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# Classification of quality of life subscales within the ICF framework in burn research: Identifying overlaps and gaps

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## ABSTRACT

**Objective:** Quality of life (QOL) is one of the leading outcomes in burn care research. This study classifies subscales of common QOL measures within the International Classification of Functioning disability and health (ICF) framework to determine to which extent the measures are complementary or overlapping and to investigate whether the instruments are able to describe the full spectrum of patients' functioning.

**Methods:** A literature search was performed to determine the most frequently used questionnaires in burn research. The subscales of the three mostly used questionnaires were classified within the ICF framework.

**Results:** Two generic measures, the Short Form-36 items (SF-36) and the European Quality of Life 5 Dimensions (EQ-5D), and a disease specific measure, the Burn Specific Health Scale-Brief (BSHS-B), were analyzed. The BSHS-B covered most domains and was the only scale that included personal factors. The SF-36 included only one domain in the activity limitations and similar to the EQ-5D no contextual factors were included. Environmental factors were not addressed in the questionnaires, even though these may have an impact on the quality of life in patients with burns.

**Conclusion:** To capture the full spectrum of dysfunctioning a combination of the BSHS-B with a generic questionnaire seems obligatory. However still some domains of functioning remain uncovered.

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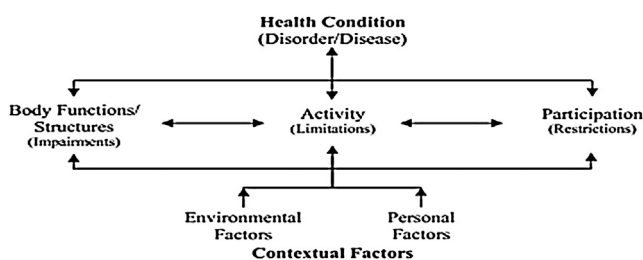
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## 1. Introduction

Two decades ago, the World Health Organization (WHO) defined quality of life (QOL) as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment” [1,2]. Since then, QOL has received increasing attention, including in burn populations, and a burgeoning body of research documented burn survivors’ health-related quality of life (HRQOL) [3–7].

In burn research various generic HRQOL self-report measures have been used. The most common burn specific questionnaire available is the Burn Specific Health Scale (BSHS) that has a long history of several adaptations [4,8,9]. The most frequently used version in recent years is the Burn Specific Health Scale Brief (BSHS-B) that has been translated in several languages all over the world [4,10]. The BSHS-B has been shown to be measurement invariant across two European countries, indicating its stability across cultures [11]. However, it is currently unclear to which extent the BSHS-B and generic HRQOL measures are complementary or overlapping in measuring different aspects of HRQOL following burns and whether the full spectrum of disability is captured by using (a combination of the) questionnaires.

To elucidate which HRQOL aspects are covered by the currently used self-report measures a broad bio-psycho-social framework is of interest. The International Classification of Functioning Disability and Health (ICF) is a worldwide used framework to describe the health condition of a patient in such a context. The ICF inventories all domains of disability from body, individual and societal perspectives [12]. As presented in Fig. 1, disability involves dysfunctioning at one or more of these levels: impairments in body function or structures, activity limitations and participation restrictions. The environmental factors (physical and social environment) and the personal factors, such as age, gender and marital status, may influence human functioning in a positive or negative manner. In sum, the ICF enables the understanding of phenomena related to function that may be particularly relevant when assessing quality of life following burns.



**Fig. 1 – Illustration of the international classification of functioning, disability and health by the World Health Organization.**

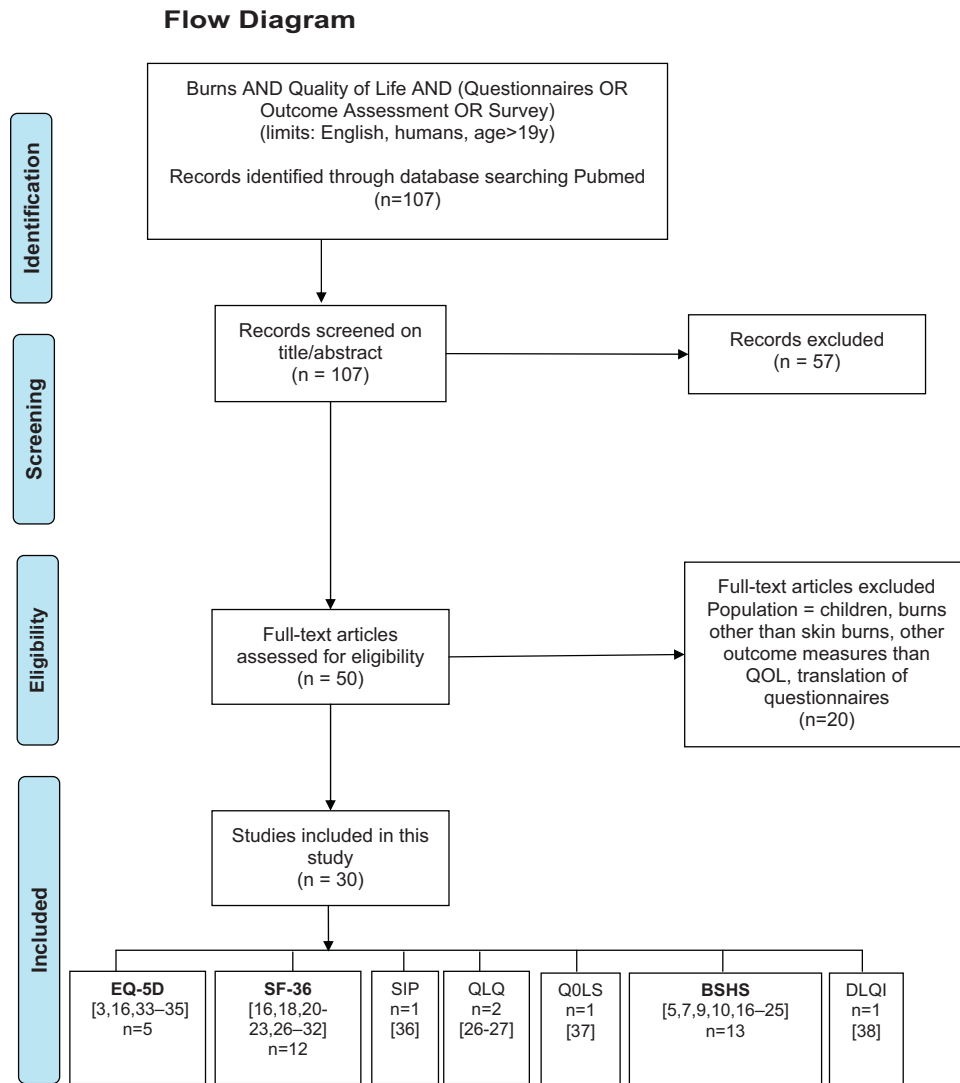
Despite the growing attention for functional outcome during the last fifteen years in burn research the limited application of HRQOL measures within the ICF framework is notable with very few burn articles on this subject [12,13]. One review on functional outcome identified seven core domains that were considered essential to comprehensively assess outcome after burns [15]. The core domains proposed are skin, neuromuscular function, sensory and pain, psychological function, physical role function, community participation and perceived quality of life, but it is unclear to which extent the proposed domains are captured in the most commonly used self-report measures. In a systematic review concepts of common outcome measures in burn care were considered within the ICF framework using standardized linking rules. HRQOL questionnaires were included in this study and it was reported that 43 concepts (out of 50) of the BSHS-B could be linked to the ICF [14]. In clinical practice, however, the interpretation of the outcome is often based on the subscale scores of the questionnaires, rather than interpreting the distinct items. Currently, no reports are available linking the subscales of the HRQOL questionnaires to the ICF framework in an attempt to describe functioning following burns.

The aim of this study is to classify the subscales of frequently used HRQOL measures within the ICF and to answer the question if these instruments are able to describe the broad spectrum of patients’ functioning. Moreover this paper seeks to address the following questions: What aspects of HRQOL do the different questionnaires measure? What aspects of HRQOL are left uncovered? Which different domains of ICF are covered by each questionnaire?

## 2. Methods

### 2.1. Selection procedure

The electronic database PubMed was searched for English-language empirical studies, published between 1990 and 2013 using a combination of Medical Subject Headings (Mesh). The Mesh terms ‘Quality of life’ and ‘Burns’ were combined with the following three keywords: ‘Questionnaires’, ‘Outcome Assessment (Health Care)’ and ‘Survey’. Articles on children, burns other than skin burns (e.g., eye burns, inhalation injury) and other outcome measures were excluded. After screening the abstracts and the full texts this search yielded 30 articles in which seven HRQOL questionnaire were used: the European Quality of Life 5 Dimensions (EQ-5D), the Short Form-36 Medical Outcomes Survey (SF-36), the Sickness Impact Profile (SIP), the Quality of Life Questionnaire (QLQ), the Quality Of Life Scale (QOLS), the Burn Specific Health Scale (with all its variants) and the Dermatology Life Quality Index (DLQI) (Fig. 2). We selected the three most commonly used questionnaires. As shown in Fig. 2, within the burn population the BSHS-B [5,7,9,10,16–25], the SF-36 [16,18,20–23,26–32] and the EQ-5D [3,16,33–35] appear the most frequently used HRQOL measures in recent literature in contrast to the SIP [36], the QLQ [26,27], the QOLS [37] and the DLQI [38]. Subsequently the BSHS-B, the SF-36 and the EQ-5D were retained for further investigation.



**Fig. 2 – Flow diagram of literature search.**

## 2.2. ICF linkage procedure

A group of four researchers (JM, NVL, KM, UVD) classified the subscales of each quality of life questionnaire into the respective ICF categories: body functions/structures, activity, participation, personal factors or environmental factors. This was done by evaluating/interpreting the items within each subscale of the QOL instruments. The Dutch ICF browser was consulted to establish the decisions [39].

## 2.3. Measures

### 2.3.1. SF-36

The SF-36 consists of eight subscales; Physical functioning (ten items), Role-physical (four items), Bodily pain (two items), General health (six items), Vitality (four items), Social functioning (two items), Role-emotional (three items) and Mental health (five items) [21,40-43]. Scoring is a two step process. First precoded numeric values are transformed with a scoring key into values between zero and one hundred (a high

score defines a more favorable health status). In the second step items in the same subscale are averaged together to create the eight scale scores. All subscales of the SF-36 have a fair to good Cronbach's alpha [4,5,20,21,44-48].

### 2.3.2. EQ-5D

The EQ-5D is a generic assessment tool with five dimensions; Mobility, Self care, Usual activities, Pain/discomfort and Anxiety/depression [3,16,49]. Each dimension has three levels: no problem, a moderate problem or an extreme problem, yielding many potential combinations of health states across the five dimensions. Finally, subjects rate their overall health on a visual analog scale from zero (worst imaginable health state) to hundred (best imaginable health state). A domain-related scoring algorithm based on empirical valuations from the UK general population and subsequent statistical modeling is available [3]. Each health status description can be expressed in a summary score. This summary score ranges from one (full health) to zero (for death) and can even have negative values (-.059 as minimum). The summary score can

**Table 1 – coverage of ICF domains within BSHS-B, SF-36 and EQ-5D.**

	Body function/structures (impairments)		Activity (limitations)	Participation Restrictions	Contextual factors		Others
	body structures	body functions	Activity	Participation	Personal factors	Environmental factors	
BSHS-B subscales		Heat sensitivity	Hand function	Interpersonal relationships~	Treatment regimes		
		Sexuality	Simple abilities***	Work~	Body image		
		Affect*					
SF-36 subscales		Mental health*	Physical functioning***	Role physical~			General health
		Bodily pain**		Social functioning~			
		Vitality		Role emotional~			
EQ-5D subscales		Pain/discomfort**	Mobility***	Usual abilities~			General health
		Anxiety/depression*	Self care***				

**bolt** = unique features for the questionnaire  
*italic* = overlap between questionnaires within ICF domains  
 \*and arrows= illustrating link with other QOL scale

be understood as a measure for the relative desirability of a health status compared with perfect health [3,49].

2.3.3. BSHS-B

The BSHS-B is the most recent version of this disease specific tool and has 40 items with nine well defined domains; Heat sensitivity (five items), Affect (seven items), Hand function (five items), Treatment regimens (five items), Work (four items), Sexuality (three items), Interpersonal relationships (four items), Simple abilities (three items) and Body image (four items) [9,10,16]. Responses are made on a five point scale from zero (extremely) to four (none/not at all) for each of the 40 items and patients are asked to select the best answer. Mean scores are calculated for each of the domains [50]. All subscales of the BSHS-B have a fair to good Cronbach’s alpha [4,5,20,51].

**3. Results**

**3.1. Comparison of the ICF domains across the questionnaires (horizontal comparison in Table 1)**

Table 1 represents the ICF framework subdomains covered by the respective subscales included into the three questionnaires. The generic scales covered the health condition domains, although the SF-36 provided more different information relative to the EQ-5D, in particular in the body function and the participation domain. Both generic questionnaires excluded contextual factors. The BSHS-B included all health condition domains and personal factors but excluded environmental factors. None of the scales included items on environmental factors and body structures.

**3.2. Comparison of the subdomains across the questionnaires (vertical comparison in Table 1)**

In general, subscales addressing impairments in body structures or environmental factors were not included in any of the questionnaires. Regarding the body functions domain there was an overlap between the questionnaires for mental function (see \* in Table 1). Heat sensitivity and Sexuality were uniquely assessed by the BSHS-B whereas Vitality was uniquely assessed by the SF-36. Regarding the activity domain all three questionnaires showed overlap to some extent. All questionnaires measured physical functioning including aspects of small and gross motor skills (see \*\*\* in Table 1). The BSHS-B comprised the unique subscale Hand function with focus on fine motor skills of the hands. Within the participation domain all three questionnaires focused on engaging in human interactions (see~ in Table 1). The BSHS-B had a separate subscale e.g., Work. The SF-36 included several participation subscales. All three questionnaires showed an overlap. The contextual factors were not inventoried by the generic questionnaires. The BSHS-B had two unique subscales classified within personal factors: Treatment regimes and Body image.

**4. Discussion**

A literature search revealed that the SF-36 and the EQ-5D were the most frequently used generic HRQOL questionnaires in burn-related studies over the last two decades. The BSHS-B version was the only disease specific HRQOL measure available. The subscales of the respective questionnaires were linked to the ICF domains. In general this classification

revealed that the body function, activity and participation domains were covered by the three questionnaires. Contextual factors were poorly covered and the body structure domain was not addressed. The BSHS-B covered the most domains and it was the only questionnaire that included personal factors (subscales Body image and Treatment regimes).

The content comparison of the three questionnaires revealed considerable overlap across the questionnaires, particularly in the domains body function and activity domains, but some subscales were unique. All three questionnaires comprised mental functions (e.g., Affect, Mental health and Anxiety depression) and both generic measures included pain. The BSHS-B and the EQ-5D comprised two separate subscales for small and gross motor skills whereas both were included in one subscale in the SF-36. However, predominantly lower extremity activities (e.g., walking short and long distances, climbing stairs, kneeling, bending, walking) were measured in the SF-36. The participation domain seemed rather well covered by the questionnaires. However, looking into more detail, not all levels of social interactions were addressed. The SF-36 included interactions with friends, family and work, but the BSHS-B restricted participation to the 'family bond'. The EQ-5D did not directly address social participation, though it may implicitly be incorporated in the subscale Usual abilities. Considering the unique features of the questionnaires, the BSHS-B included Heat sensitivity and Hand function to measure fine motor skills, Sexuality and Body image whereas the SF-36 had the unique scale Vitality which involved energy and tiredness. Compared with the generic questionnaires, the BSHS-B provided the most burn specific information.

The majority of the subscales concentrate on three domains, while other domains remain untouched. Within the impairments domain, body structures are not addressed. The present findings seem to be consistent with the research of Wasiak et al. who found no concepts linked to body structures within BSHS-B and SF-36. Body structures do not seem primarily relevant for the QOL patient report although care givers do include body structures like skin type, type of surgical intervention (e.g., split thickness graft), upper limb and or lower involvement, etc. in the anamnesis. Considering impairment in body functions, disease specific impairments in body function were lacking in the BSHS-B, for example, pruritus is a common impairment in burn patients and was not addressed in these questionnaires [52-54]. Activity limitations and participation restrictions seem sufficiently covered by the currently used questionnaires. However participation is sometimes narrowly inventoried as described in the paragraph just above. Considering the second part of the ICF framework contextual factors were largely unaddressed. With regards to personal factors only the BSHS-B seems to contribute (including aspects of coping and self image in subscales Body Image and Treatment regimes). Personal factors (e.g., age, gender, coping style, educational level) may influence functioning as well as QOL, thus implementation within QOL questionnaires seems useful. Although the online ICF browser comprises 30 chapters (including 1424 items that are accompanied by definitions, examples, inclusion and

exclusion) no personal factors have been implemented yet [39]. Environmental factors were not addressed in the questionnaires, even though these may have an important impact on burn patients. Social factors (e.g., social care and social and family support) have been recognized as salient to influence coping, prognosis and recovery of patients [55]. The functional outcome of patients with severe burns may need long term adaptation and multidisciplinary care, therefore social factors may be interesting to measure for prognostic reasons. The findings of the current study are consistent with those of Cieza and Stucki (2005) who found that contextual factors are scarcely represented by generic QOL measures [56]. This also accords with earlier observations by Wasiak et al., who showed no concepts linked to contextual factors in the SF-36 and only 2 concepts linked to environmental factors in the BSHS-B. These findings further support the idea to add some items to existing instruments.

Some thoughts on the classification into the different categories of the ICF merit note, as it was not in all cases a straight forward decision because of the subjective nature of this exercise. Within the subscale Heat sensitivity some items inquired about situations they could no longer endure which would at first sight seem to be an activity limitation. However it was the underlying cause (skin is hypersensitive to heat) that was intentioned to measure. Consequently, it was classified within the subscale body function because the skin lost one of its functions. Considering the SF-36 subscale Bodily pain, one part of the questions (pain magnitude) was linked to impairments in body functions, the other part (pain interference) was linked to participation restrictions. These points of discussion provide an explanation as to why this classification partly differs from prior classifications [14,57].

This study showed that in order to comprehensively assess QOL in burn survivors a combination of a disease specific and generic questionnaire is necessary. This finding is in line with earlier recommendations [58]. However even when a combination of the BSHS-B, the SF-36 and the EQ-5D is chosen for QOL assessment some ICF domains remain uncovered. The SF-36 seems complimentary to the BSHS-B and with more focus on the lower extremities and the additional focus on fatigue. The EQ-5D seems feasible when the emphasis is to work quickly because the time to complete is only 5 min [59]. Within the EQ-5D and the BSHS-B vitality was not included, although vitality deficits and fatigue have been found important topics in chronic diseases and might be of interest in this population. Which combination of questionnaires to use should be chosen in light of the study goal, length of the instrument, time to complete and psychometric properties. To cover the unaddressed areas of functioning one needs additional questionnaires (e.g., itch questionnaire, scar scale, participation questionnaires).

In conclusion, from a theoretical view point, this study indicates that on the one hand the currently used instruments overlap regarding several domains and on the other hand they fail to measure domains of functioning that are of interest to patients with burns. An overlap has been empirically confirmed to some extent where prior research has shown correlations between the SF-36 subscales and the BSHS-B [21]. It would be interesting to further explore the ICF linked subscales of the respective questionnaires concerning content

overlap on an empirical dataset which might establish or abolish the results of overlap in this study. Regarding the unaddressed domains, it seems inevitable to further develop relevant subscales and add these to existing measures. Adding these domains to existing measures may broaden our understanding of functioning and may more adequately inform clinical practitioners. At the same time, adding more subscales to existing measures would increase the time needed to complete questionnaires, which is an unwanted situation in clinical practice. For screening purposes only, a brief version including the items with the highest distinctive ability for every relevant subscale could assist in overcoming the longer screening time when expanding current measures. Incorporating the unaddressed domains of functioning might be a next challenge in order to fully comprehend the broad spectrum of functioning and QOL following burns.

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### Conflicts of interest

There are no conflicts of interest to declare.

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