS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean score (SD)</td>
<td>Range</td>
<td>Mean score (SD)</td>
</tr>
<tr>
<td>Baseline</td>
<td>0.16 (0.39)***</td>
<td>-0.59–1.00</td>
<td>50 (23)***</td>
</tr>
<tr>
<td>3 months</td>
<td>0.53 (0.34)***</td>
<td>-0.35–1.00</td>
<td>67 (19)***</td>
</tr>
<tr>
<td>6 months</td>
<td>0.56 (0.36)***</td>
<td>-0.24–1.00</td>
<td>67 (22)***</td>
</tr>
<tr>
<td>12 months</td>
<td>0.68 (0.29)***</td>
<td>-0.18–1.00</td>
<td>70 (21)***</td>
</tr>
<tr>
<td>2 to 7 years</td>
<td>0.78 (0.25)</td>
<td>-0.18–1.00</td>
<td>79 (18)**</td>
</tr>
<tr>
<td>Swedish general population</td>
<td>0.84 (0.28)</td>
<td>-0.59–1.00</td>
<td>85 (21)</td>
</tr>
</tbody>
</table>

Owing to missing values, sample sizes varied between 58 and 67.
** p < 0.01, and *** 0.001 in comparison with Swedish general population data [28].

Regression analyses were performed in four steps with the EQ-5D index and the EQ VAS as dependent variables. Variables measured during hospitalization were entered in step one, variables measured at 12 months postburn in step two, a final predictive model was identified in step three, and last, the impact of concurrent variables was examined in step four in an extended multivariate model.
The regression analyses revealed that only one variable measured during hospitalization, LOS, was a significant predictor for the EQ-5D index at 2 to 7 years. In the final predictive model, only the EQ-5D index at 12 months contributed significantly and explained 17% of the variance. Concurrent variables, pain and working, significantly related to the EQ-5D index at 2 to 7 years, were added to the final model, and explained 33% of the variance together with the EQ-5D index at 12 months in the extended model.

Two variables measured during hospitalization, work status at injury and a history of substance use disorder, were significant predictors for the EQ VAS at 2 to 7 years postburn. In the final predictive model, work status at injury, PTSD and the EQ VAS at 12 months explained 41% of the variance. Four concurrent variables were considered for inclusion in an extended model: any affective disorder, any substance use disorder, pain and working. Together with the EQ VAS at 12 months, working, and any substance use disorder at 2 to 7 years explained 57% of the variance.

Return to work after burn - a prospective study (Paper III)

Most individuals had returned to work when assessed at 2 to 7 years after injury. Thus, at follow-up on average 4.5 years (SD 2.0) after burn, 39 (67%) out of the 58 participants were working (n = 37) or studying (n = 2). Of the 39 participants who had returned to work at the time of follow-up, 27 (70%) had RTW within 12 months after burn, nine (23%) between 12 and 24 months, and three (8%) later than 24 months postburn.

In univariate regressions, injury-related variables TBSA, TBSA-FT, LOS and work injury were related to a longer time to return to work. Variables reflecting psychiatric morbidity, i.e. presenting with a history of any lifetime substance use disorder, or any anxiety disorder the year before being burned, or a history of any personality disorder, were also related to time to return to work. Multiple regression analyses revealed that time to return to work was predicted by LOS and fulfilling criteria for any personality disorder, and the model explained 27% of the variance.

Of the 19 (33%) non-working participants, nine were on sick-leave, six had gotten disability pensions, three were unemployed and one participant had an early retirement pension. In univariate regressions, living alone, LOS, fulfilling criteria for having any axis I disorder, as well as having any anxiety disorder or substance use disorder either lifetime or the year before the burn, were all significantly related to not returning to work. As these variables describing psychiatric history are mutually overlapping with regard to both symptom- and time-criteria, two different logistic regressions were aimed for, one for each time period. Preliminary regressions including any
anxiety disorder and any substance use disorder showed that these were independent predictors, and together predicted no return to work better than the predictor variable any axis I disorder both with respect to lifetime morbidity and to fulfilling criteria one year before injury. In the final regressions, no return to work was predicted by LOS, any anxiety disorder and any substance use disorder. The best fit model, explaining 40% of the variance, was obtained when including psychiatric conditions the year before burn.

The group that had not returned to work at follow-up reported lower generic HRQoL and burn-specific HRQoL than the working group. This was evident at every time point of assessment, from hospitalization to follow-up. Finally, those who had not returned to work exhibited more psychiatric morbidity in the form of having any Axis I DSM-IV disorder at 2 to 7 years; 7 out of 39 who had returned to work vs. 9 out of 19 who had not.

Return to work after burn injury: burn injured individuals’ perception of barriers and facilitators (Paper IV)

The participants perceived a wide range of factors that influenced their RTW process in a positive or negative way. The results indicated that the RTW process was integrated and dynamic, with parallel events that were not exclusively in the domain of work. The content analysis resulted in five categories, and comprised factors acknowledged by the participants as facilitators or barriers in the RTW process (Figure 3).

For a description of categories, subcategories and codes, and for examples of quotations, see paper IV. In the category The individual, individual characteristics and abilities were seen as facilitators, and the participants stressed the importance of finding one’s own motivation for the essential but often painful physical training.

Some of them were convinced of the importance of having been accustomed to using their body before the burn, like with training and exercise, of having perseverance when progress in rehabilitation was slow and recovery seemed to be unreachable. Barriers in this category were seen as feelings of disappointment, a lack of plans for the future, and needing to but not wanting to change jobs because of impairments. It is noteworthy that none of the participants reporting such feelings were back at work at the time of the interview.

When fatigue and pain led to doubts about ever returning to work, support from family and friends was perceived as a facilitator in the category Social life. To a great extent the family was seen as facilitating the RTW process, while not being treated with understanding and being challenged by friends was perceived as a barrier.
In the category *Health care and rehabilitation*, personnel were perceived as promoting RTW if they provided motivation, were competent and were compassionate. Limited knowledge in primary health care concerning wound care after burn was perceived by the participants as delaying RTW. The participants stressed the importance of physiotherapy, psychological support, exercise, and in particular, individualized training. A long sick-leave period and withdrawal symptoms when stopping pain medication were also barriers to RTW.

Due to both physical and psychological impairments, the possibility of having modified work tasks and flexible working hours was perceived as important in the category *The workplace*. Being treated with compassion by the employer and co-workers was seen as facilitating, while lack of support and understanding were barriers. Difficulty in performing work tasks due to physical impairments and feelings of discomfort or fear was perceived as a considerable barrier in the beginning of the RTW process. Most participants who expressed this were back at work but had permanently changed work tasks or their workplace due to impairments.

The participants perceived that the Social Insurance Office and the Job Center facilitated the RTW process by supporting changes in work conditions and new employment. Barriers in the category *Social welfare agencies* were contacts described as time consuming, and the processes and the decisions sometimes resulted in feelings of being obstructed.
Discussion

The principal aim of the present thesis was to increase the understanding of aspects of psychosocial recovery after severe burn with focus on return to work after burn and HRQoL. First, the psychometric properties of the generic instrument EQ-5D in the assessment of HRQoL after burns were analyzed, after which several possible predictive and concurrent factors of importance for return to work and HRQoL in a long-term perspective were explored, and finally, burn injured individuals’ perceptions of the process of RTW were analyzed.

Methodological considerations

Design

A prospective and longitudinal design was chosen for papers I, II and III in order to allow for assessment of clinically meaningful predictors of return to work and HRQoL a long time after burns. This design theoretically allows for optimal assessment of risk factors [86].

The semistructured interview instruments SCID-I and SCID-II were used to assess current and previous psychiatric disorders. These instruments are currently somewhat of a gold standard, and can be considered the best alternative to fully assess a spectrum of Axis I and Axis II disorders. The instruments, however, do not completely control for the phenomenon of recall bias, particularly with respect to the retrospective assessment of lifetime psychiatric disorders. Such retrospective ascertainment is known to underestimate lifetime prevalence [87]. In fact, a recent study comparing retrospective versus prospective methods of assessing the lifetime prevalence of psychiatric disorders suggests that the prevalence is only half what it could be in reality, because a very large number of disorders have been lost to recall failure [119]. In the present thesis, all assessments were made by experienced interviewers, trained in the use of these instruments, and with known interobserver agreement. Everything possible was therefore done in order to maximize the quality of the assessment of psychiatric disorders.

In order to limit the dropout, all follow-ups were planned for and conducted with personal visits. This was done above all in order to minimize the attrition of individuals experiencing problems with adaptation, a subgroup
that is associated with a high attrition rate [62, 79], and for whom clinical experience suggests low adherence to different types of agreements including routine clinical follow-up programs. To further minimize the attrition rate the interviews were conducted in a place chosen by the participant.

The qualitative approach used in one of the studies in the present thesis provided valuable knowledge concerning participants’ perspectives and contributed added information in addition to that obtained in the self-report questionnaires used in the other studies. The interviews offered an opportunity to collect appropriate data, as the participants had wide-ranging experiences of rehabilitation measures, returning or not returning to work, and professional contacts.

In a review of qualitative research on return to work after injury, the usefulness of qualitative evidence in guiding implementation of interventions was highlighted [108]. In a recent study investigating return to work among employees with common mental disorders, a mixed-method design was used and quantitative and qualitative data were collected at the same time, with integration of the data in the interpretation [128].

**Ethical considerations**

The time for the follow-up visit, including interviews, psychiatric assessments and questionnaires, lasted from one to one and a half hours. During that time the interviewer made every effort to optimize the encounter and make the interviewee comfortable. This approach, which requires considerable skill, is particularly important in qualitative research since the researcher is the main instrument for obtaining knowledge [98, 140]. The interviewer, the author of this thesis, is a nurse specialist in psychiatry with extensive experience, and the research team was available for professional support. During the design of the study, ethical situations were considered, e.g. if a patient exhibited symptoms indicative of a need for professional psychiatric care. There was, thus, a preparedness for handling such situations.

Some of the participants expressed that they found the interview situation helpful in that they had the chance to sort through their memories by relating them to the interviewer. It was shown previously that former burn patients found a survey with burn and trauma related topics beneficial and that it was well accepted [196], and this was also the case when there was prior psychiatric morbidity [191].

**Sample**

All the studies were based on the total number of consecutive adult patients with burns treated at the Uppsala Burn Center during the specified time periods. All severe burns from a region representing 70% of the total area of Sweden, with a population of about 3 million inhabitants, were referred to
the Uppsala Burn Center during the study period in accordance with a national agreement. Thus the samples used in the quantitative part of the thesis can be considered representative for both the Swedish population and the populations of other countries with comparable social legislation and standards.

In addition to consecutive inclusion, the use of inclusion criteria reduced the risk for selection bias. The study design with questionnaires and interviews made it necessary for participants to be able to understand and interpret questionnaire and interview questions. Accordingly, the ability to understand the Swedish language and to have adequate cognitive function, measured with the Mini Mental State Examination, was part of the inclusion criteria.

It is well established that an increasing proportion of patients fail to return for follow-up assessment as time since injury increases. Previous studies have found that patients with socio-demographic risk factors [79] and minor burns [65] are more likely to be dropouts in follow-up studies after burn. A strength of the present thesis is the detailed description of non-responders and dropouts. There were few or only minor differences between the attrition groups and the participants. Furthermore, the attrition rate is lower than usually seen in studies on rehabilitation after burns.

The limited sample sizes restricted the number of possible predictors in the multivariate regressions including the number of variables in the regression analyses [82].

The qualitative part of the thesis used a type of purposive sampling, maximum variation sampling [140]. A maximum variation sample is a purposefully selected sample of persons or settings that represent a wide range of experiences related to the phenomenon, and respondents are chosen so as to be as different as possible from one another. A purposive sample is not statistically representative, but a maximum variation sample aims to assure that all aspects of importance are represented in the sample, something that can never be assured in a random sample. In the present study, aspects of importance for individuals with burns in the context of return to work that are reported in the literature were considered as variations. To comprise the variations, the sampling yielded 40 participants. The number of participants and the expected amount of interview data were considered adequate in order to increase the likelihood that all relevant aspects of the phenomenon were studied.

Method
Self-reports are easily administered and time-saving. There are, however, a number of issues related to both validity and reliability. The use of self-report questionnaires is in general associated with the assumption that the respondent will answer honestly. Nevertheless, there are a number of factors
that may influence the response given to a certain item. Even though a questionnaire may be psychometrically sound, systematic biases can be more or less pronounced. Questionnaire bias is a result of unanticipated communication barriers between the investigator and the respondents that yield inaccurate results [31]. Such biases include the tendency to select the first response option that seems reasonable, to select one answer to the first item and then use this response for all of the subsequent questions, to choose a response at random, to give socially desirable answers, and with postal questionnaires there is uncertainty about who actually fills in the questionnaire. In addition, central tendency refers to a respondent’s unwillingness to place his or her health state at the extreme ends of a continuous scale, leading to end-aversion bias [171].

The psychometric properties of the self-report HRQoL questionnaires used in the present thesis have been analyzed in burn populations. The BSHS-B was analyzed in previous studies [89, 194], and the SF-36 has recently been validated in a burn population [49]. Furthermore, one of the aims of the present thesis was to assess the psychometric properties of the EQ-5D in burns.

One limitation in the analyses in paper I is the lack of a reliability test such as test-retest. But when assessing a dynamic phenomenon such as HRQoL during rehabilitation after burn, it would probably have been difficult to choose an appropriate test-retest interval.

Use of the SCID-I for assessing psychiatric disorders and the SCID-II for assessing personality disorders is a significant strength. The SCID interviews are the most widely used and thoroughly researched psychiatric interviews. Their use makes comparisons possible with international population prevalence studies.

Qualitative content analysis and data collection through interviews was chosen in paper IV in order to illuminate the experience and interpretation of events by participants with differing perspectives [140]. In qualitative research, trustworthiness of interpretations deals with establishing arguments for the most probable interpretations. Assessment of trustworthiness can be discussed using the concepts credibility, dependability, transferability [73, 102] and confirmability [102].

The selection of appropriate meaning units, and exemplifying the meaning units, condensations and abstractions facilitates judging the credibility of the findings. With the intention of exploring perceptions and staying close to the participants’ narratives, the use of only manifest and not latent content analysis was chosen [73]. Content analysis is the least interpretive of the qualitative analyses, but interpretation always involves a balancing act between adding a perspective to the phenomenon under study and not assigning meaning to the text that is not there [157]. Furthermore, the co-authors were involved in verifying the rigor of the data and contributed with alternative coding of the data. Sandelowski [157], however, questions the value of
the dialogue between co-researchers as the reality is subjective, and when seeking to describe an experience the researcher selects what to describe and the transformation of the reality has begun.

The concept of dependability deals with the risk of interpretative errors in the analysis. In order to discover the interviewee’s own framework of meanings as far as possible and avoid imposing the researcher’s structures and assumptions, the qualitative interview was conducted first, i.e. before the participants answered structured questions and questionnaires. To further minimize the influence of preexisting assumptions, the interviewer was not a member of the staff, and had not met the participants before. To minimize great variations in data collection and to enhance the ability of others to reach similar conclusions, the interviews always started with the same phrases.

Transferability is the extent to which findings can be transferred to another context. Clear descriptions of the participants and the interview situations, description of the different steps in the analysis, and selection of quotations to illustrate the data and to be representative of the statements were undertaken to enhance transferability.

The confirmability of an inquiry is the confirmation that interpretations are clearly derived from data and the results are supported by data [102]. The aim of the study and the different steps in the analyses have been checked and rechecked in order to be internally coherent, and thus the subcategories and the categories correspond to the aim.

Health-related quality of life
Assessing health-related quality of life

There is no gold standard for measurement of HRQoL; hundreds of HRQoL instruments with different properties are in use [70]. Some generic measures have been widely used and extensively validated in clinical settings and special population studies, but their length often makes them impractical to use, particularly when a combination with a disease-specific instrument is preferable. The findings of this thesis support the use of the generic instrument EQ-5D together with a burn-specific instrument to encompass relevant HRQoL dimensions after burn, which has also been recommended previously after injury [183] and after burn [182].

The EQ-5D is short, brief and easy to administer. The structure with only three response levels makes it easy for participants to fill in, but it has been criticized for making it difficult to pick up small changes in health. There is evidence for ceiling effects when a large proportion of respondents early in a follow-up study score in the top category of domains and there is little room left for improvement [24]. However, this was not an apparent problem in the
present thesis, where the proportion of participants reporting no problems was only 19% at 12 months and 31% at 4.6 years postburn. An EQ-5D with five response levels, not yet available for clinical use, has been suggested [84].

The EQ-5D includes an assessment based on preference elicitation, the EQ-5D index. A question corresponding to cultural context is whose preferences to use for valuation of health states. Preferences can be elicited from people who have the health states, or clinical conditions, to be valued, or who have at least experienced them sometimes, or from healthy people who have to imagine being in the health states to be valued. There is no gold standard for how and from whom the valuations should be elicited. The EQ-5D uses health preferences elicited from the general population [41]. This assumes that preferences do not vary between different groups of people, particularly not between patients and healthy persons, or persons of different ages.

When measuring changes in HRQoL, the theory of response shift has been advocated. This is often the explanation when people with very disabling conditions report that their health is as high or higher than those who are objectively more healthy. Changes in an individual’s health status may prompt behavioral, cognitive and selective processes necessary for accommodating illness. These processes have the potential to change an individual’s standards, values or conceptualization of HRQoL. This response shift will thus influence perceived HRQoL. There are in fact methods for detecting and analyzing response shifts [161]. The pre- and post-measures may not be fully comparable because the situational variables are different, but on the other hand a patient-based outcome is a subjective measure and aims to capture the individual’s perception of physical, mental and social health over time [138]. Changing one’s standards or values may be equivalent to an individual’s ability to come to terms with his or her situation, a remarkable human ability. It may yet be that the inability to achieve such changes is what characterizes those who adjust least well to their situations.

Health-related quality of life after burn

One of the main findings of this thesis was that information obtainable before or at 12 months postburn could in part predict long-term HRQoL. Not working at injury and having PTSD at 12 months, as well as having low scores on the EQ VAS at 12 months, increased the risk for reporting low EQ VAS 2 to 7 years after burn. Most studies presented so far only allow limited conclusions regarding variables that predict HRQoL many years after injury. They have only measured HRQoL at one or a few time points, or have had a cross-sectional design. However, a recent prospective study showed that the deleterious effects of early PTSD on HRQoL after burn were reduced by time over two years [36]. This was largely in line with the findings of the
The present thesis, where PTSD at 12 months was not associated with HRQoL at follow-up.

The explained variance of long-term HRQoL increased considerably when including concurrent variables in the regression analyses. Currently having a substance use disorder and having everyday pain were associated with low HRQoL, and an active work status was associated with high HRQoL. In previous research it was found that current self-reported psychological illness [122], or having pain [36, 122], was associated with poor outcomes in HRQoL, as well as being unemployed [122] or not being back at work after burn [45].

It must be pointed out that there was no significant impact of concurrent psychiatric disorders other than substance use disorder on long-term HRQoL. Other studies have found that psychiatric disorders have a major impact on HRQoL [152]. Thus, the influence of depression on HRQoL, measured by the EQ-5D, was substantial [167]. Furthermore, a Finnish study identified former drinkers as scoring worst on most EQ-5D measures, even in comparison with the highest drinking decile [151]. The difference between these studies and those in the present thesis may be related, at least in part, to their limited sample size and consequently to statistical power.

In the present thesis, the trajectory of HRQoL from hospitalization to on average 4.6 years postburn was assessed. The EQ-5D index and the EQ VAS improved over time, from extremely low values during hospitalization indicating the massive impact of a burn injury on all dimensions of HRQoL, to near general population values at follow-up. Few studies have used the EQ-5D for assessment of HRQoL after burn, and different timeframes [155, 156] and different inclusion criteria [142] make comparisons almost impossible.

The reported problems in different dimensions in the EQ-5D mirrored the pattern of recovery during the first year after burn, and at follow-up 2 to 7 years later. During the first year postburn, improvement was noticeable in three dimensions, mobility, self-care and usual activities. At 12 months, most problems were reported in the dimensions pain/discomfort and anxiety/depression. In a recent study based on this patient sample and utilizing the BSHS-B, physical functions improved during the first year after burn, while difficulties remained regarding skin involvement, and affect and relations [194]. Further, a review based on studies reporting generic HRQoL in patients after intensive care has shown the same pattern of improvement [42]. However, studies on other severe traumas report fewer problems in the EQ-5D anxiety/depression dimension than in our study [80, 143]. The high prevalence of psychiatric morbidity prior to burn may be one explanation, suggesting that such a history constitutes a risk factor for post-burn psychiatric morbidity [47, 61]. At 2 to 7 years postburn, the proportion of participants reporting problems in anxiety/depression had decreased and was similar to that in the general population.
At follow-up a large proportion of participants still reported problems in the EQ-5D pain/discomfort dimension. However, only half of the participants who reported problems in this dimension at follow-up reported everyday pain utilizing the BPI-SF. One tentative explanation is that the pain/discomfort dimension in the EQ-5D captures more than pain, e.g. scar formation, joint contractures and paresthetic sensations that are established causes of discomfort after burn [14, 99, 112, 195]. The proportion of participants reporting everyday pain is in line with previous results [14, 32, 112].

Return to work

Return to work can be viewed both as an outcome and a process, and can be measured in a variety of ways. In this thesis RTW is measured as an outcome in papers I–III and as a process in paper IV. There is no substantial agreement about what constitutes a successful RTW outcome [145]. In the present thesis information provided by the participants that they were engaged in paid work or full time studies was used as an outcome measure.

The time to return to work

At follow-up 2 to 7 years after burn, 67% of the participants had returned to work or studies. The average time off work was 9 months after burn. It is difficult to make any firm comparisons with other studies because of differences in follow-up time and different inclusion and exclusion criteria, for example regarding time since burn, work at the time of injury, exclusion of those with psychiatric problems and different age limits. In a recent systematic review, the time taken to return to work after burn ranged from 4.7 weeks to 24 months [146].

In this thesis it was shown that time to return to work was predicted by LOS and having a personality disorder. LOS can in this context be interpreted as a proxy for severity of the burn. The impact of injury severity on the time to return to work has been reported previously [23, 27, 45, 76, 153, 174].

It has previously been shown that various aspects of personality are of importance in the RTW process [27, 45, 53, 62], but no earlier study has assessed the influence of personality disorder on the time to RTW after burn. A personality disorder is characterized by disturbances in behavioral patterns and is nearly always associated with considerable personal and social disruption [16]. Studies have indicated that having a personality disorder compromises work functionality, both with respect to unemployment rates and the ability to RTW [158]. Furthermore, personality disorders are associated with a poor outcome of vocational rehabilitation [181], early retirement from work [94] and perception of employment as stressful and difficult [85].
Having a personality disorder was one of the predictors of time to RTW after burn. This may be due to the inflexible behavioral pattern and social dysfunction related to the diagnosis, and their negative consequences for optimal rehabilitation. To overcome these factors it may be of importance to find communication strategies that include flexibility, optimism, creativity, and diplomacy [160]. Knowledge concerning this aspect is necessary when treating burn patients, especially in light of the high prevalence of personality disorders in burn patients [137, 144].

The fact that LOS and having a personality disorder only explained 27% of the variance of the time to RTW shows that other not yet disclosed factors are together more important than the ones studied. Such factors may be found at the workplace, in societal institutions or in the individual’s financial situation.

No return to work

One third of the participants had not returned to work on average 4.7 years after burn. This is line with previous studies investigating return to work up to 3.6 years postburn in patients employed prior to the burn [27, 45, 53, 159].

Both physical and psychological factors have been identified as associated with return to work after burn. Variables associated with not returning to work are burn severity [23, 27, 45, 174], pain and impaired mobility [46, 159] and dysfunctional beliefs [45].

In the present thesis, LOS, together with any anxiety or substance use disorder lifetime or in the year before injury were significant predictors of no RTW. In previous studies with participants employed or unemployed prior to burn, a psychiatric history has been associated with not returning to work [27, 62]. It has also been observed that a psychiatric disorder prior to burn has an impact on postburn adjustment and recovery [60, 176, 177, 185, 198], as well as on postburn psychiatric morbidity [47].

Having a history of a psychiatric disorder indicates that there is an increased individual vulnerability with a risk of not handling physical and psychological stress and strain in an optimal fashion. In fact, poor mental health, most often anxiety or depression, is regarded as being responsible for a large percentage of work absence over the long term [170] and often leads to job loss. The results obtained here point to the importance of identifying individuals who are at risk of being permanently out of work. Interventions ought to be directed toward treating and minimizing symptoms of psychiatric disorders including substance use disorder. In addition, an individualized plan for rehabilitation and vocational training seems appropriate.
Perceptions of barriers and facilitators

A qualitative approach was used to explore the previous patients’ points of view and to reveal the meaning of their experiences [98, 114, 140], here with respect to their perceptions of barriers and facilitators to the RTW process.

The participants emphasized the importance of their own ability to manage the RTW process. Several aspects including willpower, determination, trust in themselves, setting goals in the rehabilitation process and achieving them were perceived as facilitating factors. In a Norwegian interview study, burn patients experienced that achieving personal goals, and believing in their will and power to get there, were essential in their struggle to regain freedom [120]. In rehabilitation, setting goals with the patient is a core practice based on several theories [162], but with little evidence of the benefits [101].

When identifying the pattern of barriers to return to work, there is evidence concerning participants’ perception of the importance of being met with compassion and understanding. Barriers are seen as not being understood by the social network and friends, not meeting compassionate personnel in encounters in health care and rehabilitation, not having compassionate employers and co-workers, and being treated without compassion in contacts with social welfare agencies. Considered together, this may reflect feelings that no one can really understand and share the unique experience of being afflicted with a severe trauma and being exposed to very long, complex and stressful treatment. There are studies suggesting that peer support can provide a sense of being understood and belonging for burn patients [18], and can have a positive impact on hope for burn survivors [169], and can also influence psychosocial recovery [19].

Participants described a process involving many professionals and stakeholders. Barriers were perceived as time consuming contacts, with a long waiting period for decisions and compensation. Finally, navigation through institutional systems and handling a large number of contacts when feeling helpless and less than self-sufficient were found challenging.

A review recently identified barriers to return to work after injury as ineffective communication, social constructions and conflicting interests [109]. Injured workers perceived many barriers in the RTW process caused by two systems, the health care system and the RTW system, where the transfer of knowledge between them is inadequate. This fact prevented individuals from being active participants in the process [95]. Barriers in health care, in vocational retraining, in the workplace and regarding workers compensation were reported after burn injury, and the problems taken together became a “toxic dose” of system problems, which in reality slowed down or prevented return to work [110].
General discussion and clinical implications

Being able to return to work after injury can be seen as returning to pre-injury levels of functioning, i.e. having recovered. One goal of health care is to attain optimal recovery for as many as possible. For those who are back at work, RTW is one indication that rehabilitation has succeeded.

The present thesis, in line with many previous studies [22, 46, 90, 121, 122], has pointed out the interrelationship between an active work status after injury and a high HRQoL. In fact, participants who had returned to work after burns reported HRQoL comparable to that of the general population.

The ability to work is a concept comprising many aspects, from possibilities, competences and skills to motivation and will [130]. The possibility of working was illustrated in the participants' narratives. They stressed the importance of the possibility of getting modified work tasks during their first days or weeks back at work. This was an opportunity for them to participate at the workplace before being completely recovered. This was mentioned in particular in relation to physical impairments. It is reasonable that modifications of the workplace and of work tasks during the RTW process, based on psychological disabilities, would further enhance RTW.

The participants emphasized their own ability to take action as crucial for regaining the ability to work. Setting up goals in rehabilitation, having willpower, and optimistic thinking are actions that were described as important. In fact, none of the participants who reported feelings of dejection in the qualitative investigation had returned to work. Motivation and optimism were also factors that differentiated those who returned to work after musculoskeletal disorders, in contrast to hindrance and hesitation that characterized the non-working group [107]. A preburn psychiatric history was found to increase the risk for psychiatric disorders after burn [47, 61], which may lead to reduced willpower and ability to take action. Depressive symptomatology was associated with lower return-to-work expectations after vehicle accidents [134]. As mentioned above, identifying and treating psychiatric symptoms is important regarding the individual's ability to work. A recent study, although small, reported that telephone-delivered cognitive behavioral therapy positively affected return to work in workers with depression [20].

Contributing to society through the ability to work is not only financially necessary; it conveys identity, a social role, and social status. The participants stressed the importance of being back at work as soon as possible, of being back in a routine and getting structures, as well as being part of the social network at the workplace. Studies have identified that being able to resume meaningful activities, a social life, and particularly work, is related to autonomy and to quality of life [149]. This is also true for those who will never regain the ability to have an open market job [50].

An early and systematic approach to assessing recognized risk factors would enhance the possibility of discovering patients who are at risk of de-
veloping problems during postburn adaptation. Factors recognized during hospitalization, together with EQ VAS and PTSD symptoms one year post-burn are, thus, useful in the judgment of long-term HRQoL. Therefore the findings of the present thesis suggest that assessment of HRQoL one year after burn should be incorporated into standards of care. Early multi-professional assessments and individualized support during rehabilitation will reasonably support the RTW process. Interventions should include collaboration between specialists and resources in the home community to enhance the possibility for treatment continuity.

In addition, the results indicate that the RTW process is not straightforward, but is more of an integrated dynamic process, with parallel events that are not exclusively in the area of work. The complex nature of the RTW process was a decisive factor for the introduction of RTW coordinators, which in some organizations has resulted in a shorter duration of disability [69]. Moreover, a recent review has established that successful RTW coordination may depend more on competencies in ergonomic job accommodation, communication, and conflict resolution than on medical training [163].

Future aspects

A reasonable prerequisite for future research is the understanding that a complex reality with many factors predicts the ability to work and to return to work after burns. Identifying and understanding remaining problems even years after burn is of importance not only for providing adequate long-term rehabilitation but also for predicting the long-term outcome and for supporting reality adaptation. Informing patients about “what to expect” years later will facilitate their own ability to take action and have control, which will hopefully improve adaptation and recovery.

There is a need for more research to develop interventions, and to assess the effectiveness of such interventions, in order to prevent problems with adaptation after burn. In fact, a recent Cochrane review found no current support for psychosocial interventions in the prevention of mental disability following traumatic physical injury [39]. These conclusions were, however, based on a small number of disparate trials with small to moderate sample sizes. More research, using larger sample sizes, and similar interventions and patient populations to enable pooling of results, is therefore needed. Furthermore, the results suggest that future interventions should focus on screening patients at risk for poor outcomes and only treating those who develop subsequent problems.
Conclusions

Return to work and health-related quality of life after burn are influenced by factors existing preinjury, at injury, and during recovery, as well as current factors including physical, psychological and social variables. In the present thesis psychiatric morbidity, socio-demographics, work status, injury variables and their relations to return to work and to long-term HRQoL have been investigated and the main conclusions are

- The generic instrument EQ-5D has good psychometric properties, and it is short and easy to administer and thus useful in assessment of HRQoL after burn.
- Former burn patients’ HRQoL was lower than that of the general population when assessed with the EQ VAS on average 4.6 years after injury. The EQ-5D index and the EQ VAS at 12 months were predictors of long-term HRQoL, as were PTSD at 12 months and an active work status when injured.
- Time to return to work after burn was predicted by length of hospital stay and a diagnosis of a personality disorder. Predictors for not returning to work were length of stay and having any anxiety or substance use disorder prior to the burn. The non-working group reported lower generic and burn-specific health, and exhibited more psychiatric morbidity at follow-up than the group that had returned to work.
- Participants’ perceptions of facilitators and barriers in the RTW process after burn can be sorted into five categories: the Individual, Social Life, Health Care and Rehabilitation, the Workplace, and Social Welfare Agencies. There was an emphasis on own psychological resources and capabilities as facilitators. The perception of care-related barriers to RTW indicates the need for a coordinator early in the rehabilitation process. Most participants did not consider the presence of residual physical impairments as a barrier to work.
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