

The CARE Burn Scale—Adult Form: Translation and linguistic validation into Finnish

Noora-Ilona Lahdenperä^{a,*}, Jussi P. Repo^b, Eeva Aartolahti^c, Philippa Tollow^d, Catrin Griffiths^d,
Diana Harcourt^d, Jyrki Vuola^a, Andrew Lindford^a

^a Helsinki Burn Centre, Department of Plastic Surgery, Helsinki University Hospital and University of Helsinki, P.O. Box 800, FI-00029 HUS Helsinki, Finland

^b Department of Surgery, Central Finland Hospital District, Keskussairaalantie 19, FI-40620 Jyväskylä, Finland

^c Faculty of Sport and Health Sciences, University of Jyväskylä, P.O. Box 35, FI-40014 University of Jyväskylä, Finland

^d Centre for Appearance Research, Department of Health and Social Sciences, University of the West of England, Frenchay Campus, Coldharbour Lane, Bristol, BS16 1QY, UK

Noora-Ilona Lahdenperä ORCID: 0000-0003-0234-140X

Jussi Repo ORCID: 0000-0002-4688-5698

Eeva Aartolahti ORCID: 0000-0003-2938-926X

Andrew Lindford ORCID: 0000-0002-1120-8160

Jyrki Vuola ORCID: 0000-0003-1692-2344

* Corresponding author at: Helsinki Burn Centre, Department of Plastic Surgery, Helsinki University Hospital and University of Helsinki, P.O. Box 800, FI-00029 HUS Helsinki, Finland. E-mail address: noora-ilona.lahdenpera@helsinki.fi

ABSTRACT

Background: Burn injury can dramatically deteriorate health-related quality of life. Effective burn care may minimize the impact of the burn injury and ensure optimal functional outcome. This requires continuous improvement in burn care and assessment of treatment results. The aim of this study was to translate, culturally adapt and linguistically validate the CARE Burn Scale—Adult Form, a burn-specific patient-reported outcome measure, into Finnish.

Methods: The translation process followed the International Society for Pharmacoeconomics and Outcomes Research guidelines consisting of forward and backward translations, pilot-testing and cognitive debriefing interviews of five burn patients, and proofreading before finalizing. The process involved expert panel meetings and continuous discussion between the developers of the Scale and the research group.

Results: In the forward translation 10 amendments were required. After the backward translation, 12 items were reworded. Cognitive debriefing interviews led to three alterations enhancing the comprehensiveness and accuracy of the translation. The translation was reviewed by burn occupational therapists for practicality, resulting in 12 modifications. Minor grammatical changes were made after proofreading.

Conclusion: The Finnish version is the first foreign translation of the CARE Burn Scale. It is equivalent to the original Scale and ready for psychometric validation with burn patients in Finland.

Key words: burn injury, CARE Burn Scale, patient-reported outcome measure, quality of life, translation

Introduction

Every year almost 1000 burns requiring hospitalization occur in Finland (incidence 17 per 100 000). The number of these burns has decreased in recent decades [1], whereas the survival of people with more severe burns has increased [2]. Burn injuries can significantly affect patients both psychosocially and physically. Burns and their resulting scars may cause functional limitations, weaken an individual's self-esteem and considerably reduce their overall quality of life [3,4].

For evaluating the effectiveness of burn care, the outcome measure of mortality has traditionally been used. However, modern day burn care is associated with high survival rates and thus mortality as a sole outcome measure gives insufficient information [5]. The quality of life after burn injury is a long-term outcome that provides a good indicator of the success of burn care [5,6] and is of course particularly important for the patient. Consequently, evaluating tools are required to assess the health-related quality of life (HRQoL).

So far, only a few studies have measured the HRQoL among Finnish burn patients. In those studies either generic HRQoL measures [7,8] or a non-validated Finnish translation of a burn-specific measure [9] were used. Burn-specific patient-reported outcome measures (PROMs) are, nevertheless, necessary since generic questionnaires only detect general health outcomes and fail to include all of the important aspects of burn-specific health needs [6,10]. Burn-specific PROMs that have been translated into Finnish according to a guideline-based translation process and validated do not yet exist. Therefore, there is a clear need to translate, culturally adapt, and validate proper measurement tools for burn patients.

The CARE Burn Scale—Adult Form is a new burn-specific PROM designed to assess burn patients' quality of life. The scale was developed in the United Kingdom by Griffiths *et al.* [11] in the Centre for Appearance Research (CARE), according which the scale was named after. The Scale consists of 14 subscales with 59 items of which 12 subscales with 45 items had satisfactory psychometric properties based on traditional analyses and a good fit in the Rasch model. A new burn-specific PROM was needed because the other existing ones did not cover all aspects of burn-specific quality of life. This PROM covers unique domains, such as trauma symptoms and positive growth, which other burn-specific PROMs do not contain [11]. For instance, trauma symptoms have been reported even 16 years post burn in one out of four participants [3]. In addition, positive growth post burn has been identified and associated with quality of life factors [3,12].

The aim of this study was to translate, culturally adapt and linguistically validate the CARE Burn Scale — Adult Form into Finnish following the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) guidelines in order to maintain the same measurement properties as the original scale [13]. The Finnish version of the CARE Burn Scale is the first foreign translation of the Scale and it will be used in assessing the HRQoL of adult burn patients with the ultimate aim of improving of burn care.

Methods

For this study adhering to the Declaration of Helsinki, the approval of Ethical Committee and research permit were received from the Helsinki University Hospital. In addition, the license to translate the PROM, the CARE Burn Scale— Adult Form, into Finnish was obtained from the

University of the West of England. The translation process, described in Figure 1, followed the ISPOR guidelines [13].

Firstly, two health-care professionals, native speakers of Finnish and fluent in English, performed independent Finnish translations of the CARE Burn Scale. The project manager was one of the two forward translators. The reconciliation into one forward translation was first completed by the two translators and thereafter the whole research group inspected the translation resulting in version 1.

Secondly, a professional translator, a native speaker of English and fluent in Finnish, translated version 1 back to English. The developers of the CARE Burn Scale reviewed this backward translation and commented on any items with wording discrepancy or with a change of meaning. Furthermore, a person from outside our research group (a native speaker in Finnish and fluent in English, a health care professional and Master of Arts) was asked to translate into English certain items that were considered to be mistranslated. The original version and the previous backward translation were of course not shown to the translator. Finally, the translation was harmonized by the expert panel consisting of our research group members, and led to the Finnish version 2.

Thirdly, pilot-testing and cognitive debriefing interviews were conducted to assess the feasibility, comprehensiveness and verbal clarity of the Scale from the patient's point of view. The interviews were carried out in the outpatient clinic of the Helsinki Burn Centre simultaneously with the patients' routine appointments (16.-30. Apr 2019) by the project manager. Prior to this, an outpatient clinic nurse went through the patient files selecting at least five patients who fulfilled the following criteria: a history of a deep second degree or third degree burn treated with skin grafting, adults aged 18 years and over, and fluent in Finnish. The nurse contacted by telephone suitable patients who met the inclusion criteria to recruit participants for the interviews. After the routine appointment, the interviewer gave information about the study both orally and in written form and the participants gave their informed consent to take part in the study. The participants were asked to 'think aloud' meaning that they should verbalize what the question is asking and to complete the questionnaire and identify words or phrases that were difficult to understand [14]. If the wording was unclear, the interviewer then explained the meaning of the word or expression to the participant and asked to provide an alternative, which would be easier and more understandable. After the interviews, the expert panel reviewed the results of the pilot-testing and cognitive debriefing interviews. Certain issues were discussed with the developer before making the required changes.

Outside our research group, two health care professionals (burn occupational therapists), proofread and inspected the translation for practicality and potential modifications. Thereafter, the research group members proofread the Finnish translation for any further corrections in order to finalize the Finnish version of the CARE Burn Scale— Adult Form.

Results

Forward translation

The two independent translations of the CARE Burn Scale into Finnish were quite similar and for the most part easily reconciled into one forward translation. However, 10 items were more complicated to translate in order to reach equivalence with the original Scale.

For five items, difficulty was experienced when translating a word or a phrase to retain the original meaning. For instance, in the expression '*I get upset*', neither of the independent forward translations was accepted. Yet, after discussions, the translators reached a consensus with a third alternative. Moreover, the item '*respected at work*' was easy to translate as such, but it is somewhat formal in Finnish, thus, it was translated into a Finnish word that in English means '*appreciated*'.

Because the meaning of the word 'family' differs in various cultures, the translation of four items concerning family was considered challenging. In the original English Scale two separate expressions '*close family*' and '*family*' are used. In Finnish the word '*family*' means parents, children, spouse and siblings, so, it means the same as '*close family*' in English. Therefore, the two translators agreed to use the translation '*family*' whether it concerns '*close family*' or '*family*'.

After reconciliation by the two translators, the expert panel approved version 1 of the Finnish translation of the CARE Burn Scale without any changes.

Backward translation

As a result of the backward translation from Finnish into English, 12 items were found to be problematic and needed re-translation as shown in Table 1. In some items, words were easily changed to match the original ones, whereas for other items finding the correct wording was challenging. A few items that were hard to translate, for instance due to cultural differences, had to be discussed thoroughly with the developers of the Scale and between research group members.

The developers were not satisfied with the use of the word '*family*' in all four items. Instead, they emphasized the difference between '*close family*' and '*family*', and explained that the word '*family*' is applied in the broader sense to include not only members of the '*close family*', but also aunts, uncles, and grandparents. For this reason, we added the Finnish words meaning '*family/close relatives*' to items 7.1 and 7.2, and the Finnish word '*family*' was used in items 7.3 and 7.4.

The developers of the Scale commented that '*respected*' and '*appreciated*' are considered different concepts. Therefore, the earlier translation '*appreciated*' in item 6.1 was changed into a Finnish word that means '*respected*'. In four items (10.1-10.4; Table 1), the word '*wound*' was added on the developers' request, to make clear that it also means the period of time before the wounds are healed.

Three items were discussed more thoroughly prior to amendments. In item 9.2 concerning scar appearance, the developers commented that the word '*noticeable*' in the original item means spontaneous noticing by others, whereas the back translated word '*visible*' implies noticing only when you choose to reveal your wounds or scars. The expression was changed into Finnish meaning '*that other people can see your wounds/scars*'. In item 10.5 the original word '*upsetting*' was back translated to '*distracting*', hence, the developer remarked that the former suggests psychological distress, whereas the latter is more related to attention. Thus, the developer clarified the word '*upsetting*' in this context, so that we could find the right Finnish translation without altering the meaning of the item. As a result, two different words were used instead of just one to achieve the same wide meaning as the developers had intended. The developers also commented that in item 12.4 '*feel short tempered*' is more a description of mood, whilst '*lose my temper*' in the back

translated version describes more of a behaviour. So, we changed the expression to match the original item.

Additionally, in order to get an independent review, five titles, instructions or items were translated by a second translator from Finnish into English, because certain words did not match correctly with the forward translation. For instance, in the original Scale '*because I have experienced a burn injury*' was first back translated '*because I have suffered a burn*', even though the Finnish word meaning '*suffered*' was not used in the forward translation. The second translator actually translated the items into English with the same way as they were in the original Scale.

Harmonization after the backward translation was accomplished by the expert panel meeting leading to version 2 of the Finnish CARE Burn Scale.

Pilot-testing and cognitive debriefing interviews

Five males aged 32 to 75 and native speakers of Finnish participated in the pilot-testing and cognitive debriefing interviews. Three of them had earlier sustained deep second degree burns, whereas two had mixed deep second and third degree burns. All participants had been treated with skin grafting and their wounds and scars were located in different parts of the body. Detailed demographic information of the participants in Table 2.

Pilot-testing and cognitive debriefing interviews with burn patients revealed three issues that required alteration in the Finnish version 2 of the CARE Burn Scale. Two participants were uncertain about what '*nerve sensation*' means. Thus, an explanation '*e.g. pins and needles, burning sensation, numbness, pain*' was added to the item with the approval of the developers.

The interviewer observed the participants while they completed the form and noticed that in one subscale concerning seven items, the '*Not applicable*' category was left unnoticed by two participants. Therefore, with the developer consent, we added a note which points out the '*Not applicable*' category for those whom the item does not concern.

Two participants were unsure how to answer the item '*I cover my burn wounds/scars with clothes/make-up*', because in their cases clothes are covering the wounds anyway, but they aren't covering them on purpose. So, this issue was discussed with the developers and the wording of the item was changed to '*I deliberately cover my burn wounds/scars with clothes/make-up*'. Hence, it is in line with the rest of the items related to the patient reaction to the burn, and with the developers' interpretation accordingly in which it refers to a deliberate covering of the wounds or scars.

Proofreading and finalizing

Burn occupational therapists identified several points that might need corrections while proofreading the Finnish CARE Burn Scale. On the basis of their comments, altogether 12 slight modifications were made in the expert panel meeting concerning better wording without changing the main idea of the items. Finally, the research group members proofread the Finnish translation and any remaining small corrections concerning grammar and spelling were made resulting in the final Finnish version of the CARE Burn Scale—Adult Form that is linguistically valid and equivalent to the original Scale.

Discussion

In the present study, the CARE Burn Scale—Adult Form was successfully translated, culturally adapted and linguistically validated into Finnish. The produced Finnish version is equivalent in content and comprehensiveness to the original English version. The present cross-cultural adaptation is the first foreign translation of the CARE Burn Scale. The Scale can be used to follow burn patients' therapeutic progress, to assess the results of burn treatments and to compare outcomes between burn centres leading to improvement in burn care [11]. As the Finnish version of the CARE Burn Scale—Adult Form accurately corresponds to the original version, it is thus now ready for psychometric validation with burn patients.

Only limited numbers of burn-specific PROMs for adults exist [6,15,16]. Legemate *et al.* [6] made a systematic review of the measurement properties of the HRQoL instruments for burns using the CONsensus-based Standards for the selection of health Measurement INSTRUMENTS (COSMIN) methodology and guidelines. The review in question covered 12 disease-specific HRQoL instruments. Of these instruments, the best measurement properties were found in different versions of the Brisbane Burn Scar Impact Profile (BBSIP) and the Burn Specific Health Scale-Brief (BSHS-B). The latter one of these has been used most often [17]. The 40-item instrument was developed in the Uppsala Burn Unit in Sweden by Kildal *et al.* [18] from the previous versions of the BSHS. The original BSHS was published in 1982 [19] and subsequently it has been abbreviated (BSHS-A) [20] and revised (BSHS-R) [21]. The other burn-specific HRQoL instrument that was discussed in detail in the systematic review of Legemate *et al.* [6] is the Brisbane Burn Scar Impact Profile (BBSIP) [22], which is scar-specific. However, none of these burn-specific HRQoL instruments have been found superior to the others. The recently developed CARE Burn Scale—Adult Form was not included in the review, because it was first published only after the literature search for the review had been carried out.

Publications focusing in particular on the translation process of PROMs have been emerging in plastic surgery [23,24], but to our knowledge, not until now of burn-specific HRQoL measures. For example, the BSHS-B has been translated and validated to at least 15 different languages [18,25-38], but the attention has been on the validation, whereas the translation process and the problems confronted have been in a minor role or not handled at all. Our detailed description of the translation process of the CARE Burn Scale with the difficulties encountered and the solutions found will give better understanding about the translatability of the Scale and hopefully help other translators in the future.

An advantage of the new CARE Burn Scale has been its development following standard guidelines for the development and validation of PROMs ensuring the reliability of the Scale. Another factor in its favour was the involvement of burn patients during the development of the Scale. This helps to ensure that the CARE Burn Scale includes essential issues of burn-specific quality of life. For instance, the BSHS-B, the most often used burn-specific HRQoL instrument, does not cover all the important aspects of HRQoL that are affected by burns as Gauffin and Öster [39] concluded in their study. Issues that were missing in the BSHS-B but are included in the CARE Burn Scale were the avoidance behavior and skin related problems such as cold sensitivity, pruritus, paresthesia, and pain. The CARE Burn Scale has also good measurement properties [11].

This study showed that the CARE Burn Scale was meaningfully translated into Finnish. For the most part, the Scale was translated without problems even though English belongs to Indo-European language family whereas Finnish is one of the Finno-Ugric languages, which means that they totally differ from each other for instance in word order and meaning structure [40]. However, certain issues concerning the translatability of the CARE Burn Scale into Finnish were noticed during the process. Translatability review categories are culture, language, and item construction [41]. Challenges posed by all of these categories were met also in this translation process. During the translation, there were similar problems in getting the original conceptual meaning of words as met in the translation process of BODY-Q meant for assessing results of bariatric and body contouring surgery [23].

Finnish words are typically long, but the tendency is to shorten them in both colloquial and official language. Also the use of English words is becoming more and more common in Finnish. As a combined example of these practices, we can mention the application of the word 'ok' in the Scale. As many as five of the occupational therapists' comments concerned the phrase '*It's ok*'. We had also discussed the use of '*ok*' in the Finnish version earlier during the process and considered whether it would be acceptable amongst the elderly as well. Our decision, including also the occupational therapists' opinion, was that '*ok*' is nowadays acceptable as such, because it is a loanword already completely adopted and incorporated into the Finnish language.

The presence of the interviewer was perceived to be necessary while testing the Scale with burn patients. The interviewer observed that the patients failed to notice the '*Not applicable*' category in seven items. Besides, a few issues required discussion between the patient and the interviewer while filling out the question form. We also gained information about items that can be misunderstood by the patients and could ask their own alternatives. In addition, the interviews confirmed issues that the translators had anticipated. As an example, the expression '*nerve sensations*' was not clear enough to some participants.

With the permission of the developers, we made a few minor modifications to the Finnish version that were not in the original Scale. However, we did not change the meaning of any items but only made the Scale more comprehensible. Our study focused only on the translation of the Scale, and the content issues will be considered later after the psychometric validation, which will reveal better how the Scale functions in practice.

The translation process followed the ISPOR guidelines accurately, although as an exception, we used a second backward translator for a few items that were assumed to have been mistranslated. Even though there are excellent English skills in our research group, even one native speaker, we wanted an objective opinion from a person outside the research group. The use of the second translator is a clear strength of this study, because it confirmed that the first back translation contained faulty wording and the forward translation was correct.

Another strength of our study is that the translation was performed in close collaboration with the developers of the Scale in all phases of the translation. Involving the developers in the process not only improved the quality of the translation and ensured that the items were understood correctly by the translators [13], but it also enabled the implementation of changes that deviated from the original Scale. Furthermore, one strength of this study is that our research group consists of health

care professionals with different backgrounds and also people with experience in translation processes. Additionally, input from the occupational therapists was valuable, especially because they work closely with burn patients at all stages of their care and often see their problems in practice.

All participants in our cognitive debriefing interviews were male which can be considered as a potential limitation. By coincidence, all participants who fulfilled the inclusion criteria during the interview period were male. This can be accounted for by the fact that in Finland, as in other western countries, male predominance (70%) with burn patients has been established [1]. The purpose of the cognitive debriefing interviews is to ensure that the translation is easy to understand [13], and in our opinion, gender does not influence the ability to assess the comprehensiveness of the translation. So, it is unlikely that adding a female participant would have altered the results. Consequently, it was concluded that the lack of females in the cognitive debriefing interviews does not affect the validity of the Scale.

Because we carefully followed the ISPOR guidelines in our translation process, clear further limitations are hard to identify. Nevertheless, the guidelines suggest that cognitive debriefing interviews should include 5 to 8 participants and we had the minimal amount, five. It is not known whether a higher amount of participants would have brought out additional information. However, the translation was assessed not only by participants but also by the members of our research group, and the scale is now sufficiently clear and comprehensible.

Conclusion

The CARE Burn Scale—Adult Form was successfully translated, culturally adapted, and linguistically validated into Finnish. The translated version will next be psychometrically validated in burn patients. After that, the CARE Burn Scale will be available for use in the Helsinki Burn Centre, which is the National Burn Centre of Finland. Other hospitals in Finland treating patients with smaller burns can also benefit from the CARE Burn Scale.

Conflicts of interest

None.

Funding

The only funding for this research was for the fee of the professional translator and it was received from the Musculoskeletal and Plastic Surgery Research Center Helsinki, Finland.

Acknowledgements

We would like to thank the following persons: M. A. and Bachelor of Health Care, Selja Riikonen for being the second backward translator, Senior Burn Nurse, Pia Tiimo, for selecting and recruiting patients to cognitive debriefing interviews, and Burn Occupational Therapists, Salla Lempiäinen and Anna Piironen, for their input in reviewing the translation.

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