Patients' perspectives on quality of life after burn

Marianne B. Kool [a,b,*], Rinie Geenen [b], Marthe R. Egberts [a,b],
Hendriët Wanders [c], Nancy E. Van Loey [a,b]

[a] Association of Dutch Burn Centres, Postbus 1015, 1940 EA Beverwijk, The Netherlands
[b] Utrecht University, Department of Psychology, Heidelberglaan 1, 3508 TC Utrecht, The Netherlands
[c] Dutch Association of Burn Survivors, Postbus 1015, 1940 EA Beverwijk, The Netherlands

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ABSTRACT

Background: The concept quality of life (QOL) refers to both health-related outcomes and one's skills to reach these outcomes, which is not yet incorporated in the burn-related QOL conceptualisation. The aim of this study was to obtain a comprehensive overview of relevant burn-specific domains of QOL from the patient's perspective and to determine its hierarchical structure.

Methods: Concept mapping was used comprising a focus group (*n*=6), interviews (*n*=25), and a card-sorting task (*n*=24) in burn survivors. Participants sorted aspects of QOL based on content similarity after which hierarchical cluster analysis was used to determine the hierarchical structure of burn-related QOL.

Results: Ninety-nine aspects of burn-related QOL were selected from the interviews, written on cards, and sorted. The hierarchical structure of burn-related QOL showed a core distinction between resilience and vulnerability. Resilience comprised the domains positive coping and social sharing. Vulnerability included 5 domains subdivided in 13 subdomains: the psychological domain included trauma-related symptoms, cognitive symptoms, negative emotions, body perception and depressive mood; the economical domain comprised finance and work; the social domain included stigmatisation/invalidation; the physical domain comprised somatic symptoms, scars, and functional limitations; and the intimate/sexual domain comprised the relationship with partner, and anxiety/avoidance in sexual life.

Conclusion: From the patient's perspective, QOL following burns includes a variety of vulnerability and resilience factors, which forms a fresh basis for the development of a screening instrument. Whereas some factors are well known, this study also revealed overlooked problem and resilience areas that could be considered in client-centred clinical practice in order to customize self-management support.

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1. Introduction

An important aim of the treatment of burn survivors is to keep or attain a favourable quality of life (QOL). Defining QOL after a burn is complex because of its multifactorial nature as virtually all organs can be affected [1,2], and because of the heterogeneity of the population in terms of injury severity, age, socio-economic background and its impact on all domains of physical, psychological and social functioning [3]. Currently, QOL after burns is measured using generic and burn-specific

QOL questionnaires. These existing instruments are useful in research to examine outcomes on group level and for comparisons in international studies [4–6], and in clinical practice for rapid assessment and to monitor improvement [7]. However, which components define QOL following burns area topic of debate [3,8]. Studies using the International Classification of Functioning Disabilities and Health framework point to gaps in the extant literature [4,5,8].

Several studies emphasize different elements of QOL. From the professionals' perspective, Falder et al. present a conceptual framework comprising seven core domains: "skin, neuromuscular function, sensory and pain, psychological function, physical role function, community participation, and perceived QOL" [3]. Qualitative studies, that have the advantage to get an in-depth assessment of a phenomenon and make the patient's voice heard, point to a broader range of both negative and positive outcomes after burns. These, for example, include skin problems, fatigue, negative social interaction, existential and sexual problems, personal growth, self-esteem, empathy, gratitude, identity, and new relationships [9–19] as well as sensory symptoms, impact of burn scar interventions, impact of burn scar symptoms, personal factors and change over time [16]. This shows some discrepancy between the professional's point of view and the patient's perspective and emphasizes the additional value of qualitative studies that echo the patient's voice, particularly when health care needs are to be addressed.

Modern definitions of QOL do not only reflect a static outcome, but also indicate one's ability to adapt and to self-manage physical, psychological, and social challenges of life [20]. To get insight in these outcomes and processes, it is valuable to obtain an ideosyncratic, in-depth assessment of an individual. This broad assessment could include problems that only apply to a small subgroup of patients, particular issues that are sensitive or emotional, and ways of managing QOL issues. In clinical practice, it could for instance be used in shared decision making to support self-management or to offer tailored care. To reach this aim, a comprehensive understanding of positive and negative QOL components is needed.

To further inform clinical practice, there is a need to better understand the whole spectrum of QOL, particularly from the perspective of individual patients. Concept mapping is an appropriate technique to elucidate an encompassing conceptual representation of QOL. It results in an interpretable, representative and structured pictorial view of ideas and concepts and how these are interrelated. In contrast to factor analysis, it does not reduce the number of concepts that is represented by latent factors reflecting consistent individual differences, but instead it organizes concepts by their meaning in a hierarchical map. This gives insight into target population perspectives, and provides a foundation for analytical and clinical choices [21]. Starting with interviews with burn survivors can basically help to understand what this concept means for them and can reveal the different components of QOL of interest to these patients. Subsequent sorting of these components by patients allows to group the qualitative information into interpretable domains. This can form the basis for the development of an in-depth assessment, or tailored screening instrument, to inform clinical practice as

patients will differ in their need for (type of) treatment and support to help them maintain or restore their QOL.

The aim of this study was to obtain a comprehensive overview of domains of burn-related QOL including (in) capacities to self-manage QOL, by using patients' views in a bottom-up approach. Specific emphasis was placed on including relatively uncommon problem areas that may be overlooked on group-level but are of notice to individuals.

2. Methods

The study was conducted according to the principles of the Declaration of Helsinki (revision, Fortaleza, Brazil, 2013). The Institutional Review Board of the Faculty of Social and Behavioural Sciences of Utrecht University reviewed the study and concluded that the study could be done without being subjected to review according the Dutch Medical Research Involving Human Subjects Act, because the study did neither involve a high load or risk for the participants nor medical acts (29/11/2012). The study used a concept mapping approach involving three successive steps: 1) a focus group, 2) patient interviews, and 3) a card-sorting task. All participants received an information letter and they provided written informed consent.

2.1. Participants

Eligible participants were recruited from two burn centres in the Netherlands between November 2013 and May 2015 or by a patient research partner at a peer-group meeting. The focus group and the card-sorting task group included adults who sustained a burn during childhood or adulthood 6 months to 33 years before participation in this study. Interviews were performed with adults admitted to a burn centre 6 months to 5 years prior to the interview to ensure the inclusion of short-term and long-term QOL problems or benefits. Table 1 presents the participants' characteristics for the separate study waves.

2.2. Focus group and interviews

The aim of the focus group was to choose the terminology, to identify relevant domains to start with, and to get acquainted with terms and language used by burn survivors in preparation of the interviews.

The interviews were aimed to uncover domains of QOL that may be affected by burns. The interviews were semi-structured and comprised open questions concerning QOL. Example questions are shown in Table 2. More detailed information was collected by using probes (i.e., asking follow-up questions when answers are not fully understood or when more specific or in-depth information is desired). Constant data comparison, i.e., checking if interviews obtained information that was reported by other participants, was used in subsequent interviews. When no new aspects emerged during at least two interviews (saturation) the recruitment of participants was stopped. The interviews took place at home or in the burn centre in a private room. They were carried out by the first author (MK) or by one of two

Table 1 – Demographic characteristics of participants of the focus group, interviews, and card-sorting.			
Characteristics	Focus group (n=6)	Interviews (n=25)	Card-sorting (n=24)
Age, mean (SD)	48 (17)	52 (12)	50 (16)
Gender, female, n (%)	5 (83)	14 (56)	15 (63)
Education level[a], n (%)			
Primary			1 (4)
Secondary	3 (50)	14 (56)	11 (46)
Tertiary	3 (50)	11 (44)	12 (50)
Marital status, n (%)			
Single	1 (17)	9 (36)	8 (33)
Married/partnered	4 (66)	13 (52)	13 (55)
Divorced	1 (17)	3 (12)	2 (8)
Widowed			1 (4)
Work status, n (%)			
Employed full-time	2 (33)	8 (32)	6 (25)
Employed part-time	2 (33)	7 (28)	8 (33)
Unemployed and seeking work	1 (17)		
Retired	1 (17)	2 (8)	5 (21)
Workmen's compensation act/benefit		4 (16)	2 (8)
Housewife		4 (16)	3 (13)
Years post-burn, mean (SD)	17 (9)	2 (1)	4 (5)
TBSA burned, mean (SD)	35 (23)	27 (20)	27 (16)
Face burned, n (%)	4 (67)	13 (52)	10 (42)
Genitalia burned, n (%)	0 (0)	2 (8)	3 (13)

TBSA=total body surface area.

[a] Education level: primary=primary school, secondary=middle-level school and low and middle-vocational education, tertiary=higher-professional education and university.

Table 2 – Examples of open questions from interviews 1 and 2.
Examples of open questions from interviews
Interview 1
After the accident, what changed in your life?
After the accident, which problems/symptoms did you encounter?
What turned out better than you expected?
What makes your life good?
What do you need to experience a nice life?
Are there problems/symptoms that you did not discuss with a physician or health professional?
What advice do you have for medical and health professionals to help patients the best way they can?
Interview 2
How did you see yourself after the accident?
Have you been wearing different clothes since the accident?
How is it for you to make contact with others?
How do people react to your scars?
How do you cope with the reactions of others?
What experience do you have with fellow sufferers?
What influence do the scars have on your relationship with your partner?
What influence do the scars have on your sexual relationship with your partner?
To what extent would you be open to having sexual contact with your date?
What is your experience with the help given by medical and health professionals concerning negative social interactions, and intimacy and sexuality?

psychology master students (MS, JD). Participants were interviewed once or twice depending on the duration and content of the interview. Usually, sexuality, intimacy, and social rejection were topics to be discussed in a second interview unless the participant preferred only one interview. Interviews were audio-recorded and transcribed verbatim. Interviews lasted on average 107 min (range 46–198 min; including one or two interviews).

The aim of the card-sorting task was to structure the qualitative information as reported by burn survivors in the interviews. Three interviewers independently selected statements comprising aspects of QOL from the interviews. Corresponding statements were combined and statements mentioned by only one participant were excluded. Ambiguous and abstract statements were removed. The remaining statements were evaluated on their suitability and comprehensibility for the card-sort task by the project group, including researchers (MK, RG, ME, & NVL) and patient research partners (HW & AZ). The resulting statements were pilot tested in four burn survivors and four health professionals.

All 99 statements were printed on a card for use in the card sorting task. The task took place in a burn centre supervised by a researcher or (un)supervised at the participant's home. Instructions were given verbally or on paper. Participants performed the tasks individually. First, they were instructed to place the statements in piles based on content similarity in response to the question: "After the accident, the life of burn survivors is negatively or positively reflected by . . . .". To prevent that too few or too many piles were formed, four rules applied: all statements had to be placed in a pile; each statement could be placed in one pile only; each pile could contain 2–25 statements; and 4–20 piles could be formed [22]. The participants labelled the piles in order to assist the researchers in the interpretation of the sorting. Second, the participants were asked to order the statements along a continuum of five piles going from considerable negative influence to considerable positive influence. They were instructed to sort the statements according to the influence on their life.

2.3. Statistical analysis

Hierarchical cluster analysis in SPSS statistical software version 22 (SPSS Inc., Chicago, IL) was used to classify the individually sorted statements. A sample size of 10–20 people has been suggested to assure a variety of opinions and to receive a stable hierarchical structure that enables interpretation of clusters [23]. In cluster analysis, the cells of the input matrix of statements comprise the frequency that two statements were not sorted in the same pile. Squared Euclidean distances were computed between each pair of statements and Ward's method was used to derive the hierarchical structure of QOL. The number of clusters was based on the criterion that the clusters should reflect distinct components of statements. First, the outcome of two clusters was

interpreted, subsequently three and four etc. until additional clusters did not yield new content. The members of the project group (MK, RG, ME, HW, AZ & NVL) determined the final number of clusters, guided by the dendrogram and the agglomeration schedule produced by the statistical software program. As regards the second sorting task, all statements were given a score based on the pile they were put in; pile 'considerable negative influence'=score 1, pile 'little negative influence'=score 2, pile 'no influence'=score 3, pile 'little positive influence'=score 4, and pile 'considerable positive influence'=score 5. These scores were used to calculate a mean influence score and standard deviation for each cluster and statement.

3. Results

3.1. Statement selection

From the interviews 207 statements reflecting aspects of QOL were selected. This number was reduced to 108 statements because they were ambiguous, not relevant or showed overlap with another statement. These 108 statements were pilot tested and subsequently 9 statements were removed or combined with another statement. The final set included 99 statements (see Appendix A).

3.2. Participants

Twenty-six participants performed the card-sorting task. Two of the 26 participants were excluded from the hierarchical cluster analysis (task 1) and the perceived influence score analysis (task 2), because they sorted less than 90% of the cards. For the same reason, an additional four participants were excluded from task 1 only. Four other participants failed to cluster two or three statements. These missing statements were considered single-item piles. Therefore, data of 20 participants could be used in the hierarchical cluster analysis. For the perceived influence score analysis, one participant was excluded from the analysis because of more than 10% missing

data, resulting in data of 23 participants that could be used in this analysis.

3.3. Hierarchical cluster analysis

Fig. 1 presents a schematic representation of the hierarchical cluster analysis representing the different domains of burn-related QOL. The 15-cluster solution was judged to fit the sorting of the 99 statements best. Increasing the number of clusters to sixteen or seventeen resulted in single-item clusters that seemed irrelevant. Decreasing the number of clusters to fourteen resulted in the combination of two meaningfully different clusters, i.e., 'cognitive symptoms' and 'negative emotions'.

The hierarchical structure showed a core distinction between two broad categories of burn-related QOL, including 'resilience' and 'vulnerability' clusters. 'Resilience' included two domains, i.e., 'positive coping' and 'social sharing'. 'Vulnerability' could be further subdivided into five domains named, 'psychological', 'economic', 'social', 'physical', and 'intimacy/sexuality', which all together represented 13 subdomains.

The psychological domain included five subdomains: 'trauma related symptoms', 'cognitive symptoms', 'negative emotions', 'body-perception', and 'depressive mood'. The economic domain included the two subdomains 'finance' and 'work'. The social domain included one subdomain that represented problems with regard to invalidation and stigmatisation. The physical domain included three subdomains representing 'somatic symptoms', 'scars', and 'functional limitations'. The intimate/sexual domain included the two subdomains, 'partner' and 'anxiety/avoidance'.

3.4. Perceived influence on burn-related QOL

Before computing average scores, positively phrased statements were reversed within the vulnerability category: four scores within the sub-domain 'partner', two within 'work', and one within 'invalidation/stigmatisation'. Table 3 shows the mean cluster scores. The mean scores varied from a negative
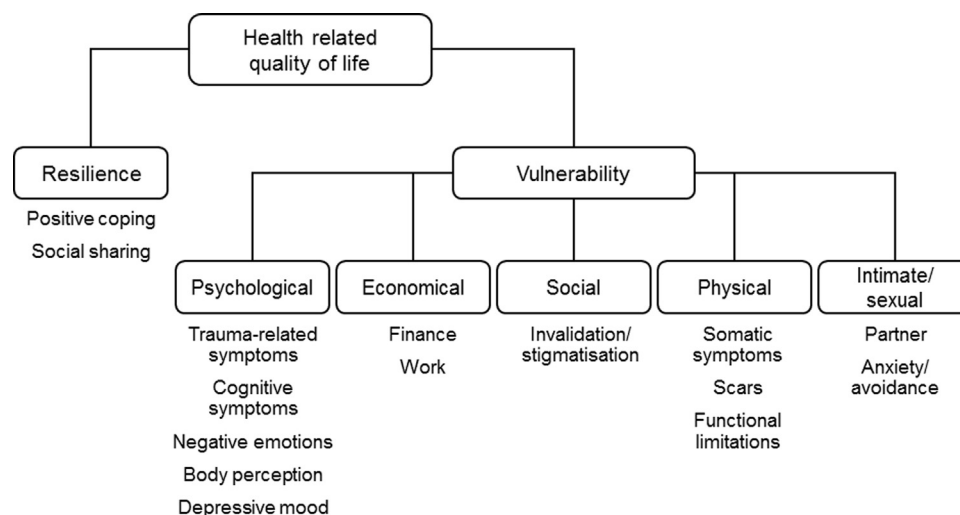
Fig. 1 – Schematic representation of the dendrogram of burn-related QOL of persons with burns.

Table 3 – Clusters of burn-related QOL, label of the cluster with one example item (in *italics*), the mean and standard deviation of the perceived influence on burn-related quality of life.

Cluster label	Mean	(SD)
Positive coping	4.42	(0.26)
Accepting yourself as you are		
Social sharing	4.16	(0.44)
Sharing experiences with those who have been through it too		
Trauma-related symptoms	2.48	(0.60)
Reliving the accident		
Cognitive symptoms	2.03	(0.59)
Concentration problems		
Negative emotions	2.10	(0.62)
Anger and irritation		
Body perception	2.27	(0.59)
Finding yourself unattractive		
Depressive mood	2.41	(0.46)
Loneliness		
Finance[a]	2.02	(0.83)
Negative effects on your financial situation		
Work	2.48	(0.37)
No longer being able to work at your previous level		
Stigmatisation/invalidation	2.54	(0.34)
Family and friends who don't understand		
Somatic symptoms	2.17	(0.48)
Fatigue		
Scars	2.15	(0.52)
Tightness of scars		
Functional limitations	2.39	(0.69)
Difficulties with mobility such as walking and cycling		
Partner[a]	2.53	(0.46)
Your partner's avoiding touching the scars		
Anxiety/avoidance	2.61	(0.42)
Fear of no longer being able to have a sex life		

Note. 1=considerable negative influence, 2=little negative influence, 3=no influence, 4=little positive influence, 5=considerable positive influence.

[a] The subdomains 'Partner' and 'Finance' were differently rated by participants with and without partners. T-test analyses showed that participants with a partner rated 'Partner' more negative (mean 2.20 versus 2.80; $p<0.001$) than participants who were single, while participants who were single rated 'Finance' more negative (mean 1.59 versus 2.42; $p=0.014$) than participants with a partner regarding the perceived influence on their QOL.

influence particularly for 'finance' (M=2.02, SD=0.83) and 'cognitive symptoms' (M=2.03, SD=0.59) to a positive influence for 'positive coping' (M=4.42, SD=0.26) and 'social sharing' (M=4.16, SD=0.44). Of notice, 'finance' was rated more negatively by burn survivors who were single whereas 'partner' was rated more negatively by burn survivors with a partner, tentatively suggesting burn-related QOL may differ between life situations.

4.   Discussion

The purpose of this study was to conceptualize burn-related QOL from the patient's perspective in order to facilitate an idiosyncratic assessment that can inform clinical care. This study resulted in a hierarchical structure of burn-related QOL

showing a core distinction between vulnerability or barriers and resilience or facilitators of burn-related QOL. Vulnerability comprised a broad variation of aspects grouped into 13 meaningful subdomains clustered into five domains, i.e., psychological (trauma-related symptoms, cognitive symptoms, negative emotions, body perception, and depressive mood), economic (finance and work), social (invalidation/stigmatisation), physical (somatic symptoms, scars, and functional limitations), and intimate/sexual (partner, anxiety-avoidance) vulnerabilities. Resilience comprised two meaningful domains, i.e., positive coping and social sharing.

The 13 vulnerability subdomains showed partial overlap with prior studies. Problems in the physical domain, e.g., functional limitations, somatic complaints and scar-related problems, were put forward previously [3]. On the item-level, aspects such as fatigue appeared to be of relevance to physical functioning. A recent study showed that the assessment of fatigue in the burn population informs clinical practice [24]. The economic domain, comprising financial aspects and therefore closely related to return to work, partly confirmed existing evidence [25]. However, most attention in the burn literature concentrates on return to work as the primary outcome [26]. The current study revealed that those who return to their job may be faced with difficulties that need to be managed and that can be facilitated by professional support. The process and obstacles to work reintegration showed to be a relevant part of burn-related QOL of burn survivors.

Within the psychological domain, cognitive problems such as problems with memory and concentration, and difficulties to perform multiple tasks simultaneously have received little attention [10,27]. Cognitive problems, but also fatigue, may be associated with traumatic stress symptoms and depression, or may result from anaesthesia or the inflammatory response to the burns [28]. However, in general, cognitive problems and the underlying causes are rarely a topic of attention in clinical practice and research [24,28] despite their significance for functioning. Of notice, the extant literature on cognitive problems in burn survivors is mainly connected to electrical injury [29], while it was a problem area reported by individuals with a different aetiology in the current study. More research into disabling cognitive problems is needed.

Another notable domain that emerged from this study included intimacy and sexuality-related problems, which has not explicitly been mentioned as a core aspect of burn-related QOL [3]. Fear and avoidance relating to intimacy and sexuality was indicated to be a mutual problem in some couples. However, it is a topic that does not receive much attention by professionals [30]. Lately, the topic received renewed interest in the literature [31,32], but there is still scant evidence providing knowledge on risk factors such as inter-personal factors and scar characteristics. A first step to anticipate fear and avoidance among partners may be assisting the partner in touching the scars or applying a moisturizing cream on the scars before discharge from hospital [33]. It is important that health professionals are aware of these problems, are open to discuss these problems, and are able to offer prompt support or refer to specialized help.

Stigmatisation such as staring of others, people who are frightened by the scars, and others who make negative comments about the scars was found an important topic

affecting QOL. This is in line with the extant literature [9,11,15,34–38]. On top of these reactions, more subtle remarks which were labelled invalidation, were also reported. Invalidation comprised a variety of interpersonal problems that are more implicit, such as others who do not understand, feeling disappointed by others, and loss of friendships because of the accident. These reactions can cause suffering. Consequently, burn survivors may distance themselves from others, become angry, or suffer from suicidal ideation [38,39]. Supporting self-management skills (e.g., cognitive reappraisal or acceptance) may help to decrease invalidation [40]. However, also educating the social environment about the consequences of burns is important.

The two resilience domains, positive coping and social sharing, helped burn survivors adapting to the consequences of their injury. The highly perceived positive influence of these clusters on QOL indicates its importance for burn survivors. Positive coping, such as 'a positive state of mind', 'putting into perspective', and 'enjoying the little things in life' have been identified as a resilience factor in earlier studies [9–11,17,25,36–38,41–44]. In other burn studies, it has been indicated that social support is a way of positive coping [35,45] and associations with posttraumatic growth have been found [19,46]. The label social sharing has not been used earlier in the burns literature, but may be of interest to this population [18,47–49]. It refers to sharing one's experiences with peers and other people, and receiving support from them. It is a specific aspect of social support that involves sharing illness-related emotions or an emotion-eliciting event [39,50]. A study indicated that approximately 80% of trauma victims manifested the need to share their experiences and it has been shown to enhance psychological, physical, and social health [50]. However, shame and guilt can play a critical role in restraining social sharing of emotions [51]. Particularly these emotions may be prevalent in burn survivors with regard to scars and the burn event as indicated in this study. It may constitute an obstacle to share their experience. Further research examining these dynamics can inform clinical practice how to overcome adversities of burns.

A strength of this study includes the combination of qualitative and quantitative methods, which preserved the richness and individual variation of participants' views while minimizing the subjective interpretation of researchers. However, this study has also limitations. First, the project was ambitious in its aim to capture the full spectrum of burn-related QOL. The 99 statements about the impact of burns made the task difficult, as was acknowledged by approximately a quarter of the participants. Particularly participants who performed the task unsupervised at home had more missing data. This suggests that the card sorting had a high difficulty that required adequate explanation in some participants. Sorting the statements from negative to positive was judged frustrating when statements did not apply, for example partner-related statements in case the participant was single. It is important to note that a cluster that is rated less important on average by our sample with burns, can be of primary importance for an individual patient. This was tentatively indicated by comparing scores of participants with and without a partner. Third, a cultural influence in determining the clusters cannot be excluded despite the broad range of

statements included in this study. Finally, although a sample size between 10 and 20 persons was suggested to be sufficient [23] a resampling study involving 168 subjects indicated that a sample size between 20 and 30 may be required to increase the stability of the clustering [52].

This study can inform clinical practice to assess the individual needs for tailored help. The hierarchical structure of QOL may form the basis for the development of a screening instrument to promptly and exhaustively identify problems in different areas that bother the person with burns. The screening instrument can be applied during the first year post burn at several time points before an outpatient visit to assess care needs. Personalised computerised adaptive testing can be used to limit the burden of comprehensive testing by asking supplementary questions only when a patient reports problems in overarching domain. Identifying problem areas can help professionals and burn survivors to make problems and management skills overt and may limit the risk that problems are overlooked. Topics that are difficult to discuss, such as sexuality, might be less often neglected this way. The overview of vulnerability and resilience factors can help health professionals to estimate patients' self-help capacity and need for professional help. The domains found in the current study can also be used to develop a face-to-face or online self-management support intervention with different optional modules customised to the individual needs, preferences, and values of the patient. This is in line with self-determination theory [53], which assumes that when an intervention is customized to the individual needs, preferences, and values of the patient, the patient will be more motivated, adhere better and benefit more and for a longer time. In assessment, the hierarchical overview of burn-related QOL can also inform adaptations of existing burn-specific health instruments.

5. Conclusion

The conceptualisation of burn-related QOL from the patient's perspective comprised a variety of vulnerability and resilience factors which provides a fresh basis for a screening instrument in clinical practice. It revealed under-addressed topics such as cognitive problems, fatigue and intimate and sexual anxiety, that can inform the research agenda.

Conflict of interest

The authors have declared that there a no conflicts of interest.

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Appendix A

See Table A1.

Table A1 – The 99 statements of the clusters of burn-related QOL with the label of the cluster and the mean (M) and standard deviation (SD) of the perceived influence on health-related quality of life: range 1 (negative)-5 (positive).		
Cluster Statement	M	SD
Positive coping	4.42	0.26
Doing things with awareness	4.61	0.50
Empathizing with others	4.57	0.60
Being open to others	4.57	0.50
Feeling you can take on a lot	4.57	0.73
Standing up for yourself	4.65	0.57
Accepting yourself as you are	4.65	0.57
Thinking that the inside is more important than the outside	4.04	1.15
Gaining strength from spirituality or faith	3.96	1.02
Perseverance	4.96	0.21
Positive attitude	4.96	0.21
Being able to put things in perspective	4.57	0.51
Being able to enjoy people and things	4.70	0.47
Being able to make jokes about it	4.52	0.67
Having become a different person	3.78	1.09
Living one day at a time	3.78	1.24
Thinking it could have been worse	3.83	1.07
Social sharing	4.16	0.44
Sharing experiences with those who have been through it too	4.26	0.75
Being able to talk what is on your mind	4.39	0.72
Starting new and rekindling old relationships	4.09	0.90
Support and help from others	4.30	0.97
Being focused on beauty-enhancing treatment	3.74	1.14
Trauma-related symptoms	2.48	0.60
Fear of things that remind you of the accident (e.g. fire, smell, situations)	2.30	1.06
Reliving the accident	2.35	1.03
Heightened awareness of danger	3.00	1.31
Less able to carry out pleasurable activities	2.26	0.81
Cognitive symptoms	2.03	0.59
Memory loss	2.09	0.79
Concentration problems	1.74	0.75
Problems sleeping	2.09	0.90
Difficulties with multitasking	2.22	1.00
Negative emotions	2.10	0.62
Sadness and despondency	1.96	0.93
Feelings of guilt	2.26	0.96
Anger and irritation	1.78	0.85
Feeling vulnerable	2.39	1.12
Body perception	2.27	0.59
Seeing and feeling your scars is confrontational	2.30	1.02
Finding yourself unattractive	2.26	0.75
Being ashamed of your body	2.17	0.89
Wanting to hide your scars with clothes	2.23	0.87
Feeling insecure about your body	2.22	0.90
Thinking you look different	2.39	0.94
Depressive mood	2.41	0.46
The idea you are complaining	2.39	0.58

Table A1 (continued)		
Cluster Statement	M	SD
Fear of the reactions of others	2.68	0.72
Thinking you want to die	2.74	0.62
Ruminating over why it happened	2.00	0.91
Worrying about the future	2.39	0.94
Loneliness	2.22	0.85
Finance	2.02	0.83
The financial burden of the treatment	2.13	0.92
Negative effects on your financial situation	1.91	0.95
Work	2.48	0.37
No longer being able to work at your previous level	2.00	1.00
Adaptations to work (revised)	2.96	1.22
No desire to work anymore	2.52	0.73
Being able to build up work at your own pace (revised)	2.30	1.33
Lack of understanding from colleagues	2.61	0.94
Stigmatisation/invalidation	2.54	0.34
People being shocked by the scars	2.70	0.97
The effect of the accident on those around you	2.13	1.10
Not being able to go out without being recognized	2.87	0.63
Losing friends	2.26	0.96
Hearing from others that it could have been worse	2.43	1.04
Family and friends who don't understand	2.35	0.86
Being disappointed in others	2.26	1.10
People staring	2.57	0.73
People making negative comments on your scars or accident	2.52	0.79
People avoiding you	2.78	0.80
People pitying you	2.70	0.70
Being asked unwanted questions	2.78	0.90
Thinking that people need to look the other way if they don't want to see it (revised)	2.70	1.11
Somatic symptoms	2.17	0.48
Excessive sweating	2.48	0.79
Not being able to get rid of excess body heat	2.43	0.90
Side effects of medication	2.57	0.90
Weather conditions, e.g. heat, cold or dry air	2.22	1.13
Itch	2.04	0.88
Fatigue	1.65	0.78
Reduced physical fitness	1.78	0.80
Scars	2.15	0.52
Wearing pressure garments	2.48	1.16
Taking care of scars is time-consuming	2.57	1.41
Painful scars	2.17	0.83
Tightness of scars	1.91	0.79
Delicate skin	1.83	0.72
Skin that is sensitive to touch	2.04	0.83
Appearance of the scars such as colour and surface roughness	2.04	0.83
Functional limitations	2.39	0.69
Difficulties with mobility such as walking and cycling	2.39	0.78
Restricted movement in your hands	2.35	0.83
Restrictions in taking care of yourself, e.g. washing, dressing, shopping	2.70	0.88
Having to depend on others	2.13	1.01
Partner	2.53	0.46
Feeling safe to expose yourself to your partner (revised)	2.22	1.24
Support, understanding and acceptance from your partner (revised)	2.00	1.09
Strong relationship with your partner (revised)	1.83	0.83
Your partner's avoiding touching the scars	2.91	0.42
Your partner's becoming the carer (revised)	2.87	1.06
Reduced sexual desire of your partner	2.91	0.29
Your partner's fear of hurting you	2.96	0.64

Table A1 (continued)		
Cluster	M	SD
Statement		
Anxiety/avoidance	2.61	0.42
Avoiding kissing, hugging and touching	2.87	0.76
Scars inhibiting starting a new relationship	2.43	0.79
Reduced sexual desire in yourself	2.70	0.64
Fear of physical contact	2.65	0.94
Fear that your partner will find you ugly	2.57	0.59
Fear of no longer being able to have a sex life	2.52	0.79
Fear of losing your partner	2.61	0.58
Restriction of movement during sexual contact	2.65	0.71
Wanting to hide your scars for your partner	2.52	0.79

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