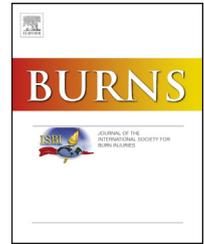


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# Health related quality of life 5–7 years after minor and severe burn injuries: a multicentre cross-sectional study

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## ABSTRACT

**Introduction:** Burn injury can affect health-related quality of life (HRQL). Knowledge concerning long-term HRQL in burn patients is limited. Therefore our aim was to evaluate long-term HRQL and to study predictors of impaired long-term HRQL.

**Methods:** All adults with a length of stay (LOS) of  $\geq 1$  day (2011–2012) were invited. Also, adults with severe burns, i.e.,  $>20\%$  total body surface area (TBSA) burned or TBSA full thickness  $>5\%$  (2010–2013) were invited. Participants completed the EuroQol(EQ)-5 D-5L+C and visual analogue scale (EQ-VAS) 5–7 years after burns.

**Results:** This study included 256 patients (mean %TBSA 10%); 187 patients with minor burns and 69 patients with severe burns. Mean EQ-5D summary was 0.90 and EQ-VAS 83.2 in the minor burn patients, and 0.79 and 78.1 in the severe burn patients. Some problems in at least one dimension were experienced by 81% of patients with severe burns and 45% of those with minor burns. However, a minority reported severe or extreme problems; 15% of those with severe burns and 6% of those with minor burns. Patients with severe burns reported significantly more problems, except for anxiety/depression. In both patient groups most problems were reported on pain/discomfort. Length of hospital stay, gender and age were associated with lower long-term HRQL (EQ-VAS) in multivariate analyses, whereas only length of stay was associated with a lower summary score.

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*Conclusions:* The majority of patients experienced some problems with HRQL 5–7 years post burn. This emphasizes that burns can have a negative impact on an individual's HRQL, particularly in more severely burned patients, that persists for years. The HRQL dimensions most frequently affected include pain/discomfort and anxiety/depression. Patients with a prolonged hospital stay, females and older patients are at higher risk of poor HRQL in the long-term.

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## 1. Introduction

A burn injury suddenly disrupts a person's daily life and can cause short- and long-term physical and/or psychological problems [1]. Improvements in burn treatment resulted in a decreased mortality rate [2]. As a result, an increasing number of people live with the consequences of burns such as extensive scarring or functional problems. In order to understand and quantify the consequences of burns, documenting outcomes of burns and burn rehabilitation becomes a topic of interest [3,4]. An increasingly studied outcome to qualify and quantify the impact of burns is health related quality of life (HRQL) [1]. HRQL is a self-reported outcome measure that reflects a patient's perception of how a health condition affect patient's physical, psychological and social wellbeing after an injury or disease [5].

The course of HRQL until two years after burns is quite well documented [1,6,7]. However, not all burn survivors may have reached their stable end situation by then. Less information on HRQL in the longer term is available [1]. Some problems, like physical functioning, show significant improvements after 24 months, whereas other problems, like participation restrictions due to mental well-being, seem to develop later [1,8]. Therefore, a longer follow-up of burn survivors is warranted. Along with a limited follow-up in previous studies there is also a lack of information regarding factors that predict a diminished long-term HRQL. Most studies investigated predictors up to 24 months post burn and found that burn severity and post burn psychological status were related to impaired HRQL [9].

A recent systematic review showed that long-term burn specific HRQL is more often studied than generic HRQL. Interestingly, information regarding generic HRQL in the long-term showed to be limited [1]. Studying generic HRQL is interesting for several reasons. Generic instruments facilitate comparison between different diseases or injuries and provide valuable information on how HRQL of burn patients corresponds to that of the general population [10]. Two instruments are most frequently used in burn populations, i.e., SF-36 and EQ-5D [1]. The latter is easy to use and understand, has a good feasibility and only takes a few minutes to complete [11]. EQ-5D is underused in burn outcome studies given these advantages [1].

The aim of this study was to document long-term generic HRQL 5–7 year post burn and to study predictors of diminished HRQL. A cross-sectional study was conducted using the EQ-5D -5L in two severity groups: burn patients with minor burns and severe burns.

## 2. Methods

### 2.1. Participants

Adult burn patients ( $\geq 18$  years old) with a hospital stay of  $\geq 1$  day or surgical treatment in one of the three dedicated Dutch burn centres (Red Cross Hospital Beverwijk, Martini Hospital Groningen, and Maasstad Hospital Rotterdam) in the period 08/2011–09/2012 were selected from the Dutch Burn Repository R3 [12]. We extended this sample with patients with severe burns ( $>20\%$  total body surface area (TBSA) burned in adults  $\leq 50$  years old, over  $10\%$  TBSA burned in adults  $>50$  years or TBSA full thickness  $>5\%$  (based on the criteria of the American Burn Association [13]) admitted between 01/2010 and 03/2013. Eligible patients had no cognitive impairments, had sufficient knowledge of the Dutch language, and contact details were available.

### 2.2. Study procedure

This study is part of a larger cross-sectional study that assessed the long-term consequences of burns in the Netherlands: the Burden of Burn Injuries study. Participants completed two surveys. The first survey was a short survey on generic HRQL and scar quality, the second one was a more extensive survey on other long-term consequences of burns. Between 03/2017 and 03/2018 eligible patients were invited to participate by a postal invitation including an information letter explaining the nature of the study. This letter was accompanied by an informed consent form and the first survey. Patients received a telephone call or postal reminder to increase the participation rate. The study was performed according to the principles of the Declaration of Helsinki, registered at the Netherlands Trial Register (NTR6407), and approved by the Ethics Committee (registration number NL59981).

### 2.3. Measures

Patient and injury characteristics were derived from the Dutch Burn Repository R3 [12]. Patient characteristics included age at injury and gender, and injury characteristics included %TBSA burned, % full-thickness burns, anatomical site(s) affected, aetiology, date of injury, number of surgeries, length of hospital stay (LOS), reconstructive surgery, artificial ventilation and time since burn.

Generic HRQL was assessed using the EuroQol (EQ)-5D-5L. This instrument consists of a descriptive system and a visual analogue scale (VAS) [14]. The EQ-5D -5L consists of five

dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. We used the 'EQ-5D-5L + cognitive dimension' (EQ-5D-5L + C) version of the instrument, which includes a sixth dimension: cognitive functioning (memory, concentration, coherence, IQ) [15,16]. Each dimension has five response categories: no problems, slight problems, moderate problems, severe problems and extreme problems/unable to. Based on the answers of the five original dimensions, an EQ-5D summary score was calculated ranging from 0 (death) to 1 (full health) [17]. The summary score can also have a negative value for health states worse than death. The VAS for general health consists of a scale ranging from 0 (worst imaginable health) to 100 (best imaginable health) [11].

#### 2.4. Data analyses

We performed a non-response analysis to study whether responders differed from non-responders. Mann Whitney U tests were used for continuous variables and chi-square tests for categorical variables. We used descriptive statistics to assess the EQ-5D summary score, dimension scores and EQ-VAS scores. The sample was divided into two subgroups based on the criteria of the American Burn Association [13]: patients with severe burns (>20% TBSA in adults ≤50 years old or >10% TBSA in adults >50 years old or TBSA full thickness >5%) and patients with minor burns (patients not meeting the criteria of severe burns). Characteristics and outcomes were compared among the two subgroups. AregImpute was used to impute missing characteristics, but not outcomes [18]. To determine which patient and injury characteristics were associated with generic HRQL, uni- and multivariate analysis were performed with the EQ-summary score and EQ-VAS scores as dependent variables. Characteristics with a p-value of  $p < 0.20$  in univariate analyses were checked for collinearity ( $>0.8$  or  $<-0.8$ ) and entered into the multivariate model. Burn center was entered as a random effect. The significance level was set at  $p < 0.05$ . Regression coefficients and standard errors were presented. We used IBM SPSS Statistics 23 and R software (version 1.0.153) for the analyses.

### 3. Results

#### 3.1. Participants

There were 666 adult patients registered in the burn database in the given time period. Of these, 517 met the study inclusion criteria of which 257 were willing to participate into the study (Fig. 1). One patient did not complete the EQ-5D and was excluded. The study sample included therefore 256 patients (49.5%). Responders were statistically significantly older ( $p = 0.002$ ), included more female patients ( $p = 0.03$ ) and had more reconstructive surgery ( $p = 0.04$ ) than non-responders (Appendix A).

Participants had a mean age of 47.7 years (SD 16.9) and 62.1% was male (Table 1). Patients had a mean LOS of 17.5 days (SD 22.0) and the mean %TBSA burned was 9.6% (SD 12.3). The majority of patients (63.7%) had at least one surgical procedure and most burns were caused by flames (57.9%). Median time since injury was 5.5 years (IQR 5.3–5.7). Seventy-three percent of the sample ( $n = 187$ , response rate:

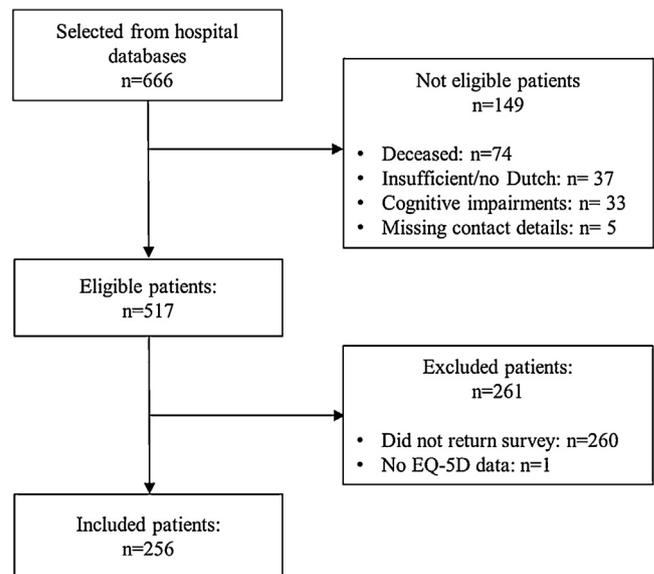


Fig. 1 – Flowchart of inclusion.

49.6%) had minor burns. Sixty-nine patients with severe burns participated (response rate: 49.3%). Characteristics of patients with minor burns were compared with severe burn patients. Except for the percentage of males, all characteristics were statistically significantly different (Table 1).

#### 3.2. Long-term health-related quality of life

Between 5 and 7 years post burn, 45.7% ( $n = 117$ ) of the included patients experienced no problems in any of the six dimensions measured by the EQ-5D + C, whereas 54.3% experienced mild to severe problems in at least one dimension. Severe or extreme problems in at least one dimension were reported by 8.2% of the patients. The mean EQ-5D summary score was 0.87 (range: 0.02–1.00) and the EQ-VAS was 81.9 out of 100 (range: 29–100) (Appendix B).

Overall, the most frequently reported problems were pain/discomfort (38.7%) and anxiety/depression (31.0%) (Appendix B). Problems with usual activities and cognitive problems were reported by 22.7% and 21.1% of the patients, respectively. Problems with mobility (15.3%) and self-care (7.8%) were less frequently reported. Only few patients reported severe or extreme problems, ranging from no patients with severe/extreme problems on self-care to 4.7% of the patients reporting severe/extreme problems with anxiety/depression.

When comparing patients with minor and severe burns, the EQ-summary score was 0.90 in minor burn patients and 0.79 in severe burn patients, and EQ-VAS was 83.2 (range: 29–100) in minor burn patients and 78.1 (range: 40–100) in severe burn patients (Table 2). More than half (55.1%) of the minor burn patients reported no problems in all dimensions (Fig. 2A), whereas 18.8% of the severe burn patients reported no problems (Fig. 2B). Patients with severe burns reported significantly more problems on all dimensions ( $p < 0.001$ ), except for anxiety/depression ( $p = 0.072$ ), than patients with minor burns. Extreme or severe problems were reported by

**Table 1 – Demographic characteristics of study population.**

Variable	Total sample (n = 256)	Minor burns (n = 187)	Severe burns (n = 69)	P-Difference
Gender: Male, n(%)	159 (62.1%)	118 (63.1%)	41 (59.4%)	0.590
Age at survey (M, SD)	47.7 (16.9)	45.7 (17.0)	53.1 (15.5)	0.001
Age at burn (M, SD)	42.1 (16.9)	40.3 (17.0)	47.0 (15.7)	0.004
%TBSA (M, SD)	9.6 (12.3)	4.4 (4.0)	23.8 (15.4)	<0.001
%TBSA full-thickness (M, SD) <sup>a</sup>	3.7 (8.4)	0.8 (1.2)	11.7 (13.2)	<0.001
LOS (M, SD)	17.5 (22.0)	9.2 (10.2)	40.0 (28.6)	<0.001
Number of surgeries (M, SD)	1.3 (1.9)	0.6 (0.7)	3.0 (2.9)	<0.001
Number of surgeries, n(%)				
0	93 (36.3%)	87 (46.5%)	6 (8.7%)	
1	115 (44.9%)	88 (47.1%)	27 (39.1%)	
>1	48 (18.8%)	12 (6.4%)	36 (52.2%)	
Reconstructive surgery, n(%)	30 (11.7%)	8 (4.3%)	22 (31.9%)	<0.001
Artificial ventilation, n(%)	40 (15.6%)	14 (7.7%)	26 (37.7%)	<0.001
Aetiology (%) <sup>b</sup>				<0.001
Flame	147 (57.9%)	94 (50.5%)	53 (77.9%)	
Scald	47 (18.5%)	40 (21.5%)	7 (10.3%)	
Other	60 (23.6%)	52 (28.0%)	8 (11.8%)	
Time since burn (years) (M, SD)	5.6 (0.5)	5.4 (0.2)	6.1 (0.7)	<0.001

Note: Severe burns: >20% total body surface area (TBSA) in adults ≤50 years old; >10% TBSA in adults >50 years old or TBSA full thickness > 5% (criteria American Burn Association). M, SD = mean, standard deviation.

<sup>a</sup> 3 missing values.

<sup>b</sup> 2 missing values.

**Table 2 – Health related quality of life outcomes measured by the EQ-5D in patients with minor burns versus patients with severe burns 5-7 years post burn.**

	Minor burns(n = 187)	Severe burns <sup>1</sup> (n = 69)p-values	P-Difference
EQ-5D summary score			<0.001
Mean (SD)	0.90 (0.16)	0.79 (0.21)	
Range	0.020-1.000	0.020-1.000	
EQ-VAS			0.002
% (range)	83.2 (29-100)	78.1 (40-100)	

<sup>1</sup> Severe burns: >20% total body surface area (TBSA) in adults ≤50 years old; >10% TBSA in adults >50 years old or TBSA full thickness > 5% (criteria American Burn Association).

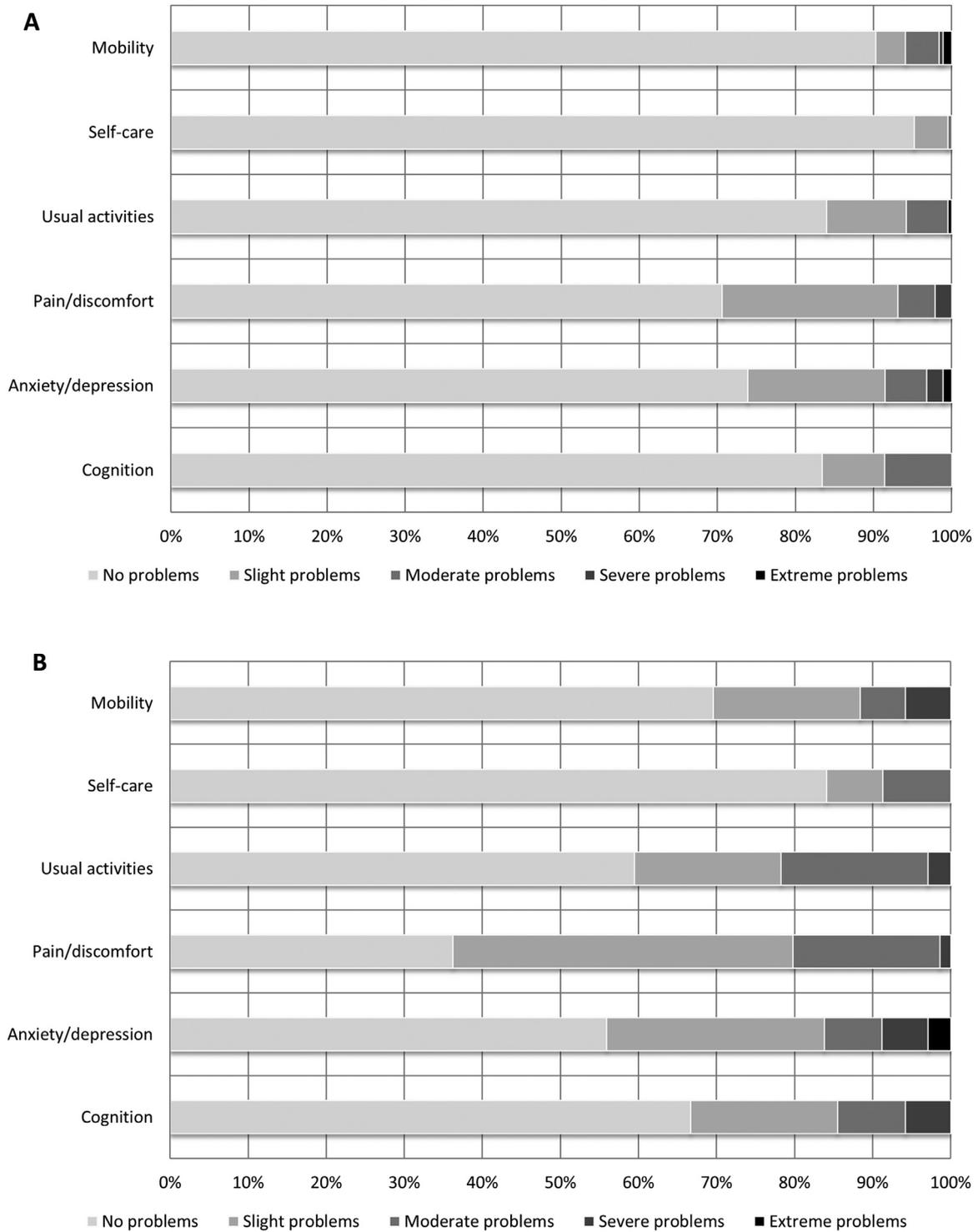
5.9% of patients with minor burns and 14.5% of patients with severe burns. Especially pain/discomfort was more prevalent and severe in severe burn patients: 63.8% of the severe burn patients reported these problems, whereas 29.4% of minor burn patients experienced such problems (Supplementary Appendix B). Also large differences were seen in problems with usual activities: 16.0% of patients with minor burns and 40.6% of patients with severe burns reported these problems. Problems with anxiety/depression were reported by 26.2% of patients with minor burns and 44.1% of patients with severe burns. Cognitive problems were experienced by 16.6% of patients with minor burns and 33.3% of patients with severe burns. Both patient groups reported less problems on self-care (4.8% minor burns; 15.9% severe burns) and mobility (9.7% minor burns; 30.4% severe burns). Severe or extreme problems were reported by a minority of patients in both groups. The proportion of minor burn patients reporting such problems ranged from no patients experiencing severe/extreme problems for self-care to 3.2% for anxiety/depression. In the severe burn patients, no patients reported severe/extreme problems

for self-care. And most severe/extreme problems were reported for anxiety/depression (8.8%).

### 3.3. Predictors of long-term health related quality of life

Univariate regression analyses for the EQ-5D summary score indicated that %TBSA burned, % full-thickness burns, LOS, number of surgeries, reconstructive surgery and the need for artificial ventilation were significant univariate predictors of HRQL 5-7 years after burns (EQ-5D summary score) (Table 3). Multivariate regression analyses showed that only LOS was a significant predictor of HRQL assessed with the EQ-5D summary score (Table 3).

Regarding the EQ-VAS, univariate analyses showed that age at injury, gender, %TBSA burned, % full-thickness burns, LOS, number of surgeries, reconstructive surgery and the need for artificial ventilation were significant predictors (Table 3). Age at injury, gender and LOS remained significant predictors of HRQL measured by the EQ-VAS in multivariate analyses (Table 3).



**Fig. 2 – (A) Frequency of responses to EQ-5D-5L + C dimensions in patients with minor burns 5-7 years post burn. (B) Frequency of responses to EQ-5D-5L + C dimensions in patients with severe burns 5-7 years post burn.**

#### 4. Discussion

This study is one of few reporting on generic HRQL beyond five years after burn injuries. The study revealed that almost half of the patients with minor burns (45%) and the vast majority of

patients with severe burns (81%) experience mild to extreme problems in at least one dimension 5-7 years post burn. However, severe to extreme problems were reported by a minority of patients, 6% and 15% for the minor and severe burn groups respectively. Patients with severe burns reported statistically significantly more problems on all dimensions

**Table 3 – Prediction models for long-term (>5 year) EQ-5D summary and EQ-VAS score.**

Variable	EQ-5D summary						EQ-VAS					
	Univariate regression			Multivariate regression <sup>a</sup>			Univariate regression			Multivariate regression <sup>b</sup>		
	Regression coefficient	SE	p Value	Regression coefficient	SE	p Value	Regression coefficient	SE	p Value	Regression coefficient	SE	p Value
Male gender	0.02	0.02	0.339				4.73	2.00	0.019	4.69	1.90	0.015
Age at injury	−0.02	0.01	0.123				−3.20	0.96	<0.001	−0.16	0.06	0.005
%TBSA	−0.06	0.01	<0.001				−2.42	0.97	0.013			
%TBSA full-thickness	−0.06	0.01	<0.001				−2.89	0.96	0.003			
LOS	−0.08	0.01	<0.001	−0.08	0.01	<0.001	−4.02	0.94	<0.001	−3.63	0.94	<0.001
Number of surgeries	−0.07	0.01	<0.001				−3.91	0.94	<0.001			
Reconstructive surgery	−0.05	0.01	<0.001				−3.02	0.96	0.002			
Artificial ventilation	−0.06	0.01	<0.001				−3.44	0.96	<0.001			
Facial burn	0.07	0.04	0.072				4.24	3.62	0.242			
Hand burn	0.03	0.03	0.368				−1.57	2.71	0.564			
Flame burns	−0.004	0.02	0.876				−0.08	1.98	0.968			
Scalds	−0.03	0.03	0.383				−0.57	2.52	0.821			
Time since burn	−0.01	0.01	0.486				−0.75	0.98	0.444			

<sup>a</sup> Explained variance: 21.7%.  
<sup>b</sup> Explained variance: 11.7%.

compared to patients with minor burns, except for anxiety/depression, although there was a trend towards more problems in the more severely burned group ( $p=0.07$ ). In both patient groups pain/discomfort was the most frequently reported problem. Prolonged LOS was the only predictor of long-term HRQL impairment when using the EQ-5D summary. Prolonged LOS, female gender and older age predicted impaired HRQL when using the EQ-VAS.

HRQL of patients with minor burns 5–7 years post burn was comparable to that of the general Dutch population (EQ-5D summary 0.90 vs. 0.89; EQ-VAS 83.2 vs 82.0) [19], but this should be interpreted with caution because the burn population included a substantial larger proportion of younger persons. This may underestimate the impact of burns because older age affects HRQL [19]. Problems with anxiety/depression were more prevalent in the minor burn population 5–7 years post burn compared to the general Dutch population (26% vs. 4%) [19]. This fits with a recent review that indicates that psychological functioning is hampered in a substantial group of patients with burns [1]. HRQL of severely burned patients 5–7 years after burns was lower compared to the general population on the summary measures and on all dimensions of the EQ-5D, indicating that severe burns impact HRQL in all domains of P. Particularly the domains anxiety/depression and pain/discomfort were rated significantly lower by severely burned patients and call for more attention.

The HRQL summary score in this study (0.78) was comparable to that of a former Swedish study (0.79) in patients with severe burns (mean %TBSA burned 25%) 4–7 years after burns [8]. There are no studies on long-term generic HRQL measured by the EQ-5D in minor burn patients [1]. Remarkably, the results of the current study are also comparable to an earlier prospective study with a follow-up of 18 months,

suggesting that after 18 months post burn, there is little to no improvement in HRQL in the years that follow [31].

In both severity groups, pain/discomfort was the most severely affected domain of functioning. A substantial proportion of the patients with severe and minor burns reported problems with pain/discomfort: 64% and 29% respectively. A recent study on burn pain reported that 42% reported mild to severe pain after 12 months [20], which indicates that these problems have the tendency to persist over years. Our study findings are also in concert with the Swedish study on long-term generic HRQL where 61% reported pain/discomfort problems [8]. High prevalence rates of pain and pain issues are also reported in other studies in major trauma patients [21,22]. However, it may be assumed that other complaints such as itch count for a large part of the problems comprised in the pain/discomfort domain. This is supported by the finding that about 65% of the severe patient group from our sample reported to experience at least mild itch in their most severe scar 5–7 years post burn, whereas 47% of them experienced at least mild pain in this scar [23]. Also earlier studies reported high itch rates (44–49%) in patients four to seven years after burns [24,25]. The clinical problem of pain, discomfort and itch is thus, even years after burns, common in burn survivors, especially in those with severe burns, and needs attention in the aftermath of burns.

Other dimensions of HRQL were fairly good. A proportion of 8–23% reported mild to extreme problems in the area of mobility, self-care, usual activities and cognition, although differences between the severity groups remained. Problems in the area of anxiety and depression did not significantly differ between the groups, but percentages (44% vs. 26%) suggest that burn severity increases the risk to experience anxiety/depression. Moreover, the prevalence

rate in both groups exceeded the population based prevalence rate. This indicates that a burn injury has the potency to elicit long-term psychological problems. Whether burn severity affects psychological functioning after burns is an inconsistent finding across studies [26]. Burn severity was found to be a predictor of severity of depression [27] and posttraumatic stress symptoms in some studies [28,29], whereas others found no relation [26,30].

Our study demonstrated that a prolonged hospital stay predicts HRQL in the long-term, as well as gender and age at injury. Multivariate analyses identified LOS as predictor for diminished long-term generic HRQL, both measured by the EQ-5D summary score and the EQ-VAS. This is consistent with earlier studies that also found that a longer LOS resulted in a poorer HRQL in burn patients, although measured shorter after burns [8,9,31,32]. Earlier studies also found other indicators of burn severity, including %TBSA burned and number of surgeries, to predict HRQL [9,33–35], which is in line with the results of our univariate analysis that showed that these factors are associated with lower long-term HRQL. LOS seems to be a better indicator of long-term generic HRQL than %TBSA burned, probably because it indicates both burn severity (including burn depth), complex wound healing (i.e. due to infections) and other medical or psychosocial complications that prolong hospitalization.

Older age at injury and female gender were associated with a lower EQ-VAS, but were not associated with the EQ summary score. Previous studies showed mixed results on whether these two factors predict HRQL although most evidence points to a better HRQL in male burn patients [9]. This is in line with other trauma populations [36,37] and with norm scores in the Dutch population [38]. Possibly, females are more willing to report any problems or it may be more difficult for females to live with a changed appearance [39]. Female burn patients had more difficulties with social participation, had higher levels of fatigue and mortality rates are higher than male patients [39–41]. Regarding age, results from previous studies are mixed [9] which is consistent with other trauma populations. However, it is well established that older persons have a lower HRQL [19], due to a decreased physical condition, co-morbidities and impaired protective mechanisms [42]. This was seen in our study population and is an indication for extra attention for older patients in the aftercare of burns.

#### 4.1. Strengths and limitations

Strengths of our study include the multicenter measurement of generic HRQL with a long-term follow-up, which is scarce in the field of burns, and the relatively large sample size with only few missing data which provided enough power to test associations. Furthermore, our study is the first that used the EQ-5D-5L version of the instrument. Earlier studies applied the EQ-5D-3L, whereas the 5L version is recommended as it is more sensitive, especially for mild problems [43]. Furthermore, our studies gives an indication that this 5L version is sensitive to be used in the burn population as it discriminates between the different study groups based on burn severity. However, because other studies used the 3L version and

currently, no norm score is available for the 5L version, the comparisons with the general population and other studies may be affected.

This study has also some limitations. First, the response rate was 49.5% (49.6% in patients with minor burns and 49.3% in patients with severe burns) and responders were statistically significant older (mean 42 vs. 38 years old), more often female (38% vs. 29%) and had more reconstructive surgeries (12% vs.7%). These differences may limit the generalization of the results. Systematic outcome registry might overcome this issue in the future [44]. Second, this study did not include psychological measures as predictors of HRQL. A recent review showed that in-hospital psychological factors are among the most important predictors in HRQL for burn patients [9].

#### 4.2. Conclusions

This study shows that 5–7 years after the burn event, a significant proportion of patient experiences problems with HRQL. However, only a small proportion of patients experienced severe problems. The HRQL dimensions most frequently affected include pain/discomfort and anxiety/depression. A smaller proportion experienced problems in the other dimensions. This emphasizes that burns can have a profound negative impact on an individual's HRQL, particularly in more severely burned patients, that persists for years. Patients with a prolonged hospital stay, females and older patients are at higher risk of poorer HRQL in the long-term.

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#### Author contribution

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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#### Declaration of interest

None.

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## Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.burns.2019.03.017>.

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