From qualitative data to a measurement instrument: a clarification and elaboration of choices made in the development of the Patient Scale of the Patient and Observer Scar Assessment Scale (POSAS) 3.0.

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All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by **Michelle Carrière, Lidwine Mekkink, Zephane Tyack and Marjan Westerman**. The first draft of the manuscript was written by **Michelle Carrière and Lidwine Mekkink** and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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ABSTRACT

Purpose: To clarify and elaborate on the choices that were made in the development of the Patient Scale of the Patient and Observer Scar Assessment Scale 3.0 (POSAS 3.0), based upon the rich information obtained from patients during focus groups and pilot tests.

Methods: The discussions described in this paper are a reflection of the focus group study and pilot tests that were conducted in order to develop the Patient Scale of the POSAS3.0. The focus group took place in the Netherlands and Australia and included 45 participants. Pilot test interviews were performed with 15 participants in Australia, the Netherlands, and the United Kingdom.

Results: We discussed the selection and wording of 9 included items. The merging 8 characteristics into 4 items was discussed. Finally, the reasons for exclusion of 23 characteristics are given.

Conclusion: Based upon the unique and rich material of patient input obtained, two versions of the Patient Scale of the POSAS3.0 were developed: the *Generic* version, and the *Linear scar version*. The discussions and decisions taken during the development are informative for a good understanding of the POSAS 3.0 and are indispensable as a background for future translations and cross-cultural adaptations.

INTRODUCTION

The role of health professionals is to determine the most appropriate treatment strategy tailored to the patient's opinion of the scar, the likely efficacious treatment options and the patient's preference. Previous research has demonstrated that patients and professionals may value characteristics of the scar differently, and also use different language when describing the same scar characteristics [1-3]. This complicates the communication between both parties. Due to these differences in perspective, language and operationalization, a complete and thorough scar evaluation should include both the professional and patient perspective of the scar. Patient-reported outcome measures (PROMs) address the latter and must be developed with the patient's insight[4][5].

In 2004, the Patient and Observer Scar Assessment Scale (POSAS) was the first scale to measure scar quality from the patient perspective (www.posas.org)[6]. The POSAS consists of two scales: the Patient Scale and the Observer Scale which assess two different perspectives of scar quality. The second version of the POSAS, which dates back to 2005, has been translated from the original Dutch and English versions into twelve additional languages and is now widely used[7]. This POSAS version has been described as the best available instrument for measuring scar quality in several systematic reviews because it has good measurement properties and includes both the patient and the professional perspective[8-11]. However, the main limitation of the Patient Scale in earlier versions of POSAS was that they were developed without input from patients. To address this point, a third version of the POSAS was developed ('POSAS 3.0') for measurements of scar quality in patients with all scar types[12]. *Scar quality* is defined as the visual, tactile and sensory characteristics of a scar[12-14]. In terms of sensory characteristics (*i.e.* symptom status), only local symptoms that are related to and experienced within the scar (*e.g.* itch) are captured within the construct *scar quality*. *Systemic symptoms* that are caused by the initial trauma or injury and are experienced in the body as a whole are not considered part of the construct scar quality (*e.g.* fatigue). During the development of the Patient Scale 3.0, we gained insight into the patient perspective of scar quality using focus groups

with individuals living with scars. In a separate publication, the method and process of the development of the Patient Scale 3.0 is described in detail[12]. In this paper, we clarify and elaborate on the choices that were made during the development of the Patient Scale 3.0, based upon the rich information obtained from patients. The rationale underpinning the selection, formulation and merging of included items is discussed. In addition, the reasoning behind the exclusion of scar quality characteristics is explained. This background information will inform future translations and cross-cultural validation studies.

METHODS

Two versions of the Patient Scale of the POSAS 3.0

Two versions of the Patient Scale 3.0 have been developed: 1) the *Generic version* (Appendix A), applicable to all types of scars, except linear scars; and 2) the *Linear Scar version* (Appendix B), specific for linear scars. The Generic version contains 16 items. The Linear Scar version contains the same 16 items, and one additional item referring to “widening or stretching apart of scar edges”. All items are rated on a verbal rating scale with five response options.

Development of the Patient Scale of the POSAS 3.0; concept elicitation

The development of Patient Scale 3.0 consisted of focus groups and pilot tests[12]. Six focus groups were conducted to identify all relevant characteristics relating to scar quality. Four focus groups took place in the Netherlands (the Red Cross Hospital in Beverwijk, and the Amsterdam UMC (location VUmc) in Amsterdam) and two in Australia (Royal Brisbane and Women’s Hospital in Brisbane). In total, 43 English- and Dutch speaking adults with different scar etiologies (*i.e.* scar caused by burns, surgery, trauma, necrotizing soft tissue infections (NSTI) or acne) participated in the focus groups (Table 1). Guided by trained moderators, the focus groups followed an iterative approach: topic guides and interview schedule were refined after each session. The aim of the focus groups was to identify all characteristics of scar quality that patients with scars considered to be important, as well

as all the different ways to describe these characteristics. A detailed description of the methods used during each focus groups can be found in a separate publication[12].

All focus groups were audio-recorded and transcribed *ad verbatim*. The anonymized transcripts were analyzed by MC, LW, and ZT using a thematic analysis[15]. During analysis, all characteristics mentioned by participants that related to the construct *scar quality* were extracted from the transcripts. Figure 1 presents 45 characteristics that were identified during the focus groups, categorized into biological and physiological variables (i.e. visual and tactile scar characteristics), and symptom status (i.e. sensory characteristics).

Item generation and refinement

Considering feasibility, acceptability, usability, and adoption[16] of the Patient Scale of the POSAS 3.0, it was important to keep the scale as concise as possible in order to optimize implementation in clinical practice. The POSAS is meant to be a readily assessable, quick, and user-friendly instrument that assesses the key attributes of scar quality. Therefore, the scale should only contain items that could be assessed by looking at and feeling the scar, without the need for objective measurement devices. Adhering to these requirements, 23 of the identified characteristics were formulated into 21 items, using the language that participants had used during the focus groups. This resulted in the first drafts of the POSAS3.0 Patient Scale, which were pilot tested on 15 patients in Australia, the Netherlands, and the United Kingdom. The Three-Step Test-Interview (TSTI) method[17] was used to test the comprehensiveness of the scale, as well as the relevance and comprehensibility of the included items. Some items were excluded, and some were merged together, reducing the total number of included items to 17. Revisions regarding wording and order were also made according to the comments of pilot test participants.

RESULTS

Included characteristics

Table 2 presents the 17 included items, accompanied by a definition, and example quotes by focus groups participants. The focus group participants strongly agreed on the relevance and wording of five characteristics: *colour, shine, hardness, itch, and dryness* (Appendix A, item 1, 2, 4, 11, 16). Consequently, these characteristics were not the main topics of focus group discussions during the development of the Patient Scale, and therefore they will not be further discussed in this paper.

Item selection and wording

Thickness and height

The characteristics *thickness* and *height*, and the subcategories *raised* and *sunken*, were used interchangeably during the focus groups. During the focus group discussions, we aimed to explore the difference between these characteristics. Most participants considered them to be strongly related. One participant with a burn and surgical scar stated: “*Everything that is raised, is automatically thick.*”. However, another participant with a burn scar demonstrated that a sunken scar can also be thick:

“*Mine is definitely sunken. I've had two, what is it called, debridements. That already took a fair bit away. Unfortunately between the two I had muscle die away from my calf, so they cut even more away. So my scar is definitely sunken, but it feels thicker than the rest of the skin around it.*”

As focus group participants did not have a clear preference for thickness or height, we included both characteristics as items in the drafts which were subjected to pilot tests. After the pilot tests, we decided to include one item about the degree to which the scar is *raised* or *sunken* compared to normal skin (Appendix A, item 3), because participants found these categories the easiest to understand and assess.

Hypersensitivity and insensitivity

The characteristics *hypersensitivity* and *insensitivity* are both included as individual items in the Patient scale (Appendix A, items 6 and 7), because many participants experienced both sensations in the same scar. Participants with linear scars described the insensitivity or numbness in their scar as a “weird feeling”, which did not really bother them. On the contrary, it was reported as impacting on the daily activities of some participants with traumatic and burn scars (Table 2).

Pain

Pain (Appendix A, item 8) was experienced differently among participants with different scar types. Participants with linear scars noted that their pain was provoked by pressure on the scar, for example by a bra strap, as described in the example quote in Table 2. One participant with keloids explained that pain felt like, “...stinging from the inside of the scar”. Other participants with burn scars noted that their pain was provoked by stretching of the scar. Furthermore, many participants mentioned that pain was triggered by both cold and warm environments. Due to the highly variable description of pain in participants, it was decided to not specify the item ‘pain’ any further. We acknowledge that the most complete form of assessment of *pain* would encompass the nature, frequency, intensity and duration. However, in the prospect of keeping the Patient Scale as concise as possible, this was determined infeasible for the item *pain*, as well as for all the other sensory items. Therefore, it was decided to include only one question regarding the degree to which pain is present within the scar. As a result, the patient’s answer to this question may be dependent upon their subjective interpretation, the weight which they apply to influencing characteristics (e.g. the weather), and their perception of all dimensions (nature, frequency, intensity and duration). However, the POSAS is meant to assesses the key attributes of scar quality, of which pain forms but one component. If professionals were particularly interested in the different patterns and dimensions of pain, a pain-specific questionnaire in addition to the POSAS 3.0 Patient Scale could be utilized, for example, the McGill Pain Scale[18].

A shooting or stinging sensation

Participants explained that they experienced a shooting or stinging sensation in their scar. They described it as, “...a brief sensation as if someone sticks a needle in your skin” (Table 2). During the focus groups, we explored whether a *shooting* or *stinging sensation* could be merged with pain, but participants were decisive about it being an entirely different entity to pain or ‘pins and needles’. We decided to use the term, “a shooting sensation” (Appendix A item 9), because “a stinging sensation”, could easily be interpreted as well-localized, static, sharp pain, which would make it overlap with the item pain (Appendix A, item 8).

Tightness, pulling, and movement restrictions

The terms *tightness*, *pulling*, *contraction*, *flexibility*, *ability to stretch*, and *movement restrictions* were all mentioned as important characteristics by participants. These characteristics were highly valued by nearly all participants, but particularly by participants with scars caused by burns or NSTI. During the focus groups, the most popular terms were *tightness* and *pulling*. Participants differentiated between “tightness at rest” (Appendix, item 13), and “tightness with movement” (Appendix, item 14), as demonstrated in the following quote:

“...when I move my fingers, it is tight across all my knuckles and that is only when I am moving with my flexibility, but there are also spots that just pull tight all the time. They just feel tight, even though I am not moving.” (Participant with burn scars)

Furthermore, participants reported experiencing *movement restrictions*, or rather the inability to achieve the pre-injury range of motion in the scarred region. However, this characteristic refers to the health domain functionality and therefore falls beyond the scope of the construct scar quality.

Fragility

Participants described their scarred skin as *fragile skin* (Appendix A, item 15), which can be thin and breaks down faster and more easily than normal skin. They explained that the insensitivity (Appendix A, item 7) also contributed to damage of the skin, because participants did not perceive pain when

they sustained minor trauma. The characteristic *fragility* was often reported in combination with *prolonged wound healing* and *open wounds*. These three related characteristics were pilot tested, and participants favored fragility. Another reason to exclude the characteristic *prolonged wound healing* was that this could be caused by underlying issues unrelated to scarring (e.g. diabetes or vascular diseases).

Widening of scar margins

Participants with linear scars considered the width of their scars to be an essential characteristic of the quality of the scar, and therefore it had to be included in the final scale (Appendix B, item 6). Initially, our goal was to develop one universal Patient Scale for the assessment of all scar types. However, the item referring to the “widening or stretching apart of scar edges” was unique to linear scars, and participants with other scar types did not understand or recognize this characteristic with respect to their own scar. Therefore, the research team decided to develop two versions of the Patient Scale 3.0, one version for the use in all non-linear scars (*Generic version*), and one specifically for the use in linear scars caused by trauma or surgery (*Linear scar version*).

Merging of characteristics (Appendix A, items 5, 9, 10, 12)

To avoid overlapping items within the scale, focus group and pilot test participants were asked to compare characteristics that seemed similar, and to describe them in their own words to find potential differences between them. In this way, the possibility of merging characteristics was explored. An example of such merging can be found in the item *irregularity of the skin surface* (Appendix A, item 5). During the focus groups, participants reported different types of imperfections of the skin, which they described as, “bumps”, “lumps”, “ridges”, “folds”, and, “criss-cross or diamond-patterns”. In the final focus group, participants were asked if these characteristics could be captured within the item *irregularities of the skin surface*. Initially, they did not agree to this proposal, because it was unclear what irregularities of the skin surface really meant. This ambiguity was solved by providing the different descriptors as explicit examples to the item *irregularities of the*

skin surface. During the pilot tests, the different types of irregularities were tested as four individual items, as well as one merged item. Participants reported that they preferred the merged item, because it reduced the overall complexity of the item due to the examples provided.

During the focus groups, the following sensations were mentioned by participants: *tingling*; *pins and needles*; *electric shocks*; *a shooting sensation*; and *a burning sensation*. Participants reported different triggering stimuli for *a shooting sensation* (e.g. associated with stretching and unexpected contact) and *a burning sensation* (e.g. often described as a persisting sensation). In addition, participants pointed out that they did not always occur simultaneously. Therefore, we decided to include *a shooting sensation* (Appendix A, item 9) and *a burning sensation* (Appendix A, item 10) as individual items in the final scale. We chose to exclude the term, “*electric shocks*”, to avoid confusion with the overlapping item “*a shooting sensation*”. Two of the aforementioned sensations, *tingling* and *pins and needles*, were used interchangeably by participants during their descriptions. These sensations were explained as, “*a sensitive wave through scars on the entire body*”, and, “*a pull, funny feeling and a sprinkling of pins and needles at the same time*”, and were associated with itch, hot or cold environments, and emotional moments by participants. Based on the context-dependent usage of the terms, it was felt that *tingling* and *pins and needles* were different expressions of the same underlying characteristic. For this reason, they were combined within one item (Appendix A, item 12).

Excluded characteristics

Twenty-three of the identified characteristics were excluded from the final versions of the Patient Scale. Table 3 provides an overview of the excluded characteristics, accompanied by the reason for exclusion and the phase of development in which this occurred. To clarify the characteristics, quotes from focus groups participants are provided. Based upon how scar quality was defined (see Method Section), systemic sensations (i.e. symptoms caused by the initial trauma or injury that are

experienced in the body as a whole) were excluded. Fatigue was described as the most debilitating scar consequence by the majority of participants living with burn scars, independent of the duration of the scar's presence. Participants discussed, in detail, the irreversible effect that burn scars had on their energy levels, and the inability to return to the regular hours of work that preceded the burn incident. Fatigue was described as the, "...invisible side-effect", of living with burn scars, which engendered a lack of understanding from other people.

The characteristic *stitch/staple marks* was excluded because participants did not consider them relevant enough to include. These marks were explained as: "*white stripes*", aligned next to the (linear) scar. When the focus group moderator asked the participants if this was relevant to them, every participant who had these marks replied that they considered them as part of the scar and were not bothered by them. Based upon this information, the steering committee decided during item generation to exclude *stitch/staple marks*, because they were automatically considered as part of the scar and its characteristics were already being evaluated using other included items (*e.g.* color and thickness).

Items referring to the dimensional magnitude of a scar (*e.g. length, size*), rather than characteristics relating to the quality of a scar, were also excluded. Although the size of a scar is without doubt important to patients, most professionals using the POSAS will assign patients a specific area of interest of a large scar to assess for a specific clinical or research purpose.

The characteristic *scar growth*, indicative of the benign proliferative growth of keloids, was excluded because this item could not accurately be measured by looking and feeling the scar at one moment. Keloid growth would be established by comparing the current size to the size of the original lesion, but the exact size of the original lesion is often not precisely known (not even by patients themselves). Also, follow-up measurements would entail measuring keloid size, which could be measured more accurately using "objective" measurement devices.

DISCUSSION

At the time of its introduction, the POSAS was the first scar assessment scale to recognize the importance of systematically assessing the patient perspective by developing a separate patient-reported scale including important characteristics of the scar, including scar symptoms. To date, the POSAS remains to be the only instrument which combines the perspective of the patient and the professional on scar quality within one assessment tool. To further improve content validity of the Patient Scale, the POSAS3.0, was developed through the input of a large number of individuals living with scars. The current paper describes the discussions that took regarding the selection and formulation of scar characteristics. The content of the Patient Scale 3.0 arose from the data collected and will continue to support future translations, cross-cultural validations and implementation in clinical practice.

Qualitative studies are essential in PROM development to establish the relevance and comprehensiveness of the content, as well as to make sure the formulation of the included items, answering categories, and instructions included in the scale are understood by patients in the intended manner[19]. In the field of scars, five PROMs, including the Patient Scale 3.0, were developed on the basis of qualitative data obtained by interviews or focus groups with the target population[20-23]. When comparing these instrument to the Patient Scale 3.0, several differences can be noted. First, all scales measure different constructs. The POSAS focusses strictly on scar quality, whereas other PROMs measure different health domains, such as health-related quality of life (HRQOL)[20; 21], consciousness and satisfaction regarding appearance and symptoms[23] and psychosocial functioning[22]. Second, the POSAS3.0 was developed for adults with all scar types, whereas the other PROMs have different target populations: children and adults with burns scars[21], surgical scars[20; 23], and a combination of burn, surgical and traumatic scars[22]. Third, the number of included items differ between the PROMs. The POSAS is the shortest instrument, counting 17 included items, whereas the others range from 29 to 66 included items[24; 25]. As time constraint is one of the most important barriers for PROM implementation in everyday, busy clinical

practice[26], it was an important goal to keep the POSAS concise, user-friendly, and quick to complete by including only the key attributes of scar quality and restricting the construct to local scar symptoms. This makes the POSAS suitable for use in practice that extends beyond research. For example, in cancer care, PROMs that focus on symptoms rather than HRQOL are often used as a substitute to clinical encounters and function as a screening tool to prompt professionals to discuss identified problems with patients or offer support for symptom management[27].

The strengths and limitations of the development of the POSAS3.0 Patient Scale were discussed in a previous paper[12]. In brief, strengths referred to the combination of deductive[13] and inductive methods used in our study. Furthermore, the lead author was present in all focus groups and the multidisciplinary steering committee was composed of qualitative, clinical and clinimetric experts[28]. An additional strength was that patients had input into all phases of the development process and were enthusiastically engaged. In all focus groups, but particularly in the burn and NSTI groups, we experienced synergy and bonding amongst the participants. Participants exchanged their experiences, personal difficulties, tips for coping and treatments. For example, participants discussed a feeling of “survivorship”; scars were a reminder of their strength, since they had overcome traumatic and sometimes life-threatening situations, as previously described by Brewin and Homer[29]. Additionally, partaking in the focus groups also provided new insights. For example, one participant noted that, up until the focus group discussion, he had never recognized that excessive sweating could be part of his injury. Furthermore, participants mentioned that it felt good to give something back to healthcare professionals and to share experiences with a peer group with similar problems.

As described earlier, it was an important goal to keep the scale as concise and user-friendly as possible to promote implementation in clinical practice. Additionally, we aimed to develop a generic scale, suitable for measurements scar quality in different scar types. Consequently, characteristics

that were not applicable to the general scar population or were not considered relevant enough by participants were excluded (e.g. allergic reactions or ingrowing hairs). These characteristics were already excluded at the beginning of phase 2 (i.e. item generation), whereas it may have been more appropriate to have them (pilot)tested first before excluding them.

During the focus group discussions, several important characteristics emerged which did not fit the construct scar quality, but which were nonetheless deemed important by participants. We identified influencing factors, both individual and environmental, that played a role in scar quality. Individual influencing factors included scar location, emotions, movement, mood, self-consciousness, motivation, and behavior. Extreme temperatures, both cold and warm, as well as temperature changes, were mentioned as influential environmental factors, making scars more red, fragile, itchy, painful, tight, and causing *pins and needles*. As identifying influencing factors was not the main focus of our study, it is most likely that additional factors exist. It is important that professional users of the Patient Scale are aware of these influencing factors, as they may have an indeterminate effect upon scoring. This is a prime topic for future study as the POSAS3.0 evolves.

Currently, field test data is being analyzed in order to establish the scoring algorithm, as well as the reliability, measurement error and responsiveness of the scales[30]. More information on how to obtain and use the POSAS3.0 scales can be found on our website (www.posas.org).

CONCLUSIONS

The Patient Scale of the POSAS is already widely used for assessing the patient perspective on scar quality. For the new version 3.0, an essential step has been taken by including the missing input from people with scars; this information was needed to improve the content of the scale according to the patient's needs. Based upon the patient input obtained, two versions of the Patient Scale 3.0 were developed: the *Generic* version, and the *Linear scar version*. The discussions and decisions taken

during the development are informative for a good understanding of the POSAS 3.0 and are indispensable as a background for future translations and cross-cultural adaptations.

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Appendix A. PatientScale_3.0_Generic.pdf

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Appendix B. PatientScale_3.0_LinearScar.pdf

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Table 1. Characteristics of participants and their scars included in the focus groups and pilot tests.

	Phase 1						Phase 2		
	FG 1 (NL)	FG 2 (NL)	FG 3 (NL)	FG 4 (NL)	FG 5 (AUS)	FG 6 (AUS)	Pilot tests (AUS)	Pilot tests (NL)	Pilot tests (UK)
Participants, <i>n</i>	7	6	6	9	8	7	5	5	5
Male	3	2	1	2	6	5	4	3	1
Female	4	4	5	7	2	2	1	2	4
Age in years, <i>median (range)</i>	50 (37-60)	48 (25-79)	38 (24-81)	38 (20-61)	43 (19-70)	44 (21-72)	25 (18-49)	53 (38-72)	34 (23-47)
Cause of scars*, <i>n</i>									
Burns	6			8	8	7	5	1	1
Surgery		4**	3					3	1
NSTI	2			1				1	
Acne		1**	1**						
Trauma		1	2						2
Other (piercing)									1**
Age of scars in years, <i>median (range)</i>	3.0 (1.0-37.0)	5.0 (0.5-11.0)	14.0 (0.5-18.0)	15.0 (0.5-35.0)	1.2 (0.1-3.0)	1.0 (0.1-3.0)	0.2 (0.1-1.0)	34.0 (0.5-56.0)	1.2 (0.3-6.0)
TBSA in %, <i>median (range)</i>	19 (10-67)	N/A	N/A	18 (2-68)	17 (1-60)	15 (1-33)	2 (1-16)	40	20
Location of scars, <i>n</i>									
Trunk		5	3	3				2	
Arm(s)	1	1		1			1		
Hand(s)							1		1
Leg(s)	1		3		3	1		2	1
Feet					1		1	1	
Face									2
≥ 2 locations***	5			5	4	6	2		1

FG: focus group, NSTI: TBSA: total burned surface area, SD: standard deviation, N/A: not applicable

* By “cause of scars”, the initial cause of the wound, which eventually resulted in a scar, is meant. If the initial wound was caused by burns and received surgery in a later stage, the cause of the scar is noted here as being burns.

** In phase 1, three participants had keloids, of which two were caused by acne, and one was caused by surgery. In the UK pilot tests, one participant had a keloid, which was caused by a piercing.

*** Nearly all of these 20 scars were extensive burn scars, of which six also covered the face.

Figure 1. Characteristics that were identified during the focus groups, categorized into two groups: (1) visual and tactile characteristics and (2) sensory characteristics. The sensory group is further subdivided into symptoms that occur within the scar, and symptoms that occur in the body as a whole (i.e. systemic). Characteristics that are marked grey were not included in the final version(s) of the POSAS3.0, Patient Scale.

Table 2. Included items, accompanied by a definition and example quotes provided by focus group participants.

Included items	Definition	Example quotes	Participant's scar type
Color (Appendix A, item 1)	The color of the scar compared to unaffected skin. For example, the scar can be lighter or more pink, red or purple than the unaffected skin.	Some parts are red, some parts have a normal skin color but I also have parts where there is just no pigment at all and that is the color pink.* My scar is very red and thickened.* I just have a white line.* Mine is very red, but I really make sure to never get myself into situations where I can be seen without a shirt on. So, in my case it's just the situation with clothes on, so that redness is irrelevant to me.*	Burn scar Linear surgical scar Traumatic scar Keloid
Shine (Appendix A, item 2)	The degree to which the scar surface looks shiny (i.e. glossy, smooth, reflective), compared to unaffected skin.	And my donor site was quite shiny My scar is very shiny and smooth. And because of that, it stands out.* But you keep the smoothness. I'm quite tanned now, but it's still smooth. But it's less red now, because I'm tanner, so it's less noticeable. But that shiny, it is there whether I'm white or sun tanned.*	Burn scar Traumatic scar Linear surgical scar
Height: Raised – Sunken (Appendix A, item 3)	The level of the scar surface compared to unaffected skin, which can be raised (higher) or sunken (lower).	It is elevated. More raised. Yeah, it is definitely not flat. “Mine is definitely sunken. I've had two, what is it called, debridements. That already took a fair bit away. Unfortunately between the two I had muscle die away from my calf, so they cut even more away. So my scar is definitely sunken, but it feels thicker than the rest of the skin around it” It's a little thicker, though. It is raised comparatively to the rest of the skin. So it's really like on top of it.*	Burn scar Burn scar Linear surgical scar
Hardness (Appendix A, item 4)	The degree to which the scar tissue feels harder and firmer compared to unaffected	My skin was hard, especially in the beginning, but skin therapy did make it smoother. That helped a lot.*	Burn scar

	skin. This makes the scar less supple and flexible.	<p>I did have a lot of hard scars, but they pretty much removed most of them.</p> <p>It has become much softer from treatment. Yeah, it is indeed still stiff, which is actually better. Not that it's necessarily hard. I would rather say stiff.*</p>	<p>Burn scar</p> <p>Keloid</p>
Irregularity of the scar surface (Appendix A, item 5)	The degree to which the scar surface looks and feels irregular, compared to the unaffected skin. Unaffected skin is usually smooth and consistently shows this relative uniformity across its surface. For example, the scar surface can appear 'bumpy', 'lumpy', with ridges, folds or diamond-patterned.	<p>I have hard, bumpy skin. I call that crocodile skin.*</p> <p>No, because the criss-cross pattern is not bumpy skin and people always ask if you sat on a patio chair. *</p> <p>I have ridges, it's not a strict one. It's like a bumper*</p> <p>And it is probably more wrinkly than bumpy right now. Just wrinkly, it's not so. Bumpy is a big, like a speed bump. It is not called a speed wrinkle.*</p>	<p>Burn scars</p> <p>Burn scar</p> <p>Burn scar</p> <p>Burn scar</p>
Sensitivity – Hypersensitivity (Appendix A, item 6)	The degree to which the scar feels more (abnormally) sensitive than unaffected skin when it is touched.	<p>It is a different sensation than you used to have that you are just not used to. Everything is just way over the top.</p> <p>It is hard to explain because it is numb and sensitive at the same time. It is numb to touch let's say with your hand, but if you even just touch it lightly with the tip of a needle and you would feel it through your whole leg.</p> <p>I would agree with sensitive to touch. Mine is more numb in general. I don't have to think about it that much, day to day just doing as I do. But let's just say if my dog walked past and just nick it with the tip of its tail, you would feel that tenfold.</p> <p>No, I just have more feeling. That it is very sensitive. Yes, if you accidentally hit it then it hurts more than normal skin.*</p>	<p>Burn scar</p> <p>Burn scar</p> <p>Burn scar</p> <p>Keloid</p>
Numbness – Insensitivity (Appendix A, item 7)	The degree to which the scar feels less (abnormally) sensitive or numb when it is touched, compared to unaffected skin.	<p>As a 16-year-old girl, I found it funny to stab my leg with the sharp side of a pen compass. "Look what I can do". That's how dead that skin is. *</p> <p>Numbness, that definitely plays into it. I sometimes marvel that you can have itching without feeling in the skin. I really don't feel anything, so you don't feel</p>	<p>Burn scar</p> <p>Traumatic scar</p>

		<p>the pressure. That's also kind of annoying with shaving now and then. Suddenly there is blood.*</p> <p>Yes, that [the feeling] is gone. That doesn't feel the same as elsewhere. On my foot I also have a scar and that's exactly the same, that's a little numb. It's like rubbing over a piece of nothing.*</p>	Linear surgical scar
Pain (Appendix A, item 8)	The degree to which pain is being experienced within the scar.	<p>I have pain from the scar itself and that again is related to pulling, tearing, chaps*</p> <p>Well, my scars on my shoulder are very sensitive, especially with pressure. When your bra strap hangs over it you really think... Yes, pain. And if it's cold then I really feel it. Then it pulls and then it's just really sensitive.*</p> <p>My main issue is the pressure when sleeping and you unknowingly turn over and lie on it. And then you wake up at night from the pain.*</p>	<p>Burn scar</p> <p>Traumatic scar</p> <p>Linear surgical scar</p>
A shooting sensation (Appendix A, item 9)	The degree to which a brief, sharp and stinging sensation is experienced in the scar.	<p>I still get it when I grab something in the wrong way. I have scars on my whole hand, it feels as if someone sticks a needle in my hand. This will last for about a minute and then it will disappear. But when it happens, my eyes are full of tears. It also happens when I buy a new ring, I really have to get used to it being there. It is different than pain.*</p> <p>I get up every morning and I stretch everything out and it stings like hell for a couple of minutes and just as quickly goes away and you will be all right for the rest of the day</p> <p>Stinging, very much so. I can occasionally squeeze my arm so terribly it is almost completely mush. That's because it stings. Totally different from tingling, doesn't fall under pain.*</p> <p>My nerves are damaged. It stings.*</p>	<p>Burn scars</p> <p>Burn scars</p> <p>Burn scar</p> <p>Traumatic scar</p>
A burning sensation (Appendix A, item 10)	The degree to which a burning sensation is experienced in the scar.	<p>I explain it to others as if you have a very big scrape, and this I feel all of the time, so now as well.</p> <p>I still get a burning sensation.</p>	<p>Burn scar</p> <p>Burn scar</p>

<p>Itch (Appendix A, item 11)</p>	<p>The degree to which itch (uncomfortable, irritable sensation that causes a desire to scratch) is experienced in the scar.</p>	<p>Itchy is a big one for me. I know when itch gets to the point of no return and that's when I get the ice or the lidocaine crème. That's recently. Particularly when I am tired, I am up to late, and I have been sitting still for a long time that when I get it.</p> <p>Oh my god, last night I was lying in bed and I said to my wife, Jesus, can you scratch my leg. She was scratching my leg and oh god it was so itchy. I was thinking god I need this to stop. No pain, just itchiness, really bad itchy.</p> <p>You can't satisfy the itch</p> <p>My scar on the left itches. A scar. You try scratching that, it won't work. Not a nice feeling, let me tell you. It goes away for a while, but then it keeps coming back. Always in the same place. And those scars are thin, of course, that skin.*</p> <p>And mainly itching, it itched a lot. They didn't help me [scar revision] because I didn't like the appearance. But I was really bothered by it, itching and pain.*</p>	<p>Burn scars</p> <p>Burn scars</p> <p>Burn scars</p> <p>Linear surgical scar</p> <p>Keloid</p>
<p>Tingling and pins and needles (Appendix A, item 12)</p>	<p>The degree to which the sensations tingling, and pins and needles are experienced in the scar. These sensations can feel like a sensitive wave through scars.</p>	<p>I wrote down tingling. Do you guys recognize that? It can also be due to blood flow. It also depends on the temperature. When it's warm it doesn't bother you as much, but when it's freezing it bothers me a lot.</p> <p>Does anyone have pins and needles that just come in waves, just like bloop! That was it. Through the body, you get all sort of pins and needles and you get oeh. Yeah, especially when I am going sleeping, you just sleeping away and then suddenly it is like ahh. No, mainly in the burns. you wouldn't feel it anywhere that is not burned. Just go through the burns as a wave.</p> <p>I've noticed when I get that funny feeling, that wave, it is often an emotional moment. When I get emotional about things, like when my grandson walks in, boom, it hits me. Every time I feel emotional about something. Especially happy I get that whole wave. Yes, it is sensitive. Pin and needles are very sensitive. I feel them here and there and there. It's a combination. It is like, the best way I can describe is like putting an Elastoplast on it and then go on like that, it pulls. It's like a pull and funny feeling and a sprinkling of pins and needles at the same time. All that together.</p>	<p>Burn scars</p> <p>Burn scars</p> <p>Burn scars</p>

		Tingling is of course because my nerves are damaged, but yes it does bother me.*	Traumatic scar
Tightness (Appendix A, item 13)	The degree to which a tight or pulling sensation is experienced within the scar.	<p>It's like you are wearing a jacket that is too tight.*</p> <p>When I move my fingers, it is tight across all my knuckles and that is only when I am moving with my flexibility, but there are also spots that just pull tight all the time. They just feel tight, even though I am not moving. If that makes any sense.</p> <p>Pulling the skin. Obviously, a whole chunk of my back is gone. That also makes sense of course.*</p>	<p>Burn scars</p> <p>Burn scars</p> <p>Linear scar caused by surgery</p>
Pulling tight with movement (Appendix A, item 14)	The degree to which the scar pulls tighter with movement.	<p>When I first started physio, the stretching and you get that stinging feeling when they are really stretching it out. And I still get it every morning when I wake up, my leg is relaxed and during my first couple of steps you can really feel it stretching down your whole calf I guess just because the skin is relaxed again and the scar is contracted a big overnight and when you get up that first stretch kind of pulls it all out.</p> <p>The pulling of the skin was THE problem at the beginning because I couldn't go any further than this. And I couldn't possibly reach my shoes. But over the course of time, I also lost 5 kg in that period, and now it's already been gained back. So, there is fat formation under the scar and I also feel that the scars move much more, are more loose. Before that they were really tight on the muscle. But over the course of time, it's clearly diminished. Now I can bend over indefinitely. At the beginning I was surprised at how strong the skin can be, that you never thought, "Well, I have to be careful because I'm going to tear it apart".*</p> <p>Pulling. Especially with my surgical scar, because it [my scar] was on the abdomen and that wasn't so convenient.*</p>	<p>Burn scars</p> <p>Scars caused by a necrotizing soft tissue infection</p> <p>Linear scar caused by surgery</p>
Fragility (Appendix A, item 15)	The degree to which the scar is more fragile (i.e. vulnerable to trauma), which makes the skin break down more easily than unaffected skin.	Even now, I kicked a milk crate last week and I looked down and my whole boot was covered in blood. Just from kicking a little plastic milk crate, and I remember when I did it and I had a little tear in my eye. It was just a little milk crate that is ridiculous. It is just different than it used to be, you just have to be a little bit more protective. Baby skin.	Burn scar

		<p>I was playing with my nephew the other day and he was sitting in between my legs and he was rubbing my leg with his little fingers. When I looked a little bit later I had a wound just because he had been in the same spot for a minute. So, it really does break down that quickly. And it takes a very long time before it is healed.*</p> <p>I do have super super fragile skin. Pretty much any shoe will rip my foot open, if I go out in heels, it is not a good time.</p> <p>I played sports a lot, so I had a special cast made to stop the field hockey ball [from hitting my shin]. I am very carefully with it because it hurts a lot if something bumps into it. It might also be a little more susceptible to it breaking down faster. But if just one person would bump into it, it hurts a lot. Because it's directly on the shin. I would literally put fragility down here*</p>	<p>Burn scar</p> <p>Burn scar</p> <p>Traumatic scar</p>
Dryness (Appendix A, item 16)	The degree to which the scar feels dry when it is not moisturized.	<p>I moisturize 3 times a day to prevent dryness, as well as my sprays, because I can feel when I haven't had it. When you put it on your skin is just like ahhhhh thanks. I call moisturizing feeding my skin and I call spraying drinking. I feel my skin just relaxing afterwards.</p> <p>Yeah, dry skin. For sure.*</p>	<p>Burn scar</p> <p>Linear surgical scar</p>
Widening – Stretching apart (Appendix B, item 6)	The degree to which the edges of a surgical scar (i.e. linear scar) look stretched apart or widened, compared to direct after surgery. Scar widening makes the scar bigger as a whole.	It's quite a wide scar, I think. It was a little narrower, but it has gotten a little wider. There was also an infection in the wound and that piece is wider than the rest. I think that's ugly*.	Linear surgical scar

*Quote has been translated from Dutch

Table 3. Excluded characteristics, including the reason for exclusion, the phase in which it was excluded and an example quote provided by focus group participants

Characteristic(s)	Reason(s) for exclusion	The phase of the development process	Quotes	Participant's scar type
Thickness	-Overlap with the item <i>height (raised or sunken)</i> - Participants favoured the item <i>height (raised or sunken)</i>	Item refinement (pilot tests)	The most important thing for me is the thickness of the scar because that influences if you see it under your clothes or not. *	Keloid
Open wounds	- Overlap with the item <i>fragility</i> - Participants favoured the item <i>fragility</i>	Item refinement (pilot tests)	My skin is very vulnerable, very quickly damaged. Not specifically from dryness or chapping, but the slightest stub and there is a cut. This fragility is also very long lasting because if my skin is damaged that it takes forever. A normal scab doesn't form and it stays open and leaks fluids. Very annoying. *	Scar caused by a necrotizing soft tissue infection
Prolonged wound healing	- Could be easily caused by underlying issues unrelated to scarring (e.g. diabetes or vascular diseases)	Item refinement (pilot tests)	The wounds on my scar took 9 months to close. That was a long journey. But it happened. *	Burn scar
Strands - bands (contractures)	- Overlap with the items <i>tightness</i> and <i>pulling tight</i> - Participants favoured sensory consequence (<i>tightness</i> and <i>pulling tight</i>)	Item generation	Strand formation. Well, I don't have it so much anymore now, because I had it removed. I had one on my lower leg that completely pulled inwards because it was so tight. Consequently my foot was pulled inwards because there was just so much tension on the scar. *	Burn scar
Retraction of skin	- Overlap with the items <i>tightness</i> and <i>pulling tight</i> - Participants favoured sensory consequence (<i>tightness</i> and <i>pulling tight</i>)	Item generation	The scar has tightened and at this age almost everyone has a fat roll there [stomach] and that hangs down over it [the scar]. You see it. *	Linear surgical scar
Growth of scar tissue	- Would encompass size measurement - Need for baseline/multiple measurement(s) - Difficult to subjectively rate on a scale, need for objective device	Item generation	Most scars have just developed spontaneously. Those also keep growing. They are being treated every six weeks to contain them. Otherwise they keep growing. *	Keloid

Softness - Smoothness	Not considered to be relevant by focus group participants	Item generation	It feels kind of smooth or soft. I don't really notice it, but lots of other people if they touch my skin, it is really, really, soft compared to other skin.	Burn scar
Length – Size	- Dimensional characteristic that is not an intrinsic scar quality	Item generation	Well it [my scar] is long, it runs from the front to the back. And it is also thicker because I have been operated twice there. *	Traumatic scar
Stitch marks	- Not considered to be relevant by focus group participants - Considered to be part of the scar and can be measured using other items (e.g. colour or height)	Item generation	Now it is a really thin scar with holes, because you can see where the staples have been. Those looks like white dots, a real scar. The scar itself is really thin, and you can see the white dots on it. *	Linear surgical scar
Restricted movement	- Part of the construct “functionality” and therefore falls beyond the scope of the construct <i>scar quality</i>	Item generation	I have restricted movement on my face and neck. I can't, well I can, but it pulls my whole face down. And then this arm as well, I had a surgery last year, so it is a lot better, but I wasn't able to move my hand down like that, my fingers would be pulled back. That's better, but still pretty tight and restricted.	Burn scar
Sun sensitivity	- Dependent upon sun exposure (e.g. climate, time of year) and topographic scar location	Item generation	Oh and this I find also so annoying in the summer. I always used to wear a sleeveless shirt. That is not possible anymore. My entire back was burned second-degree. So if I walk in the sun now, blisters will form on my back. * I cannot withstand the sun, and that is a major point for me because I love the sun. Well, I can withstand it but I have to be very careful. And that I find an issue. Last year I was at the beach in Brazil with my baby and was very careful with both his skin and my own skin, and was almost unable to enjoy myself. So I was basically the whole entire time rubbing it in. *	Burn scar Burn scar
Discomfort	- Overlap with <i>hypersensitivity</i> and <i>pain</i> - Too non-specific for scars	Item generation	Sometimes when my T-shirt rubs on the scar it just feels uncomfortable. *	Linear surgical scar

Swelling	<ul style="list-style-type: none"> - Overlap with <i>height (raised)</i>. - Too non-specific for scars - Other causes possible 	Item generation	My hand was like a balloon the first two months.	Burn scar
Blood rush	<ul style="list-style-type: none"> - Overlap with the items <i>colour</i> and <i>pins and needles</i> - Too non-specific for scars 	Item generation	It's like you feel blood being pulled through your legs. *	Burn scar
Allergic reactions	<ul style="list-style-type: none"> - Only important to a small subset of scar patients - Insufficient applicability for the general scar population 	Item generation	For example, I cannot put my hands in detergent or soaps because then they get completely dry and blistered.*	Burn scar
Ingrown hairs	<ul style="list-style-type: none"> - Only important to a small subset of scar patients - Insufficient applicability for the general scar population 	Item generation	I have had hairs that grown underneath the skin. So you got a hair travelling around in there and I gotta get a needle under it and my son does it. Whips it out and then cuts the skin with a Stanley blade and pulls it out. I have at least 60 of those. And they are on the edge of the skin and the scar. And you think you just got an itch while it is actually a rotten hair follicle	Burn scar
Fatigue	Systemic sensation caused by the initial trauma or injury	Item generation	<p>Yes, that is actually the biggest [issue] that there is. My injury is now 10 years ago and I have never been able to work more than 16 hours [per week], despite the fact that I used to have a full-time job. More is not possible. You are also very vulnerable. For example, last week, I had the flu, and it takes ages for me to recover.*</p> <p>The outside world doesn't understand what burn wounds do to your energy, people expect a lot of you because they don't see anything from the outside (and the scars are so much better at this point). You don't see how active they still are, what is still going on inside of your body. For me, the loss of energy is bigger than the scar itself.*</p>	<p>Burn scar</p> <p>Burn scar</p>
Inability to lose heat	Systemic sensation caused by the initial trauma or injury	Item generation	Because I am unable to lose heat, I always want to be close to a swimming pool in the summer.*	Burn scar

Feeling cold	Systemic sensation caused by the initial trauma or injury	Item generation	I am terribly cold. No matter what, I can't get warm. Despite the fact that I have a quite some fat, I am always cold. The scar can be intensely cold, really super cold. The scar is cold and you are also uncomfortable*	Burn scar
Change in sweating	Systemic sensation caused by the initial trauma or injury	Item generation	<p>There are all full-thickness scars everywhere, so I just sweat more from the head and the legs. Yeah, my legs aren't burned because I had jeans on, and my head isn't. So I sweat more from my legs and my head. It is making up for everywhere. And I always have like a sweatband on my arm, because I have this little strip that isn't burned so I always have sweat in my shirt and in my garment when I wear them.</p> <p>Yeah, I am the same. And it's not even hot, it could be like cool and yet I will be sweating, just thinking what is going on?</p>	<p>Burn scar</p> <p>Burn scar</p>
Changed body odor	Systemic sensations caused by the initial trauma or injury	Item generation	My scent, my scent is gone. I liked how I smelled, but I don't have a scent anymore. Of course it is logical, but I do think it is a shame.*	Burn scar
Thirst	Systemic sensations caused by the initial trauma or injury	Item generation	I have a terrible desire to drink water, in all sort of situations. I have a bottle with me constantly. I often need water, for example when something is exciting. I definitely did not have this before.*	Burn scar

*Quote has been translated from Dutch