Perceived Physical and Psychological Outcome After Severe Burn Injury

BY

MORTEN KILDAL
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Abstract

There is very little data on physical and psychological long-term outcome after severe burn injury. The aim of the present thesis was to improve current instruments for assessment of these issues, to assess long-term outcome in a cohort of patients with burn injuries, and to explore the contribution of the individual factors of personality and coping on perceived outcome.

Patients treated at the Burn Unit, Uppsala University Hospital, between 1980 and 1995 were included on a consecutive basis if they were 18 years of age or older at follow-up, had burn injuries of ten percent or more, or hospitalization times of seven days or more. A total of 350 patients fulfilled these inclusion criteria.

A factor analytic approach was used to derive a 40-item instrument called the Burn Specific Health Scale-Brief (BSHS-B), resulting in nine well-defined domains. Most burn patients reported a very good perceived outcome but a subgroup reported problems years after injury. On a group level most problems were related to Heat Sensitivity, Work and Body Image. The depth of injury, gender, marital status and living conditions were all related to outcome. Neurotic personality traits were related to perceived health, and were not confined only to psychological aspects of life but also included physical aspects. A 33-item burn-specific coping scale, the Coping with Burns Questionnaire (CBQ), with six clearly separated domains with acceptable internal consistencies was developed. Coping strategies were strongly related to outcome in the subgroup of patients reporting most problems in perceived health, and coping contributed more to psychosocial than physical health. Avoidant coping and Emotional support seeking had independent effects on outcome.

The observation that Neuroticism and Avoidant coping strategies are related to bad outcome after severe burn injury indicates that patients with such characteristics should be given special attention during rehabilitation.

Keywords: Burns, Outcome Assessment, Health Status, Quality of Life, Personality, Rehabilitation, Wounds and Injuries, Accidents, Coping

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## Abbreviations

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<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>ABA</td>
<td>American Burn Association</td>
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<tr>
<td>BSA</td>
<td>Body Surface Area</td>
</tr>
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<td>BSHS</td>
<td>Burn Specific Health Scale</td>
</tr>
<tr>
<td>BSHS-A</td>
<td>The abbreviated Burn Specific Health Scale</td>
</tr>
<tr>
<td>BSHS-R</td>
<td>The revised Burn Specific Health Scale</td>
</tr>
<tr>
<td>BSHS-B</td>
<td>Burn Specific Health Scale-Brief</td>
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<tr>
<td>CBQ</td>
<td>Coping with Burns Questionnaire</td>
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<tr>
<td>DALY</td>
<td>Disability Adjusted Life Years</td>
</tr>
<tr>
<td>HPA</td>
<td>Hypothalamic-pituitary-adrenal</td>
</tr>
<tr>
<td>IADL</td>
<td>Index of Activities of Daily Living</td>
</tr>
<tr>
<td>KSP</td>
<td>Karolinska Scales of Personality</td>
</tr>
<tr>
<td>LOS</td>
<td>Length of Stay</td>
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<tr>
<td>MANOVA</td>
<td>Multivariate Analysis of Variance</td>
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<tr>
<td>MOSI</td>
<td>Medical Outcome Study Instrument</td>
</tr>
<tr>
<td>PAIS</td>
<td>The Psychosocial Adjustment to Illness Scale</td>
</tr>
<tr>
<td>PTSD</td>
<td>Posttraumatic Stress Disorder</td>
</tr>
<tr>
<td>SD</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>SF-36</td>
<td>Medical Outcomes Study Instrument Short Form, 36 items</td>
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<tr>
<td>SIP</td>
<td>Sickness Impact Profile</td>
</tr>
<tr>
<td>SSP</td>
<td>Swedish universities Scales of Personality</td>
</tr>
<tr>
<td>TBSA</td>
<td>Total Body Surface Area</td>
</tr>
<tr>
<td>TBSA-FT</td>
<td>Total Body Surface Area-Full Thickness</td>
</tr>
<tr>
<td>WCQ</td>
<td>Ways of Coping Questionnaire</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td>YPB</td>
<td>Years Post-Burn</td>
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Introduction

Burn injury

Throughout history as well as in literature, the devastating effects of fire on man and property have created both fear and respect for this element, and for good reasons. Major burn injury is one of the most severe traumas a person can experience, with devastating effects on the skin, the largest organ in the body. Normal skin protects us from invasive infection by microorganisms, prevents fluid losses, and helps regulate body temperature. These protective properties are destroyed after burn injury, and without proper treatment the natural prognosis for extensive burns is poor because of burn shock, multiorgan failure and sepsis.

Viewed globally, burn injury is one of the leading causes of trauma death and one of thirty leading causes worldwide of loss of life years due to premature mortality and years lived with disability (Disability Adjusted Life Year, DALY) (129). The severity of a burn injury depends on burn-specific as well as general factors, such as body surface area affected, depth of injury, age of the victim, associated injuries or diseases, and to a certain extent also on location of injury. Burn-specific factors affecting morbidity and mortality are best described by:

a. The surface area of the burn measured as the percentage of the total body surface area (TBSA) burned.

b. The depth of the burn with superficial burns being limited to the epidermal or superficial dermal parts of the skin (1\textsuperscript{st} and superficial 2\textsuperscript{nd} degree burns). Deeper injuries penetrate further down to the deep dermal skin layers (deep 2\textsuperscript{nd} degree burns) or through all skin layers down into subcutaneous tissue as full thickness or subdermal injuries (3\textsuperscript{rd} degree burns). Muscular or skeletal structures can also be damaged as a result of severe burn injury.

The older the burn victim the more serious the injury. Furthermore, concurrent inhalation injury increases mortality and morbidity considerably.
A deeper burn (deep dermal, full thickness and subdermal) requires surgical excision and skin coverage and therefore often a longer time for healing with an increased risk of wound infection and sepsis during the healing period. Superficial burns (epidermal and superficial dermal), on the other hand, heal spontaneously in one to three weeks. Severe burn injury is clearly a serious threat to physical health, but also to the psychological and social well-being of the individual.

Epidemiology of burns

The incidence of burn injuries varies greatly in different regions and countries throughout the world as a result of both economic and social factors. Burn related problems in third world countries are thus both greater than and different from problems encountered in the western world (2, 39, 48, 125). The estimated incidence of burns requiring hospital care in the United States and Canada ranges between 19 and 26 admissions per 100 000 inhabitants (146). In Finland, a figure of 35 per 100,000 inhabitants was reported in the 1970s (132), in Italy the figure is 31 (11), in Britain 29 (152) and in New Zealand 25 per 100 000 (191). In Sweden the reported incidence of 17 admissions per 100 000 inhabitants per year is low, and corresponds to approximately 1500 hospitalizations yearly (1). Tentative explanations for the low rate in Sweden are multifold. Early recognition of preventive measures with extensive legislation, more emphasis on ambulant treatment, and a primary health care that emphasizes preventive measures are some possible explanations.

Mechanisms of injury also vary widely among different countries and communities depending on such factors as the ways in which food is prepared, heating systems, industrial environments and general living conditions. The use of specific products or the existence of specific habits may explain why some types of burns prevail in certain cultures and regions. The introduction of water heaters, for example, led to a dramatic increase in scalds in children before the heaters were properly modified (167).

Males are strongly over-represented in burn statistics all over the world, with India as the only exception, and men are known to have the highest risk of burn injury and the highest risk of death due to injury (130). Children are also at high risk, both in developed (123, 146) and in less developed countries (49).
The development of modern burn care

During the first quarter of the twentieth century patients with massive burns had little chance of survival. Advances in surgery during this period were not applicable to burn patients, survival rates were poor, and most patients died either from massive fluid shifts associated with burn shock or from sepsis. The introduction of modern antibiotics and aseptic techniques during the 1950s and 1960s reduced the death rates due to wound infection, cross-infection and sepsis (165). Later, in the 1960s and 1970s, modern intensive care with more efficient ventilators, vasoactive drugs and invasive monitoring contributed to reduced mortality rates. During this period the problems of burn shock, inhalation injuries, sepsis and hypermetabolism were recognized and to a certain extent addressed. The complexity of burn injury led to the development of centralized and highly specialized burn centers, with multidisciplinary professional teams providing more sophisticated care for severely burned patients (8).

The introduction of tangential primary excision of necrotic tissue by Janzekovic in 1970 (91, 92) was the first real surgical improvement during these years. A new concept was introduced. Non-viable tissue was removed surgically as early as possible to reduce the risk of wound infection and sepsis and to improve late results, with less scarring and fewer chronic wounds. Later, improvements in anesthesiological and surgical techniques and knowledge made it possible to excise most or all non-viable skin at an early stage. This technique was combined with immediate wound coverage with skin from the patient (autografts) (35, 56) or donor skin from centralized tissue banks (homografts) (169). The past decade was characterized by technological advances in the provision of skin substitutes such as cultured epithelial keratinocytes (45, 103, 128, 134) and artificial dermal substitutes (12, 131, 157, 203). These achievements are of importance in reducing late scar contracture, disfigurement and length of stay in hospital (56, 157).

The above mentioned improvements have dramatically increased the chance of survival after major burn injury. Fifty years ago adults aged 15 to 44 years of age had a 50 % chance of survival with a burn covering 46 % of their total body surface area, and children had a similar survival rate with a 49 % burn (34). In modern burn units today, adults have a 50 % chance of survival with a burn exceeding 70 % (81, 158). An even more impressive improvement in survival is found in young adults with reports of 50 % survival rates with burn injuries covering between 80 % (158) and as much as 98 % (81) of a child’s body.
Rehabilitation after burn injury

Rehabilitation of patients with large burns starts on the day of injury, even in a patient undergoing ventilator support. It comprises positioning of joints with splints, early physiotherapy and information and follow-up for next of kin. For the severely injured this is just the beginning of a long journey involving adaptation to a life post burn. The physical and psychological impact of burn injury can be severe, and the process of recovery or adaptation depends on individual as well as circumstantial factors.

Rehabilitation aims at optimizing the patient’s ability to return to a life that is affected as little as possible by the physical and psychological consequences of the burn injury. A variety of problems must be addressed that are related to reduced physical functioning due to skin related complications because of scar contractures. Support measures must be instituted with regard to various psychosocial problems. Early identification and treatment of common co-morbid conditions such as posttraumatic stress disorder (PTSD) and depression are of central importance. The complexity and diversity of the burn sequelae themselves and the great differences among victims regarding premorbid psychopathology, social networks and coping capacities point to the need for a multiprofessional approach to burn rehabilitation. In modern burn units, specialists such as burn surgeons, anesthesiologists, infectious medicine specialists, burn nurses, psychiatrists, psychologists, physiotherapists and vocational therapists continuously assist and evaluate the patient’s progress both during hospitalization as well as in the outpatient setting.

Several studies indicate that adaptation and psychological adjustment after burn injury are influenced by factors other than burn severity, such as premorbid personality, coping responses, gender, visibility of scars and employment status (31, 108, 189). A problem with studies of adaptation after burn injury is that they are hampered by methodological weaknesses such as small, non-representative samples and high attrition rates. This is due to the low incidence of severe burn injury and the highly centralized mode of care.

Health status and outcome

Death rates provided one of the few relevant and sensitive measures of outcome in burn care, as well as in other areas of health care, during the 1950s and 1960s (122). This was a time when mortality was significant also in moderate injuries (146). Expressing burn size as percentage of the body based on surface area proportions (16) made it possible to develop the first trauma indices that could be directly compared among different burn
populations. Demographic and socioeconomic data offered insight into patterns of need in a population, but they were incapable of generating valid measures of morbidity (51). As mortality rates dropped during the late 1960s and 1970s, estimates of death rates became increasingly less valuable for assessing improvements in patient care and for use in health care planning and research. In health status assessments more reliance was being placed on measures of morbidity. A vast amount of information was collected in different surveys, but there was no unified measure available in order to aggregate all the data (13).

According to Moriyama (122), one major obstacle in developing aggregated measures was the lack of “a conceptual definition of health capable of being translated into suitable operational definitions”. Health is a complex concept closely related to well-being and quality of life. All of these concepts have difficult and variable definitions. The World Health Organization’s (WHO) definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity” (197) is well known and is only one of many definitions that emphasize positive aspects of health, whereas most health measures used in disease surveys actually stress negative aspects. According to WHO definitions, there are different levels of disturbed function. Impairment is defined as “disturbances at the organ level”, e.g. reduced range of motion because of scar contracture, and disability as a “disturbance at the individual level”, e.g. reduced walking capacity. A handicap is defined as the “disadvantage experienced by an individual as a result of impairments and disabilities” (198). The importance of including surveys of mental and social health in addition to estimates of physical functioning is obvious when defining health as is done by the WHO. Nevertheless, researchers tend to concentrate on clinical measurements of the physical impact of impairments and disabilities when evaluating outcome after trauma. One reason for this is probably the complexity of the effect of interacting physical, mental and social health variables on outcome.

Health status measures

Measurements of health status range from measures obtained with instruments focusing on a specific range of physical functioning to those obtained from questionnaires dealing with a broad range of psychological, social and physical functioning. Health status measures should ideally be able to discriminate between individuals and groups, be able to predict outcome and evaluate change over time (184). According to Donovan (51), seven basic categories of health status can be found:
1. **General health measures** provide global profiles of health describing well-being, social health, emotional health and function. Commonly used instruments in this category include the Sickness Impact Profile (SIP), (14, 15, 71), the Nottingham Health Profile (NHP) (87), the General Well-Being Schedule (53), the EuroQol (29), and the Medical Outcomes Study Instrument (MOSI) (183), with the SF 36 (115, 116, 178, 193, 194) being one version of this instrument.

2. **Measures of physical function** are aimed at determining levels of disability, impairment, and physical function focusing on activities of daily living, and as many as 43 scales have been reported (64). Examples are the Lambeth Disability Screening Questionnaire (138), the Barthel index (107), and the Index of Activities of Daily Living (IADL) (96) aimed at the general population, and group specific health measures for the elderly, such as the Pulse Profile (124).

3. **Pain measures** are aimed at measuring the intensity of pain and include instruments such as the McGill Pain Questionnaire (119) and the Visual Analogue Scale (VAS) (164).

4. **Social health measures** examine the strength of social support networks and include instruments such as the Social Health Battery (202).

5. **Psychological measures** are aimed at assessing psychological or psychiatric morbidity with instruments such as the General Health Questionnaire (72) and the Psychological Adjustment to Illness Scale (PAIS) (50, 150). Examples of more disease specific instruments are the Hospital Anxiety and Depression Scale (HADS) (95, 172, 205), the Montgomery Åsberg Depression Rating Scale (MADRS) (120) and the Impact of Event Scale (IES) (85).

6. **Quality of life measures** such as the Quality of Life Index (174) and Four Single Items of Well-Being (7) are aimed at assessing the individual’s overall satisfaction with life and well-being.

7. **Specific disease measures** concentrate on concerns of importance to patients with specific diagnoses and are exemplified by the Arthritis Impact Measurement Scales (AIMS) (117, 118), the Oswestry low back pain disability questionnaire (59), and the Burn Specific Health Scale (17, 19, 127).
All of the above mentioned measurements are based on instruments with closed sets of questions in a defined order with limited numbers of responses. They are completed either as self-report questionnaires or, less frequently, by interviews.

These health measures are descriptions of subjective or perceived aspects of health, as opposed to clinical examinations or laboratory tests which are often considered to generate more objective data. However, the individual’s experience of the effect of treatment and final outcome can only be truly assessed from the patient’s own perspective.

Psychometric principles

Psychometric theory involves the scientific concepts of defining, measuring and scaling abstract phenomena such as personality, coping, depression and anxiety. It can be described as an approach to developing and analyzing measures based on statistical relationships between items and scales, and validity and reliability are basic concepts of psychometric theory (40).

Validity and reliability

Validity is most often defined as the extent to which an instrument measures what it was intended to measure. Three types of validity measures are commonly examined: content, criterion, and construct validity.

Content validity concerns the extent to which items in a measure accurately reflect the full breadth of the construct of interest. Content validity is usually established by the subjective assessments of experts in the field and subjects from the population for whom the instrument would be appropriate. Criterion validity is the extent to which the measure correlates with an external “golden standard” i.e. another accepted measure of the same construct. However, such a clear and well-defined “golden standard” rarely exists in the area of psychosocial science. Construct validity examines the relationship between underlying theoretical concerns and the measure. The term “construct” is the phenomenon intended to be measured by the clinician, e.g. neuroticism. Construct validity is dependent upon a sound theoretical basis for the particular measure.

Reliability refers to the consistency of a measurement, or the degree to which an instrument gives the same information each time it is used under the same conditions. There are usually two ways to estimate reliability: internal consistency and test-retest. Internal consistency estimates reliability by grouping questions in a questionnaire that measure the same concept. One common way of computing correlation values among the questions in an
instrument is by using Cronbach's α. **Test-retest** is an estimate of reliability obtained by correlating pairs of scores from the same individuals for two different administrations of the same test.

**Multivariate techniques**
When analyzing complex relationships such as outcome after burn injury, large numbers of variables, combinations of variables and observations need to be assessed and analyzed. A group of statistical methods, so-called multivariate techniques, have been introduced for this purpose. Multivariate analyses can be considered as extensions of univariate and bivariate statistics, but with the potential to measure, explain and predict the degree of relationship among a large number of variates.

In **factor analysis** underlying patterns or relationships are identified for a larger number of variables (76). After determination of correlations between all included variables, there are various mathematical techniques to simplify the intercorrelation matrix into a smaller number of common factors. The main applications of factor analytic techniques are 1) to detect structure in the relationships between variables, i.e. to classify variables, and 2) to reduce the number of variables. In this way complex multidimensional relationships can be summarized into "domains" with smaller numbers of items, thereby making it easier to understand and interpret underlying dimensions.

In **multiple regression techniques** the effect of the relationship between a number of "independent" variables on one "dependent" variable is assessed. In the most common form of **multiple logistic regression** (86) the dependent variable is binary or dichotomous (e.g. yes/no). The goal of multivariate analysis is to find the best fitting and biologically reasonable model for describing the relationship between an outcome and a set of explanatory or predictor variables (86).

**Assessment of burn-specific health status**
The standard approach to health status measurements has been based on utilizing both a generic and a disease-specific health scale. However, it was not until 1979 that Blades et al (18) decided to develop a burn-specific health scale that could be utilized to assess the clinical impact of a broad range of burn morbidities and to quantify the effect of multidisciplinary burn care (126). This approach recognized that burn survivors are known to have rather unique challenges that impact both psychosocial and physical adjustment (18, 126).
A comprehensive pool of items was included based first of all on three commonly used generic measures, the General Well-Being Schedule (53), the Sickness Impact Profile (71) and the Index of Activities of Daily Living (96). A total of 209 items were included from these measures. Secondly, a survey of burn center staff and burned patients generated additional items, resulting in a total of 369 items. In the tradition of scale development, a second panel of 35 professionals in the field of burn treatment and rehabilitation as well as former patients rated the relevance of each item regarding a burn survivor’s quality of life. The items that received the highest median scores from the panel were retained, and after minor revisions the Burn Specific Health Scale (BSHS) consisted of 114 items (17). The scale was further refined by Munster et al in 1987 (127) by eliminating duplications and inconsistencies, resulting in the 80-item abbreviated Burn Specific Health Scale (BSHS-A) with four main domains and seven subdomains: 1. Physical functioning with the subdomains of Mobility and Self-Care, Hand Function and Role Activities; 2. Mental functioning with the subdomains of Body Image and Affective; 3. Social functioning with the subdomain Family/Friends and Sexual Activity and 4. General functioning (Table 1).

Table 1. The two previously presented versions of the Burn Specific Health Scale (BSHS-A and BSHS-R), and the new version presented in this thesis (BSHS-B; see Results), together with their corresponding domains

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<th>BSHS-A</th>
<th>BSHS-R</th>
<th>BSHS-B</th>
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<tr>
<td>80 items</td>
<td>80 items</td>
<td>31 items</td>
<td>40 items</td>
</tr>
<tr>
<td>8 domains</td>
<td>8 domains</td>
<td>6 domains</td>
<td>9 domains</td>
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<tr>
<td>Mobility and Self-Care</td>
<td>Simple Functional Abilities</td>
<td>Simple Abilities</td>
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<tr>
<td>Family/Friends</td>
<td>Interpersonal Relationships</td>
<td>Interpersonal Relationships</td>
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<tr>
<td>Body Image</td>
<td>Body Image/Affect</td>
<td>Body Image</td>
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<tr>
<td>Affective</td>
<td>Affect</td>
<td>Affect</td>
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<tr>
<td>Hand Function</td>
<td>Hand Function</td>
<td>Hand Function</td>
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<td>Sexual Activity</td>
<td>Sexuality</td>
<td>Sexuality</td>
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<td>Role Activities</td>
<td>Heat Sensitivity</td>
<td>Heat Sensitivity</td>
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<td>General Functioning</td>
<td>Treatment Regimens</td>
<td>Treatment Regimens</td>
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<td></td>
<td>Work</td>
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The instrument was validated and related well to global ratings of post-burn adjustment. Internal consistency was high for physical health and mental health but lower for social functioning. Both intra and interrater reliabilities were acceptable.

The BSHS-A did not come into widespread clinical use, most likely because of its length. Items in this instrument were never factor analyzed, and a high correlation between subscales suggested a possible misclassification of items, resulting in a lack of discriminant validity among the subscales. A content validity study of the BSHS-A was later performed by Blalock et al in 1992 (20) in the form of interviews of 38 individuals previously hospitalized for burn injuries. It was found that even though important aspects of burn injury were well covered in the BSHS-A, important problems regarding work, skin sensitivity and treatment regimens were not covered adequately. Twenty-nine items were therefore added to the original instrument and a factor analytic approach was used to identify sets of items reflecting distinct dimensions of health status, thereby simultaneously reducing the number of items without sacrificing the instrument’s psychometric properties (19). The final revised version, the revised Burn Specific Health Scale (BSHS-R), consisted of a total of 31 items, of which 17 were from the original BSHS-A. Internal consistency was high, with Cronbach's $\alpha$ ranging from 0.82 to 0.94. The analysis supported the factorial validity of five domains: Simple Functional Abilities, Work, Interpersonal Relationships, Heat Sensitivity and Treatment Regimens, but could not discriminate between the domains Affect and Body Image (Table 1). For reasons that are unclear, the BSHS-A domains of Hand Function and Sexuality were not included in the final scale (19).

**Burns and premorbid psychopathology**

Pre-existing psychiatric disorders are common in the histories of burned patients (61, 140, 155), and they frequently appear to have contributed significantly to the etiology of the injury itself (133, 143). Incidence estimates of previous psychiatric illness have been difficult to obtain and reports vary widely between 23-75 % (140, 144, 155, 189). Frequently occurring premorbid conditions are problems related to substance abuse, organic brain dysfunction, depression and personality disorders (133, 140, 153). Up to ten percent of subjects have self-inflicted burns (189), and they often have complex premorbid psychopathology. Furthermore, burn patients with a history of any premorbid psychiatric disorder are more likely to have preventable injuries, require longer hospitalization and have problems with adjustment early in their recovery (140, 143, 189).
Personality and personality assessment

Measurement of different aspects of personality has become increasingly meaningful, since recent research has shown that personality traits might be important predictors of health and treatment outcome. According to WHO (199), personality is defined as “the ingrained patterns of thought, feeling, and behavior characterizing an individual’s unique lifestyle and mode of adaptation, and resulting from constitutional factors, development, and social experience”. The term personality trait was introduced by Allport (4), who proposed that a personality trait is “a generalized and focalized neuropsychic system (peculiar to the individual), with the capacity to render many stimuli functionally equivalent, and to initiate and guide consistent forms of adaptive and expressive behavior”.

An important assumption in personality research is that basic personality traits are stable over time in adulthood. Empirical evidence supports this assumption with findings of substantial rank-order stability and small changes in mean levels over time as evaluated by different personality inventories in diverse cohorts (42, 43, 73, 154, 173).

Biologically oriented personality theories tend to use a dimensional approach to classify and explain human behavior. A classical example is the three dimensional personality model by Eysenck, which includes the domains of Extraversion, Neuroticism and Psychoticism (58). Another approach to personality is the five-factor structure that arose from two different traditions, a lexical analysis of trait adjectives in natural languages and psychometric analyses of personality measures (94). The currently widespread version of the five-factor model, the NEO Personality Inventory Revised (41), includes the factors Neuroticism, Extraversion, Agreeableness, Conscientiousness and Openness. All versions of the five-factor model aim to be “all inclusive”, with descriptions of broad dimensions of personality.

Another way of conceptualizing personality was described by Sjöbring. He postulated three basic bipolar personality dimensions called Validity, Solidity, and Stability (170). An additional measure of intelligence called Capacity was also included in the model. The Karolinska Scales of Personality (KSP) is a personality instrument developed by Schalling and is based partly on the theories of Sjöbring as well as on other theories of biologically based dimensions of personality (161, 162). The primary aim was to develop an instrument that was suitable for studying vulnerability aspects of personality, and not to identify all personality dimensions. The main areas of research in which the KSP has been utilized have involved exploring associations between personality traits and biological markers, and defining personality predispositions to health and disease (60, 68, 75, 196). The KSP recently underwent further revision and development, thereby
reducing the number of items and improving psychometric properties. As the alterations were extensive, the new instrument was renamed the Swedish universities Scales of Personality (SSP) (74).

Personality traits have also been shown to be of significance in relation to burn trauma. Personality traits such as high neuroticism and high extraversion predispose to trauma exposure (26), and patients afflicted by burn injury exhibit such personality traits to a greater extent than a normative sample (62, 201). Furthermore, personality traits have been suggested to have an important impact on long-term adjustment (70). Thus, a high level of neuroticism and low level of extraversion were negatively related to successful coping and positively related to symptoms of PTSD after burn injury (62). It is consequently important to explore the concept of personality when evaluating factors contributing to perceived health status after burn injury.

Coping and coping strategies

Another important individual factor in the process of adaptation after stressful life events is the use of coping strategies (84). It has been suggested that stress or stressful life events may be of less importance to health status and well-being than how an individual appraises and copes with stress (3). 

Coping strategies refer to the specific efforts, both behavioral and cognitive, that people employ to master, tolerate, reduce, or minimize stressful events (105). In individuals with impairments, disabilities or handicaps, coping has also been defined as all those activities an individual uses to retain his or her psychological and physical integrity, whether the impairments or disabilities are reversible or not (106).

How people cope with problems can be influenced by many factors such as the type of problem faced (141), personality characteristics (101), and cultural preferences (110). No clear consensus exists as to which coping strategies are most effective for resolving problems, preventing future difficulties or relieving emotional distress (3). A coping strategy can simplistically be described as an attempt to either avoid or approach a problem or a stressor, and people tend to oscillate between the two after traumatic events. Common strategies to handle pain and general distress after burn injury are self-distraction (83), avoidance and wishful-thinking (151). Acceptance was found to be the only beneficial coping strategy related to adaptation three months after burn injury (186) but coping strategies used long-time after injury most likely differ from strategies used in the early stages.
Coping strategies can be measured by standardized instruments for self-evaluation, by interviews, or by experimental, observational techniques. A variety of coping measures exist, but two of the most widely used are versions of the Ways of Coping Questionnaire (WCQ) (3, 65, 66) and the COPE (37). These instruments have also been utilized to evaluate burn patients (104), but no coping scale has been tailored to specifically study coping strategies after severe burn injury. As items in generic scales are not formulated to suit the specific stressors of subjects exposed to burn injury, it is reasonable to suppose that generic scales may not have adequate sensitivity for specific burn related problems (177). Furthermore, high attrition rates represent a major problem in many studies of coping in burn patients, and it is possible that a burn related scale would increase compliance and motivation in subjects asked to participate.
Background

The Burn Unit at Uppsala University Hospital is one of two highly specialized National Burn Units. It serves mainly the northern part of Sweden with a population of approximately three million inhabitants. The concentration of severe burns from a geographically defined area in only one unit offers an opportunity to address important issues concerning health status and long-term outcome.

A driving force behind this thesis has been the intention to explore factors influencing final outcome beyond the more technical aspects of surgical reconstructions and physical exercises.

Over the years, both plastic surgeons and surgeons in general have often expressed their frustration to their colleagues regarding patients who were dissatisfied in spite of good or excellent outcomes based on objective investigations, and different aspects of this problem have been focused upon (147, 148). This indicates that traditional approaches to evaluating outcome after trauma or surgery based on supposedly objective findings are insufficient (79). The central issue of how life is perceived from the patient's point of view is missing in such an evaluation. In order to obtain meaningful information on these issues, there is a need for health status instruments that fulfill established criteria for reliability and validity.

In an analysis of data from previous investigations it was apparent that when assessed by a burn-specific instrument, most patients injured by burn do fairly well the first few years after injury (19, 20, 44, 100, 160). Furthermore, in an evaluation of sixty children afflicted with massive burns using the global health instrument SF-36, it was observed that most previous patients did well an average of 14 years after injury (168), although a small subgroup suffered severe physical disabilities. These data support the general clinical impression that life is dramatically changed for a small subgroup of individuals afflicted by burn injury. On the other hand, clinicians seeing burn patients are often struck by the fact that some individuals with severe objective handicaps manage their lives well, while others with only minor residual damage experience a dramatic impact on their life situation.

A reasonable assumption and putative explanation is that the behavioral repertoire prior to the onset of the disability, such as personality traits and
individual coping strategies, contribute to post-burn adjustment. This is analogous to previous studies on the role of these factors regarding the outcome of other somatic conditions (75, 175, 195, 196).
Aims of the study

The aims of the papers presented in this thesis were:

I  To use a factor analytic approach as a basis for possible further improvements in the two existing versions of the Burn Specific Health Scale

II  To report perceived health status a long time after burn injury in a consecutive group of former burn patients and to compare the three versions of the Burn Specific Health Scale.

III  To investigate how personality characteristics are related to perceived long-term consequences of a previous burn injury.

IV  To develop a burn-specific instrument measuring coping strategies.

V  To investigate whether burn localization and sociodemographic data are related to specific coping strategies and whether the use of specific coping strategies is related to perceived long-term physical or psychosocial outcome.
Patients and Methods

Study population and procedures

The in-hospital care of burn victims in Sweden, with a current population of 8.9 million, comprises 1500 admissions per year (1). Approximately 100-150 of these admissions are due to more severe burn injury. The Burn Unit at Uppsala University Hospital, one of two National Burn Units, is a referral center for patients from the northern and middle parts of Sweden with a total population of approximately three million. This thesis is based on a cohort of consecutive former patients treated at the Burn Unit from 1980 through 1995. The patient-series is described in Tables 2a and 2b. For detailed information the reader is referred to the individual papers (I – V).

Table 2a. Sociodemographic characteristics of the participants in papers I–V

<table>
<thead>
<tr>
<th>Paper</th>
<th>Total sample</th>
<th>N</th>
<th>Response rate (%)</th>
<th>M/F</th>
<th>Mean age at injury</th>
<th>Mean age at measurement of health status</th>
</tr>
</thead>
<tbody>
<tr>
<td>I, II</td>
<td>350</td>
<td>248</td>
<td>70.9</td>
<td>199/49</td>
<td>36.8 (16.1)</td>
<td>46.1 (15.6)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>range 1-78</td>
<td>range 18-79</td>
</tr>
<tr>
<td></td>
<td>III</td>
<td>227</td>
<td>166</td>
<td>73.1</td>
<td>38.3 (14.1)</td>
<td>47.6 (14.0)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>range 15-78</td>
<td>range 18-79</td>
</tr>
<tr>
<td></td>
<td>IV</td>
<td>227</td>
<td>162</td>
<td>71.4</td>
<td>38.4 (14.2)</td>
<td>47.7 (14.2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>range 15-78</td>
<td>range 18-79</td>
</tr>
<tr>
<td></td>
<td>V</td>
<td>227</td>
<td>161</td>
<td>70.9</td>
<td>38.4 (14.2)</td>
<td>47.7 (14.2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>range 15-78</td>
<td>range 18-79</td>
</tr>
</tbody>
</table>

Note: SDs are in parentheses. M/F = males/females
Table 2b. Burn-related characteristics of the participants in papers I-V

<table>
<thead>
<tr>
<th>Paper</th>
<th>N</th>
<th>Mean YPB at measurement of health status</th>
<th>TBSA burned</th>
<th>Full-thickness burn</th>
<th>LOS (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I, II</td>
<td>248</td>
<td>9.2 (4.7) range 1-18</td>
<td>23.1 (16.2) range 1-85</td>
<td>7.4 (9.3) range 0-72</td>
<td>30.8 (29.4) range 1-277</td>
</tr>
<tr>
<td>III</td>
<td>166</td>
<td>9.3 (4.7) range 1-18</td>
<td>24.6 (16.3) range 1-85</td>
<td>7.6 (9.7) range 0-72</td>
<td>30.2 (25.0) range 1-148</td>
</tr>
<tr>
<td>IV</td>
<td>162</td>
<td>9.3 (4.7) range 1-18</td>
<td>24.0 (16.0) range 1-85</td>
<td>7.2 (9.4) range 0-72</td>
<td>29.7 (25.0) range 1-148</td>
</tr>
<tr>
<td>V</td>
<td>161</td>
<td>9.2 (4.8) range 1-18</td>
<td>24.0 (16.0) range 1-85</td>
<td>7.2 (9.4) range 0-72</td>
<td>29.8 (25.0) range 1-148</td>
</tr>
</tbody>
</table>

Note: SDs are in parentheses. YPB = Years post-burn, TBSA=Total body surface area, LOS = Length of stay in the Burn Unit.

Patients and Methods in papers I and II

All records for patients treated at the Uppsala University Hospital Burn Unit from 1980 through 1995 were identified. Those fulfilling the following inclusion criteria were included in studies I and II:

- 18 years of age or older at the time of follow-up,
- TBSA burned of ≥ 10%, or
- length of stay (LOS) ≥ 7 days irrespective of TBSA burned.

After a decision not to include seven patients who were expected to be unable to answer the questions because of severe psychiatric disorders (psychosis or dementia), a total of 350 patients met the final criteria and were included in the study. Sixteen patients could not be located, and hence questionnaires with a total of 94 items from both the BSHS-A and BSHS-R (see Introduction) were sent to a total of 334 patients together with a letter describing the study and asking for their participation. A total of 248 of the 350 eligible subjects responded (Figure 1). There were no significant differences between participants and non-participants with respect to gender, age, TBSA burned, full-thickness burn, LOS or time after injury. Sixty-nine percent of the burn injuries were caused by flame or explosion, nine percent were scalds, twelve percent were electrical injuries, and the remaining ten percent were caused by other mechanisms.
Patients and Methods in papers III, IV and V

All patients with completed questionnaires from studies I and II who were aged 15 years or older at time of injury were included in studies III, IV and V. These studies were performed an average of 2.2 (SD=0.5) years after the first investigation. A total of 227 of the 248 patients were thus contacted by mail and asked to complete the personality instrument, the Swedish universities Scales of Personality (SSP) (presented below), and a questionnaire containing 35 coping-related items (also presented below). Of these, 166 responded to the SSP questionnaire and 162 to the coping questionnaire. One of the latter patients was later excluded due to missing items, which is why only 161 patients were included in paper V (Figure 2)

In paper IV, the number of eligible participants is mistakenly stated to be 223. This motivated a renewed thorough examination of all data, which
resulted in subsequent minor corrections. Some sociodemographic and burn-related figures are therefore not entirely correct, although the differences are small. The corrected figures are shown in Tables 2a and 2b. Demographic data and burn-related variables did not differ between men and women or between responders and non-responders. However, the non-responders reported significantly lower health status on three of the scales of the BSHS-B, Affect, Interpersonal Relationships and Sexuality (p<0.01).

Personality and coping instruments

The Swedish universities Scales of Personality

Personality traits (paper III) were assessed by means of the Swedish universities Scales of Personality (SSP) (74). The SSP consists of 91 items grouped in 13 different scales with seven items each (Table 3), with a four-point response format ranging from “does not apply at all” to “applies completely”. The SSP was originally standardized in a representative national sample and the level of internal consistency measured as Cronbach’s α ranged between 0.59 and 0.84. A factor analysis of a normative randomly drawn sample derived three factors called Neuroticism, Aggressiveness and Extraversion (74). The factor structure was recently replicated in a population-based study of women aged 40-74 (109). In a previous analysis of the presently investigated burn population the data were adjusted for age, and T-scores were calculated for each gender separately (201). This analysis confirmed the main structure of the three factors or main domains, but with a smaller Extraversion (Sensation Seeking) domain.

Development of a coping questionnaire

Development of the Coping with Burns Questionnaire (CBQ) was based on the theory of coping as a process (66, 67). Conceptualization of the questionnaire was based on the need for a short, burn-specific coping scale to be administered after discharge. The objective was to assess adaptation after trauma and focus on psychological factors. Items were derived from established coping scales such as the Revised Ways of Coping Checklist (65-67), later called the Ways of Coping Questionnaire (WCQ) (163), the COPE (37), and the Brief COPE (36), as well as from the burn care literature and interviews with burn victims and burn care health providers. The items were rated on a four-point response format ranging from “does not apply/not used” to “used a great deal”.

20
Table 3. Descriptions of the Swedish universities Scales of Personality

<table>
<thead>
<tr>
<th>SSP domain</th>
<th>SSP scale</th>
<th>Description of subjects with high scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neuroticism</td>
<td>Somatic Trait Anxiety</td>
<td>Autonomic disturbances, restless, tense</td>
</tr>
<tr>
<td></td>
<td>Psychic Trait Anxiety</td>
<td>Worrying, anticipating, lacking self-confidence</td>
</tr>
<tr>
<td></td>
<td>Stress Susceptibility</td>
<td>Easily fatigued, feeling uneasy when urged to speed up</td>
</tr>
<tr>
<td></td>
<td>Lack of Assertiveness</td>
<td>Lacks ability to speak up and to be self-assertive in social situations</td>
</tr>
<tr>
<td></td>
<td>Detachment</td>
<td>Avoids involvement with others, withdrawn, &quot;schizoid&quot;</td>
</tr>
<tr>
<td></td>
<td>Embitterment</td>
<td>Unsatisfied, blaming and envying others</td>
</tr>
<tr>
<td></td>
<td>Trait Irritability</td>
<td>Irritable, lacking patience</td>
</tr>
<tr>
<td></td>
<td>Mistrust</td>
<td>Suspicious, distrusting people's motives</td>
</tr>
<tr>
<td>Sensation</td>
<td>Impulsiveness</td>
<td>Acting on the spur of the moment, non-planning</td>
</tr>
<tr>
<td>Seeking</td>
<td>Adventure Seeking</td>
<td>Avoiding routine, need for change and action</td>
</tr>
<tr>
<td>Aggressiveness</td>
<td>Verbal Trait</td>
<td>Getting into arguments, berating people when annoyed</td>
</tr>
<tr>
<td></td>
<td>Aggression</td>
<td>Getting into fights, starts fights, hits back</td>
</tr>
<tr>
<td></td>
<td>Physical Trait</td>
<td>Socially conforming, friendly, helpful</td>
</tr>
</tbody>
</table>

1 calculation from (201).

Statistical methods

In general, Pearson correlation coefficients were calculated for associations between variables, and gender differences were evaluated by means of Student’s t-test. The $\chi^2$ test (for qualitative variables) and Student’s t test (for quantitative variables) were used to control for differences between participants and non-participants. Internal consistencies of subscales in the BSHS and the CBQ were measured by Cronbach’s $\alpha$. 
In papers I and IV, principal components factor analysis with orthogonal (Varimax) rotation was used to investigate the factor structure of items in the BSHS (paper I) and the CBQ (paper IV) by extracting factors with Eigenvalues greater than 1.0 in paper I and 1.2 in paper IV. Factor loadings > 0.40 were regarded as reasonably significant contributors to a factor (77).

In paper II, the responses to the BSHS items were grouped into the domains suggested by the original publications (19, 127). Scores for the different domains and for the entire instrument, “overall scores”, were given as a mean summated score for items in each domain. In one instance, in order to simplify comparisons with previous literature, scores were presented as the percentage of reduction from the maximum score for each domain and for the overall scale. A higher percentage of reduction indicates a greater impact on post-burn health status. Effects of dichotomized clinical and sociodemographic variables and gender on the BSHS-B scores were evaluated by multivariate analysis of variance (MANOVA), followed by the Bonferroni/Dunn post hoc test.

In papers III and V, a regression approach was used to study the relation between personality traits (paper III), coping strategies (paper V) and perceived health, as described by the different BSHS-B domains. As the mean scores for the BSHS-B domains had a very uneven distribution, with the highest value simultaneously being the mode, a variable transformation could not have created the normal distribution required for multiple regression. Therefore logistic regression was used according to the principles given by Hosmer & Lemeshow (86), after having grouped the BSHS-B domain scores into three discrete levels. Thus, the referent or baseline outcome was defined as the best 50 % of the observations, while “Insufficient outcome” was defined as the third quartile of the observations and “Bad outcome” as the fourth quartile of the observations. In four of the BSHS-B domains, Simple Abilities, Hand Function, Interpersonal Relationships and Sexuality, more than half of the patients had maximal ratings with respect to perceived health, so the best 75 % of the observations were classified as the baseline outcome, and the fourth quartile as “Bad outcome”.

Independent variables were selected in initial simple regressions. Only variables having a p-value < 0.25 (86) were included in subsequent backward stepwise regressions.

Ethics
The investigations were performed according to the Declaration of Helsinki and approved by the Uppsala University Ethics Committee.
Results

Development of a brief version of the Burn Specific Health Scale (BSHS-B) (Paper I)

Responses from the 248 previously injured individuals to the 94 items from BSHS-A and BSHS-R were subjected to factor analytic approaches. All psychosocial items loaded in one single factor except for a well-defined factor related to sexual activity. The physical and general health items were clearly separated in well-defined factors corresponding to the BSHS-R domains of Work, Treatment Regimens and Heat Sensitivity, but only the domain of Hand Function for the BSHS-A. A factorial structure of the BSHS-A domains of Mobility and Self-Care, Role Activities and General functioning could not be verified, and these domains were divided into completely new and different factors. In a subsequent analysis of all 31 items from the BSHS-R, the factorial structure of the findings of Blalock et al (19) were confirmed, with the exception of a larger Affect factor, and a clear separation between Affect and Body Image in the present study. The analysis defined seven clearly separated and eligible factors explaining 72 % of the total variance. Factorial validity was thus established for BSHS-R but not for BSHS-A.

Based on these two analyses, a content validity study by Blalock et al (20) and clinical reasoning, the seven items from the BSHS-A factors of Hand Function and Sexuality were added to the 31 items of BSHS-R. Only two items loaded on the Interpersonal Relationships factor, so two additional items from the Family/Friends domain of BSHS-A were included, resulting in a total of 40 items (Table 1).

A final factor analysis of these 40 items derived nine clearly defined and well separated factors explaining 72 % of the variance, with factor intercorrelations ranging between 0.11 and 0.56 and with internal consistency measured by Cronbach's α ranging between 0.75 and 0.93 (Table 4). The domains Hand Function and Sexuality were well defined without any double loadings, and Affect and Body Image were clearly separated as opposed to findings in earlier studies (19). The domains were labeled: Heat

Table 4. Factors in the BSHS-B in order of explanation of variance

<table>
<thead>
<tr>
<th>Factors in the BSHS-B</th>
<th>Number of</th>
<th>Variance (%)</th>
<th>Cronbach's α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heat Sensitivity</td>
<td>5</td>
<td>31</td>
<td>0.89</td>
</tr>
<tr>
<td>Affect</td>
<td>7</td>
<td>9</td>
<td>0.89</td>
</tr>
<tr>
<td>Hand Function</td>
<td>5</td>
<td>8</td>
<td>0.79</td>
</tr>
<tr>
<td>Treatment Regimens</td>
<td>5</td>
<td>5</td>
<td>0.90</td>
</tr>
<tr>
<td>Work</td>
<td>4</td>
<td>5</td>
<td>0.93</td>
</tr>
<tr>
<td>Sexuality</td>
<td>3</td>
<td>4</td>
<td>0.75</td>
</tr>
<tr>
<td>Interpersonal Relationships</td>
<td>4</td>
<td>4</td>
<td>0.82</td>
</tr>
<tr>
<td>Simple Abilities</td>
<td>3</td>
<td>3</td>
<td>0.81</td>
</tr>
<tr>
<td>Body Image</td>
<td>4</td>
<td>3</td>
<td>0.84</td>
</tr>
<tr>
<td>Total</td>
<td>40</td>
<td>72</td>
<td></td>
</tr>
</tbody>
</table>

The greatest negative impact on health and thereby the lowest mean domain scores were seen in the domains of Heat Sensitivity, Work and Body Image (Table 5). Simple Abilities and Hand Function had the highest domain scores. TBSA burned correlated negatively with Heat Sensitivity, Work and Treatment Regimens and higher age was related to better perceived health for Body Image but for worse perceived health status for Sexuality, Simple Abilities, Work and Hand Function. Furthermore, perceived health improved with time in all domains except for the domains of Sexuality, Interpersonal Relationships and Hand Function.

Health status in Swedish burn patients: Assessment utilising three variants of the Burn Specific Health Scale (Paper II)

All three versions of the BSHS gave similar results with respect to global outcome on a group level, and mean scores were similar (Table 6). In general, the response pattern indicated that most patients did very well with respect to most scales. This was seen in the form of a very asymmetric distribution with the maximal value simultaneously being the mode for all scales (Figure 3; not presented in the paper).
Table 5. BSHS-B domains according to mean domain score and with correlations to age, total body surface area burned (TBSA burned) and time after injury

<table>
<thead>
<tr>
<th>Domain</th>
<th>M (SD)</th>
<th>Age</th>
<th>TBSA burned</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heat Sensitivity</td>
<td>2.65 (1.03)</td>
<td>-0.23 ***</td>
<td>0.20 **</td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td>3.02 (1.29)</td>
<td>-0.13 *</td>
<td>-0.27 ***</td>
<td>0.22 ***</td>
</tr>
<tr>
<td>Body Image</td>
<td>3.05 (1.00)</td>
<td>0.21 ***</td>
<td></td>
<td>0.14 *</td>
</tr>
<tr>
<td>Affect</td>
<td>3.36 (0.77)</td>
<td></td>
<td></td>
<td>0.17 **</td>
</tr>
<tr>
<td>Sexuality</td>
<td>3.53 (0.77)</td>
<td>-0.29 ***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment Regimens</td>
<td>3.60 (0.77)</td>
<td>-0.22 ***</td>
<td>0.20 **</td>
<td></td>
</tr>
<tr>
<td>Interpersonal</td>
<td>3.67 (0.68)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationships</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hand Function</td>
<td>3.77 (0.52)</td>
<td>-0.16 *</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Simple Abilities</td>
<td>3.81 (0.52)</td>
<td>-0.31 ***</td>
<td>0.23 ***</td>
<td></td>
</tr>
</tbody>
</table>

Note: * p<0.05, ** p<0.01, *** p<0.001; M = mean of domain score; SD = standard deviation in parentheses.

Table 6. Mean scores, standard deviations and Cronbach's α values for the three versions of BSHS

<table>
<thead>
<tr>
<th></th>
<th>BSHS-A</th>
<th>BSHS-R</th>
<th>BSHS-B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean scores (SD)</td>
<td>3.44 (0.56)</td>
<td>3.27 (0.65)</td>
<td>3.36 (0.57)</td>
</tr>
<tr>
<td>Range of Cronbach's α</td>
<td>0.75-0.96</td>
<td>0.75-0.93</td>
<td>0.75-0.93</td>
</tr>
</tbody>
</table>
Figure 3. Distribution of scale score means for the BSHS-B domains and for the total BSHS-B score in the 248 previous patients. The latter is given as percent alteration from the maximal value. Numbers of patients are presented on the ordinate.
The scores for all instruments were highly correlated, least between BSHS-A and BSHS-R ($r = 0.81$) and strongest between BSHS-R and BSHS-B ($r = 0.98$). Internal reliabilities measured by Cronbach's $\alpha$ were high for all three instruments (Table 6).

Most domains of the original 80-item BSHS-A were well captured by corresponding domains in the 40-item BSHS-B, and in most respects also in the 31-item BSHS-R.

Among the psychosocial domains, Body Image and Affective in the BSHS-A were well retained in the BSHS-B ($r=0.87$ and 0.92, respectively) regardless of a considerable shortening of the scales, for Affect from 23 items to seven items, and for Body Image from seven items to four items. Intercorrelations between these two domains were lower for BSHS-B ($r=0.57$) than for BSHS-A ($r=0.71$), explaining why factor analysis could only separate Affect and Body Image in the BSHS-B version. Family/Friends in BSHS-A correlated with Affect and Interpersonal Relationships in BSHS-B and in BSHS-R. Sexuality in BSHS-A and BSHS-B was only weakly correlated to other domains and was therefore not covered by BSHS-R.

In the physical domains, Mobility and Self Care in BSHS-A correlated well with Simple Functional Abilities in BSHS-R and Simple Abilities in BSHS-B ($r=0.86$ and 0.87 respectively), but Hand Function measured by BSHS-A and BSHS-B was only moderately correlated to Simple Functional Abilities. Treatment Regimens and Heat Sensitivity were not well captured by BSHS-A.

General Functioning in BSHS-A had a modest correlation to several domains in the other two instruments, but was most strongly correlated to Affect in BSHS-B and Affect/Body Image in BSHS-R. Heat Sensitivity and Treatment Regimens in BSHS-R and BSHS-B were correlated only weakly to domains in BSHS-A. Role Activities in BSHS-A was actually best correlated to Work in the two other instruments.

Perceived outcome varied considerably between domains in all three instruments. The best perceived health status was observed for the domains Hand Function and Mobility and Self-Care in BSHS-A, in the domain Simple Functional Abilities in BSHS-R, and in the domains Simple Abilities and Hand Function in BSHS-B. The worst perceived health status was seen for Role Activities in BSHS-A, and Heat Sensitivity and Work in both BSHS-R and BSHS-B.

Several sociodemographic variables were related to outcome. In a post hoc analysis, those who were working exhibited significantly better values in all BSHS-B domains. Those living with a partner exhibited significantly better values for Affect, Interpersonal Relationships, Sexuality, Hand Function, Treatment Regimens and in the overall score. Subjects having
their own residence exhibited significantly better Affect and Interpersonal Relationships. Men rated themselves better in three psychosocial domains (Affect, Sexuality, Body Image), two physical domains (Treatment Regimens, Simple Abilities) and in the overall score. Having a job, being male, living with a partner and having one’s own place of residence were thus related to better perceived outcome.

Burn severity measured as depth of injury was related to self-reported health status. The presence of a full thickness burn, and particularly a full thickness burn of more than ten percent of the body surface area, was related to a worse perceived overall outcome. A post hoc analysis exhibited significantly lower values for six of nine domains, namely Affect, Body Image, Work, Simple Abilities, Treatment Regimens and Heat Sensitivity as well as the overall score.

Personality characteristics and perceived health problems after burn injury (Paper III)

In the first step, relationships between perceived health status (measured by BSHS-B) and the three main domains of personality (measured by SSP) were examined.

Simple regressions with either of two levels of outcome (Insufficient or Bad) were performed, and the SSP-domain of Neuroticism was significantly related to Bad outcome in all BSHS-B domains, and to Insufficient outcome in one BSHS-B domain (Affect). The main domain of Aggressiveness was significantly related to Bad outcome in only two BSHS-B domains (Affect, Interpersonal Relationships), and the third main domain of Sensation Seeking was not significantly related to outcome in any BSHS-B domain.

Stepwise logistic regressions were then performed including relevant covariates (see Statistical methods). Of the three SSP-domains, only Neuroticism exhibited a significant relationship to outcome. Neuroticism was related to all nine BSHS-B domains (explained variance 10-34 %), although the association was strongest in Bad outcome for the psychosocial domain of Affect. Neuroticism was also significantly related to Insufficient outcome in the physical BSHS-B domain Work, in Affect and in the total BSHS-B score, but the explained variance was small (6-8 %).

In the next step the eight different subscales of the Neuroticism domain were analyzed in simple regressions versus the nine BSHS-B domains. Most Neuroticism related scales were significantly related to Bad outcome in all BSHS-B domains. They were also related to Insufficient outcome in three BSHS-B domains (Affect, Work and Treatment Regimens) as well as to the total BSHS-B score.
All relevant covariates were included in a last backward stepwise regression analysis. One or more of the SSP-scales from the Neuroticism domain were associated with Bad outcome in all BSHS-B domains, and with Insufficient outcome in the physical domain Work, the psychosocial domains Affect and Body Image, and with the total BSHS-B score. Two of the subscales of Neuroticism, namely Somatic Trait Anxiety and Stress Susceptibility together with covariates explained as much as 34 % of Bad outcome for the BSHS-B total score. The subscales of Embitterment and Stress Susceptibility explained as much as 33 % of Bad outcome with respect to Affect, and at the other extreme Somatic Trait Anxiety explained ten percent of Bad outcome with respect to Hand Function.

The personality scales in general explained much less of Insufficient than of Bad outcome.

Development of the coping with burns questionnaire
(Paper IV)

A total of 35 items related to important aspects of coping were identified based on previous research and expert evaluations (see Patients and Methods). A principal components factor analysis was performed to find a possible interpretable structure among these items for comparison with previous knowledge of coping strategies and theories. The analysis revealed six well separated and intelligible factors explaining 54 % of the total variance with no secondary loadings above 0.40. Two items with low factor loadings were omitted, and the final 33-item version was called the Coping with Burns Questionnaire, CBQ. The content of each factor was interpreted and labeled Revaluation/adjustment, Avoidance, Emotional Support, Optimism/problem solving, Self-control and Instrumental action (Table 7). Primary intercorrelations were low to moderate (0.02 to -0.51), intercorrelations between scales ranged between 0.04-0.54 and internal consistency expressed by Cronbach's $\alpha$ was acceptable with a range between 0.56 and 0.83 (Table 8).

Revaluation/adjustment explained most of the variance (21.6 %) and the factor consisted of strategies related to cognitive processing with a tendency to redefine life and adjust to the injury and to experiences of meaning. Avoidance explained 13.7 % of the variance and included items describing strategies of avoiding other persons as well as activities that were previously of interest. Strategies also included in this factor were tendencies to daydream, engage in wishful thinking and use alcohol, drugs and tobacco to handle problems. Emotional support had the lowest level of internal
Table 7. Content of the Coping with Burns Questionnaire (CBQ) and abbreviations for the factors

<table>
<thead>
<tr>
<th>CBQ factors</th>
<th>Content of factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Revaluation/adjustment</td>
<td>RA Statements about adjusting to the accident and changing lifestyle in order to feel better, trying not to think about difficulties</td>
</tr>
<tr>
<td>Avoidance</td>
<td>AV Cognitive and behavioral efforts to divert attention away from difficulties or reminders of the accident by daydreaming, wishful thinking, use of substances and avoidance of other people and activities</td>
</tr>
<tr>
<td>Emotional support</td>
<td>ES Seeking of social contact and support of the emotional kind</td>
</tr>
<tr>
<td>Optimism/problem solving</td>
<td>OP Strategies such as expending efforts to make things work, using cognitive strategies in solving problems, noticing positive things and having a positive outlook on the future</td>
</tr>
<tr>
<td>Self-control</td>
<td>SC Restrained expression of feelings</td>
</tr>
<tr>
<td>Instrumental action</td>
<td>IA Seek practical help or advice and use instrumental ways of problem solving</td>
</tr>
</tbody>
</table>

Table 8. Mean domain scores, percentage of variance and Cronbach's α values for the CBQ

<table>
<thead>
<tr>
<th>CBQ factors</th>
<th>Items</th>
<th>Mean (SD)</th>
<th>% of variance</th>
<th>Cronbach's α</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Revaluation/adjustment</td>
<td>8</td>
<td>2.36 (0.68)</td>
<td>21.6</td>
<td>0.83</td>
</tr>
<tr>
<td>2. Avoidance</td>
<td>7</td>
<td>2.04 (0.67)</td>
<td>13.7</td>
<td>0.78</td>
</tr>
<tr>
<td>3. Emotional support</td>
<td>3</td>
<td>2.48 (0.71)</td>
<td>5.9</td>
<td>0.56</td>
</tr>
<tr>
<td>4. Optimism/problem solving</td>
<td>8</td>
<td>2.85 (0.64)</td>
<td>4.9</td>
<td>0.82</td>
</tr>
<tr>
<td>5. Self-control</td>
<td>3</td>
<td>2.21 (0.78)</td>
<td>4.0</td>
<td>0.60</td>
</tr>
<tr>
<td>6. Instrumental action</td>
<td>4</td>
<td>1.69 (0.65)</td>
<td>3.5</td>
<td>0.67</td>
</tr>
</tbody>
</table>
consistency (the only factor under 0.60), explaining 5.9 % of the variance. The content of this strategy was to seek social contact and comfort and to talk to others about problems. Optimism/problem solving (4.9 % of variance) consisted of confrontative and problem solving strategies with characteristics such as concentrating on positive aspects, trying to change a difficult situation or make things work. Self-control (4.0 % of variance) expressed a tendency of restrained expressions of feelings, and Instrumental action (3.5 % of variance) included strategies of engaging in practical work related to the problems and seeking practical help and advice.

There was no relationship between these six distinct coping scales and age at time of injury, gender, number of years since injury or severity of burn as determined by the TBSA burned, except for a association of age with Emotional support, with younger individuals using more of this strategy. Several strategies correlated to better health status in one or more BSHS-B domains (Emotional support, Optimism/problem solving), whereas others correlated to worse perceived health status (Avoidance, Revaluation/adjustment, Self-control, Instrumental action).

Coping strategies, injury characteristics and long-term outcome after burn injury (Paper V)

A regression model was used to identify coping scales with a unique contribution to long-term outcome after burn injury.

An initial assessment of coping related to sociodemographic data revealed that subjects who were employed and those with their own place of residence used less Avoidant coping. Those living with a partner used less Avoidance but also less Revaluation/adjustment, Self-control and Instrumental action compared to those who lived alone. Specific coping strategies had no relationship to variables describing severity of injury such as depth and specific location, with one exception: Subjects with a full thickness injury of more than ten percent used more Revaluation/adjustment strategies in coping with their injury.

In simple regressions all six coping strategies in the CBQ were related to perceived health in one or more of the nine BSHS-B domains in one or both outcome groups (Insufficient outcome or Bad outcome). Most pronounced was that Avoidance was related to all domains in Bad outcome.

All relevant variables (see Statistical methods) were finally included in a stepwise logistic regression. In this analysis Bad outcome was related to one or more coping strategies in all nine BSHS-B domains, whereas Insufficient outcome was only related to one single domain (Affect). Avoidance was again clearly the most prominent coping strategy used by subjects with Bad
outcome, and it was related to a worse perceived health status in all BSHS-B domains. Emotional support, on the other hand, was the dominating strategy related to better perceived health status, but this strategy was related to mainly psychosocial domains of BSHS-B. As much as 40% of the variance of the total BSHS-B score was explained by these two coping strategies together with the covariates Time since burn injury and Burn area.

BSHS-B scales with specific physical content were overall less well explained than scales with psychological content. This can be exemplified by the Affect scale in BSHS-B where 46% of the variance of Bad outcome was explained by three CBQ scales (Avoidance, Emotional support and Self-control). On the other hand, Avoidance was the only coping strategy related to Bad outcome in three of the physical BSHS-B scales, explaining together with the covariates only between 16-26% of the variance. The importance of the coping strategies of Instrumental action, Optimism/problem solving and Revaluation/adjustment in the single regression analysis diminished considerably in the stepwise regressions, clarifying the importance of two coping strategies, Avoidance and Emotional support, in perceived outcome.
Discussion

The principal aim of the present thesis was to acquire more knowledge concerning long-term health status and possible influencing factors, such as personality traits and coping strategies of former patients afflicted with severe burn injury. This necessitated an evaluation of the clinical utility and psychometric properties of a burn-specific health status questionnaire and development of a burn-specific coping instrument.

Methodological considerations

Sample
A critical question in all studies involves sample representativity. Most international studies of health status after burn injury are based on samples of patients from local burn units. Response rates rarely exceed 30-40 % and catchment areas are often not well defined (10, 19, 44, 100, 160), suggesting that there may be a considerable selection bias in these studies. The samples obtained in the present study have some advantages compared to those that have been reported previously.

Firstly, the sample can be considered to be population-based. The Uppsala Burn Unit is one of two national burn units covering the northern part of Sweden, with a catchment area of approximately three million inhabitants, and almost all patients with severe burn injuries within this catchment area are transferred to the unit. A possible lack of representativity is based on differences in expertise among different hospitals in handling moderate burns, thus resulting in "different thresholds" for deciding when or if patients should be transferred. Such differences are therefore related to individual doctors rather than to sociodemographic characteristics of the individual patients.

Secondly, all eligible patients treated in the Burn Unit between 1980 and 1995 were included on a consecutive basis and, thirdly, the response rates in the present studies were considerably higher compared to other studies reporting outcome after burn injury.
Self-report questionnaires

Certain limitations apply to studies where assessments are based on self-report questionnaires. Biases such as the tendency to avoid extreme values (end aversion), ticking responses one under the other (straight lining), and the tendency to agree with statements (acquiescent response) have been reported as having the potential to influence measurements (51). Results can also be influenced by motivational and recall biases.

Motivational bias refers to the tendency to overestimate improvements after major therapeutic efforts (9). The tendency to overestimate self-reported physical disability has been reported regarding certain chronic diseases such as fibromyalgia and rheumatoid arthritis (82). Others have, however, found a high level of agreement between self-reports and observed performance (89). For burn patients it has been found that clinical observers invariably rate patients physical functioning somewhat lower than the patients rate themselves (127). In two studies of the external criterion validity (self-reports compared to expert clinical examinations) of the BSHS-A acceptable correlations were found both for the psychosocial (127) and for the physical parts of the instrument (127, 159).

An alternative to self-report questionnaires would be structured interviews, but the advantage of the former is that they are free from systematic biases found in structured interviews (206) and that only small differences in reliability and validity have been found when comparing the two (24).

Another important issue is the possibility that memory processes will have an effect on the reported results, so-called recall bias. This is particularly relevant when a long period of time has elapsed since the actual event. In the present thesis this is especially applicable to the retrospective assessment of coping strategies in papers IV and V. Problems remembering specific coping behaviors a long time after injury have been reported with a tendency to over report the extent to which coping strategies were used (171). With time, reported coping strategies are probably more likely to represent dispositional rather than situational aspects of coping and therefore tend to describe how people cope in general.

Study design

There are always limitations in studies of cross-sectional design and studies where data has been collected retrospectively. Prospective studies should therefore be the “golden standard” in hypothesis testing. Consequently, measures of personality prior to the burn injury and assessments of coping near the time of injury, and then at multiple measurement points, in a longitudinal fashion, would have been ideal. This would have limited both
causal ambiguities and possible biases due to errors of memory. The scope of such an undertaking would be far-reaching due to the low incidence of burn injuries. On the other hand, several reports have shown good agreement between retrospective recordings and earlier measures of factual issues, especially when studying important life events (27, 80). However, results from retrospective studies must be considered with care, and correlation should not be regarded to be causation. A truly prospective study of causation that measures predictive variables prior to burn injury is cost-prohibitive (104) and to date has therefore never been performed. A specific limitation in the present study is that perceived health status was assessed an average of two years prior to assessment of personality and coping. This problem is related more to possible instability in the measure of coping and less to personality measurements, as personality is considered quite stable over time as mentioned earlier.

Health status measurements in burn care

A major challenge for researchers measuring health status is to choose an optimal instrument for their specific objective from among a vast number of scales. The use of some global instruments such as the Nottingham Health Profile (87) and the Medical Outcomes Study Instrument, has become widespread. The latter is available in several short forms of which the SF-36 is one of the most commonly used versions (115, 116, 194). These scales are based on summary scores and/or individual health profiles, as opposed to utility measures such as the EuroQol (29) where several dimensions of health are weighed and presented as a total score. An advantage of global scales is the possibility to compare results between studies of completely different diseases, since formulation of items is general rather than specific. It is also possible to compare general and specific populations (193).

However, the problem with general health scales when they are used in patients with specific diseases is that unique characteristics of the illness can be neglected, since global measures tend to be less responsive to small, specific and individual changes in health status (25, 78, 98, 168). This is deemed applicable to problems observed in individuals previously damaged by burns, where the need for burn-specific health measurements is based on clinical experience indicating that burn patients experience extreme and unique stress at the time of injury as well as during in-hospital care (20, 126). This stress ranges from physical and psychological effects related to the trauma itself, to frequent surgical interventions, painful mobilizations, and skin related problems a long time after injury. Many of these clinical experiences have also been identified in validation studies in different burn
populations (17, 20), and by including these more specific items of interest, the overall responsiveness of the instrument will increase (184).

A burn-specific health scale should be a psychometrically sound and clinically useful instrument that measures the impact on a broad range of burn morbidity (150). The instrument must be responsive to burn-specific problem areas, be able to follow possible improvements and/or deteriorations over time and be applicable in clinical work. The early achievement of Blades et al and Munster et al (17, 18, 127) in developing the BSHS was based on modern principles of test development. The clinical use of the final version was hampered by its length, the lack of discriminant validity between scales, and the lack of content validity regarding important aspects of burn morbidity (19, 20). Blalock and colleagues improved the content validity and psychometric properties of the scale and shortened it to less than half the original items, but at the same time some important properties of burn morbidity, such as hand function and sexuality, were lost in the process (19). The current instrument, BSHS-B, has the advantage of incorporating a broader diversity of health related aspects of burn injury with a reasonable number of items for practical use in clinical settings. This was accomplished with a preservation of psychometric properties as compared to previous versions.

Interestingly, in the present studies burn victims reported most problems on a group level in the domains of Heat Sensitivity, Work and Body Image, giving support to the content validity study of Blalock et al (20) where problems related to skin sensitivity and appearance dominated life after burn injury. This is an example of disease specific findings that are difficult to detect with general health measures.

One of the most obvious findings in the present study is that a considerable fraction of patients previously afflicted by severe burn injury rate themselves as being with little restriction with respect to perceived health. For some areas such as Simple Abilities and Hand Function, most patients reported no restriction, and the correlation with global outcome was lower than for other domains. Similar findings have also been reported previously in different burn populations (100, 160).

Inclusion of the domains Hand Function and Sexuality in the final scale was based on clinical reasoning, content validity studies (17, 20), and for the Sexuality domain also the common tendency to under-report problems related to sexual activity depending on how or if these problems are discussed (22, 52, 190). Items regarding sexual functioning have also been suggested to be important candidates for inclusion in specific health scales as this aspect has been omitted in several commonly used generic instruments (193).
In spite of these quite encouraging results for most subjects, a subgroup of individuals report serious problems in one or more areas of health status years after burn injury. Early identification of specific risk factors and predictors of outcome for this smaller group of patients with severe problems is of utmost clinical importance.

The traditional description of the severity of a burn injury has been the TBSA burned (146), although the size of the burn does not by itself determine the level of adaptation (21, 126). In the present study the TBSA burned was only related to problems of Heat Sensitivity, Work and Treatment Regimens. The area of deep, full thickness burn was, however, clearly related to worse outcome in six of the nine domains and also to the overall score for the BSHS-B, which emphasizes the importance of incorporating more detailed descriptions of burn depth as one important outcome variable.

Living with a partner, having a job, having one’s own residence and being male were all related to better outcome. This is analogous to previous studies indicating that lack of social support is a predictor of problems of adaptation (47). The tendency for men to report better perceived health status as compared to women has been a finding in several studies (30, 160). Women and girls have been shown to have more psychosocial problems in adjusting to burns (6), with reports of lower self esteem when visibly disfigured (23) and with problems in adjusting to body image and sexual functioning (140, 190). This is corroborated in the present study where women reported worse outcome with respect to the psychosocial domains of Affect, Sexuality and Body Image and the physical domains of Treatment Regimens and Simple Abilities. Women in the age group of 30-59 years have also been reported to have more than a two-fold higher mortality rate compared to men (114, 135). These findings were independent of severity of injury and specific complications, suggesting that for some reason women seem to be more vulnerable to burn trauma.

Reported health status in different burn populations

Publications based on the earlier versions of the BSHS are few, and the only comparable material is the investigations of Blalock et al (19), Salvador-Sanz et al (160) and Cromes et al (44). A Finnish material presented by Kimmo et al (100) and a Dutch study by Van Loey et al (192) were both based on more arbitrarily truncated versions of the BSHS-A and therefore do not lend themselves to comparisons.

The mean scores for most domains in the present studies were higher compared to earlier reports indicating better reported health status, and
considerably higher scores were found for certain domains. This could theoretically be associated with a sample bias because of less severe injuries, although the only available comparable measure of injury severity in all studies, the TBSA burned, was similar or higher in the present studies. Possible cultural effects on the response pattern could at least partly explain some of the differences. Another more likely explanation could be the longer time from injury to enquiry in the present study (mean of nine years) compared to the studies of Blalock et al (19) and Cromes et al (44), who reported a mean follow-up time of one year or less, and Salvador-Sanz et al (160), who reported a mean of approximately two years.

The first year after burn injury has been described as a year of mourning both physically and psychologically (176), and health status has been reported to be complex and dynamic during this period (18, 140). It is possible that measurements of health status at an early stage will not describe long-term outcome, and that further improvements over time are to be expected. In a prospective study by Cromes et al of 69 patients at two, six and twelve months after injury, BSHS-A global scores were unchanged across measurement periods (44). In that study the psychological domain scores were unchanged, although physical scores improved over time the first six months, with small improvements the next six months. In the present study, better health status was clearly related to time since injury in both physical and psychosocial domains. This suggests that results obtained from assessments early after injury must be extrapolated to other time frames with caution.

Health status, personality traits and coping strategies

Adaptation after burn injury is a complex process, and correlations with severity of injury and specific sociodemographic characteristics reflect only some aspects of this process (185). The term “small burn-big problem” illustrates that some subjects have adjustment problems after a rather small burn injury (21) and basic personality traits and coping strategies rather than physical features of the injury, have been suggested as possible long-term determinants for psychosocial adjustment (70).

Personality traits

In the present study Neuroticism was the only personality domain related to psychosocial and physical outcome after severe burn injury and the higher the scores were the worse perceived health status was reported. A person scoring high on neuroticism has a general tendency to experience negative
effects such as fear and sadness as well as restlessness, uneasiness, worry and a lack of self-confidence. Subjects without neuroticism related personality traits would be more relaxed, self-confident and energetic. Individuals with high scores on neuroticism have repeatedly been found to have increased vulnerability to depression, anxiety disorders and PTSD (62, 99, 111, 136). Furthermore, outcome after different surgical procedures such as pelvic pouch surgery and gastric surgery has been correlated to personality traits, particularly neuroticism (112, 196). Neuroticism has been related to poor outcome regarding pain from bile stones (181) and response to treatment for functional gastrointestinal disorders (182). Neuroticism has also been related to neck and shoulder pain (32) and to persisting pain after laparoscopic cholecystectomy (93). Finally, poor outcomes in chronic conditions such as diabetes mellitus (28), rheumatoid arthritis (57) and low back pain (75) have been related to neuroticism.

Specific personality traits have also been related to psychosocial adaptation in very early stages of burn injury (61, 70, 121). Furthermore, higher scores on neuroticism and extraversion compared to a normative sample were found in burn patients at discharge (62) but high scores on extraversion was found to be protective against PTSD symptomatology as opposed to high scores on neuroticism. A truly prospective study of personality in subjects having their first depression did not show any significant change in pre- or post-morbid personality traits compared to subjects remaining well, suggesting stability of personality traits and that specific traits are a vulnerability factor for developing depression (166). In one of the few longitudinal studies of associations between pre-injury psychopathology and outcome after burn injury measured by BSHS, it was found that neuroticism was negatively correlated to outcome in psychosocial but not in physical domains (61).

In the present study neuroticism-related personality traits were associated with both psychosocial and physical outcome a long time after injury. A possible explanation for the discrepancy with respect to the physical domain is that physical aspects of life have a different meaning in early and in late phases of injury. The implications of these findings are naturally of interest when evaluating the importance of early identification of individuals scoring high in neuroticism after burn injury.

Another interesting area of current research is the finding that different personality traits as measured by personality inventories are related to distinct neurobiological characteristics. Twin studies of personality traits have also shown a considerable genetic contribution of between 40-60 % (58, 90, 207) and associations between neuroticism and risk of depression has been reported to be partly due to shared genetic determinants (99). Depression and PTSD has been related to altered regulation of
The hypothalamic-pituitary-adrenal axis (HPA) (204) and a high score on neuroticism has recently been associated with a down regulated HPA-axis (111). These studies connecting results from inventories of basic personality traits to specific neurobiological mechanisms give an interesting dimension to future research and to possible clinical implications such as identifying vulnerable individuals at high risk of developing depression or PTSD.

Thus, personality traits seem to play an important role in processes influenced by both affectivity and cognition, and it is thereby likely that they have a strong impact on perceived health status.

Coping strategies

Arguments for developing a burn-specific coping measure are similar to those motivating a burn-specific health scale. Several global coping measures exist, ranging from instruments assessing a large number of coping strategies reflecting between eight to fifteen categories (37, 105, 163) to scales with fewer and broader dimensions of coping (5, 55), but none of these is tailored to any of the special stressors of burn injury. Authors of generic coping measures have also encouraged researchers to adjust items to the specific study context of interest to achieve a close match between stressors and coping statements (163). Furthermore, it was thought that a more specific scale would increase patient compliance and motivation when used in clinical settings.

In the present study, Avoidant coping was the only strategy related to perceived Bad outcome in all physical and psychosocial domains of the BSHS-B. Interestingly, Avoidant coping was not related to injury characteristics with the exception of full thickness burns of more than ten percent.

An avoidant coper can be described as a person who uses strategies of avoiding people and situations, daydreaming and wishful thinking, and of using different substances such as alcohol, tobacco and drugs to handle specific problems. Avoidant coping seems to be a common strategy in both early and late phases of exposure to stressors (63, 186) and has been related to poor psychological outcome and more symptoms of PTSD in burn patients (31, 33, 104). On the other hand, avoidance has been reported as a possible strategy for handling pain and general distress in burn patients (139).

These seemingly contradictory reports can be understood if a coping strategy is regarded as an attempt to either avoid or approach a problem, and it is recognized that individuals tend to oscillate between these two when exposed to specific stressors. Avoidance can then be seen as a protection against emotions that are too strong during the chaotic early phase of a burn...
injury, whereas strategies of a more approaching nature are associated with working through problems, which has been found to be beneficial later in the process (156). In a meta-analysis by Suls and Fletcher, similar findings were reported (180). At an early stage Avoidance was suggested to have more positive effects than strategies of a more approaching nature because an individual’s resources are not sufficient to actively cope with the stressful circumstances at this stage. It was also suggested that if the stressful life experience was brief and without serious consequences, avoidance could be a very useful means of coping, whereas avoidance could discourage action and do little to change circumstances in long-term serious events requiring major readjustments.

Emotional support was the main beneficial or adaptive strategy associated mainly with the psychosocial scales of BSHS-B. A strategy of Emotional support is characterized by seeking social support from other people and talking to other people about the problems one faces, and can thus be regarded as an example of an approaching coping strategy. Subjects using this strategy reported lower levels of symptoms at follow-up. Similar results have been reported in patients with breast cancer (175) and in the early phases after burn injury (23, 104, 140). Other studies have, though, not found a clear relationship between social support and outcome when stressors were health-related (142).

Health status, personality and coping strategies - how do they interact?

The theoretical basis of relationships between personality, coping and health status has changed over time, exemplifying the complexity of initially defining these entities. At an early stage psychoanalysts tended to equate personality and coping strategies (179). Later, these individual differences were downplayed and situational conditions affecting the coping process were emphasized, and personality traits were considered to have little predictive value in coping behavior (179). However, recent studies have suggested that both situations and personality explain significant amounts of variation in the use of coping strategies (137, 187) and that relations between coping and psychological symptoms are bidirectional (3). It is therefore reasonable to suppose that the predictive value of different coping strategies vary due to their respective stabilities (67, 179). Which strategies are stable and which are not remains to be elucidated.

In a previous cluster analysis of coping patterns, health status and personality traits in adults with burn injury, coping strategies were not related to severity of injury but rather to personality characteristics (200). Of the three identified patterns of coping, subjects with avoidant coping styles
had the lowest health status ratings and the highest ratings on neuroticism and aggressiveness. A recent path analysis of interference between personality, coping, chronic stress, social support and PTSD in burn patients exemplifies the complex nature of interacting variables (104). Neuroticism was identified in that study as being the most important dimension in predicting PTSD, but a high percentage of this relationship was mediated by both avoidant coping and social support. In another study of community-dwelling adults, the use of more effective ways of coping was related to determinants of well-being, but these associations were reduced when personality measures were excluded (113). Perceived outcome after burn injury therefore clearly constitutes an interplay between problems related to the physical sequelae themselves and different individual characteristics (38, 69, 186).

The evaluation of patients with severe burns should therefore ideally include a generic and a disease specific instrument measuring health status (78) and more comprehensive tests of mental status as complements to the clinical examination (192, 193). The measurements should be psychometrically sound, relatively brief and non-intrusive. The development and improvement of the Burn Specific Health Scale-Brief, the Coping with Burns Questionnaire, and the use of the Swedish universities Scales of Personality is one step towards the goal of a more comprehensive evaluation of health status and long-term outcome in victims of burn injury. The finding of important relationships between neuroticism, specific coping strategies and long-term outcome points to their possible use as predictors of perceived outcome in general, as well as predictors of more specific diseases such as depression, PTSD and substance abuse or problems related to disfigurement where early treatment can be of help (88, 102, 145, 149, 188).

Future aspects

This thesis has highlighted certain possible predictors of good or poor outcome such as burn severity, sociodemographic characteristics, personality traits and specific coping strategies. Future studies should concentrate on establishing causal relationships regarding these and other possible predictors by means of longitudinal, multicenter trials. This work will be time consuming and costly but of great importance due to the striking lack of knowledge in this area on which to base efficient rehabilitation routines.

The studies in this thesis have been limited to adults with severe burn injury, thus excluding one of the larger groups of afflicted individuals, i.e. children. Several attempts have been made to measure post-burn health in children (46, 54, 97), but few are accepted or used in clinical work. Future
efforts in this regard should be related to problems such as defining physical and mental aspects of health in normal child development, and finding ways for the child to provide information directly.

Another important future ambition would be to find ways to carry out early screening and identification of those individuals who will be at risk of developing future problems in one or more areas of life. Knowledge of risk factors predicting poor outcome can guide treatment and rehabilitation efforts in a more individualized and direct way, with early intervention as a primary goal. This is important both for the individual patient as well as for a health care system with limited resources.

In spite of the tremendous amount of work that has been put into scale development in the past decade in order to create reliable and validated instruments, most scales are today still mainly the tools of researchers. Incorporating such validated measurements into clinical practice is of importance. This will hardly be possible without a multiprofessional approach on the part of both clinical workers and researchers, something that is possibly the most obvious application of the present work.

And lastly, a sense of humbleness should always be present in the minds of researchers working with the complexities of health status, quality of life and well-being. The individual is always unique, and only part of the truth can be captured by our measurements. Despite this, our results have the potential to add pieces to the puzzle in order to attain a better picture of the adaptation process awaiting severely burned patients.
Conclusions

The conclusions of the papers presented in this thesis:

I The BSHS-B is a new, psychometrically valid and much shorter alternative to the previously described versions of the Burn Specific Health Scale. Important domains of post-burn distress such as Hand Function and Sexuality are captured better in BSHS-B than in BSHS-R.

II All three versions of BSHS gave similar results with respect to global outcome on a group level. The largest impact on health was found in Role Activities in BSHS-A and in Heat Sensitivity and Work in BSHS-R and BSHS-B. Having a job, living with a partner, and being male were all related to better perceived outcome, whereas full thickness burns were related to worse outcome. The apparent variability in outcome patterns in the different scales underscores the importance of utilizing a broad instrument with adequate content validity.

III Neuroticism was the most important personality dimension negatively correlated to perceived outcome after severe burn injury, and had an impact on both psychosocial and physical aspects of life.

IV The Coping with Burns Questionnaire was developed and validated based on psychometric principles. The 33-item instrument consists of six well-defined domains with acceptable internal reliabilities.

V Avoidant coping was the strategy most clearly related to more symptom reporting in all scales of BSHS-B, whereas Emotional support was the most beneficial coping strategy. There was no association between coping strategies and injury characteristics except for subjects with a full thickness injury above ten percent who used more Revaluation/adjustment.
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