



ORIGINAL RESEARCH ARTICLE

Finnish translation and linguistic validation of the FACE-Q Head and Neck Cancer Module

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ABSTRACT

Head and neck cancer (HNC) and its treatment can result in permanent changes to a patient's appearance, speaking, eating, and psychosocial well-being. To better assess the impact of the disease on HNC patients, the FACE-Q Head and Neck Cancer Module, a health-related quality-of-life instrument, was developed. The aim of this study was to produce and linguistically validate a Finnish version of the module. The module was translated into Finnish following the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) guidelines. A total of 51 patients who had undergone tumour resection and reconstruction of the oral cavity, tonsil, or tongue area between 2019 and 2021 were approached for a pilot study. They completed the translated module and provided feedback on any linguistic issues. Adjustments were made based on the pilot study comments. The FACE-Q Head and Neck Cancer Module translated well into Finnish. Twenty-one (41%) patients participated in the survey, 12 men (57%) and nine women (43%) with a median age of 66 years (range 48–89 years). The median time since surgery was 3 years (range 1–4 years). Based on the feedback from the pilot study participants, one word was changed, and one question was rewritten. Otherwise, no deficiencies were identified in the language of the module. In summary, this study produced a linguistically valid Finnish version of the FACE-Q Head and Neck Cancer Module, enabling its application in evaluating the health-related quality-of-life among Finnish HNC patients who have undergone reconstructive surgery.

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Introduction

Cancer located in the head and neck area is the seventh most common type of cancer globally [1–3]. Treatment of head and neck cancer (HNC) may involve tumour resection and reconstructive surgery of the surgical defect, frequently combined with non-surgical treatment, such as radiotherapy or chemotherapy [1, 4, 5]. Since this area contains several structures responsible for critical functions, such as speaking, swallowing, eating, and socialising, HNC and its treatments can disrupt these functions, resulting in challenges in daily activities [6–9]. Additionally, the impact of the treatment on aesthetically important structures as well as the psychosocial well-being can ultimately affect the patient's overall quality of life [6, 7, 10–12].



Several patient-reported outcome measures (PROMs) exist for the assessment of health-related quality of life in HNC patient's post-treatment, including the EORTC H&N35 and the UW-QOL [1, 11, 13, 14]. However, many of these surveys do not capture all the aspects relevant to HNC patients. In particular, several of the available PROMs focus on changes in functionality, such as swallowing and eating, but only a few address psychosocial aspects or appearance, both of which can have a significant impact on a patient's quality of life [13, 15, 16]. Furthermore, several measures were developed without any patient input, putting them at a disadvantage regarding the relevance and validity of their questions [13, 15].

To address the need for a more holistic PROM for HNC patients, the FACE-Q Head and Neck Cancer Module was developed [13]. It is a PROM specifically designed for this patient group and has currently been translated into seven languages, enabling the comparison of data between countries [17–19]. The questionnaire is divided into four domains covering facial appearance, facial functionality, psychosocial distress, and experience of care. It consists of 14 different scales, which can be used separately or together, allowing the selection of only relevant scales for each patient or research question [13]. This study aimed to produce and linguistically validate a Finnish version of the FACE-Q Head and Neck Cancer Module.

Materials and methods

Translation of the FACE-Q Head and Neck Cancer Module

The FACE-Q Head and Neck Cancer Module was translated into Finnish following the guidelines established by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) and in accordance with the Mapi Research Trust guidelines [20, 21]. Permission to translate the module was obtained from the license holder [17]. The translation process consisted of five steps (Figure 1). Initially, two separate translations of the original English module into a Finnish version were created by Finnish native speakers fluent in

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English and knowledgeable about the subject in question. Based on these two translations, a final coherent version was agreed upon. This coherent version was then translated back into English by a professional bilingual translator. The translated version was compared with the original module by the license holder and, based on the feedback, the Finnish version was created. Final amendments to the questionnaire were made following the pilot study comments.

Pilot study

Finnish-speaking patients who underwent resection and reconstruction of the oral cavity, tonsil, or tongue area at the Helsinki University Hospital between 2019 and 2021 were identified using theatre logs. Alive patients without advanced conditions affecting memory or cognition were included in the pilot study, conducted as a postal survey. The participants were asked to fill the newly translated Finnish version of the module. In addition, a section for commenting on any linguistic ambiguities, inconsistencies, or comprehensibility issues was added on each page of the module, enabling participants to comment on any language issues they identified while filling out the questionnaire. Furthermore, patients were allowed to suggest alternative phrasings and wordings, for expressions they found confusing or clumsy. Information on the study and a written consent form was included. A prepaid envelope for returning the completed module was provided. Patients who did not respond within 2 weeks were approached a second time.

Data processing

Data from the comments and suggestions regarding the language of the module and the answers to the FACE-Q Head and Neck Cancer Module scales reported by the patients were collected. The results from the pilot study were analysed according to the guidelines established by the module developer [13]. The scores for each of the 14 scales were collected separately. Scales with more than 50% of items unanswered were completely excluded from the analysis. Scales with fewer than 50% of the answers missing were supplemented with the average score of the completed sections of that same scale [13]. The total score for each scale was converted to a range from 0 to 100, using the published Rash conversion [13]. All data were analysed using SPSS (version 28.0.0) [22].

Ethics

Approval for the study protocol was granted by the ethics committee of Helsinki University Hospital, and the research permit was obtained from the division of Musculoskeletal and Plastic Surgery, Helsinki University Hospital. All participants provided written, informed consent.

Results

Linguistic translation of the module

The FACE-Q Head and Neck Cancer Module translated readily into Finnish. No major issues with either vocabulary or phrasing of the module were discovered throughout the five-step translation process. Based on the comparison between the original English and the back-translated questionnaire, no alterations were made to the Finnish version of the module.

Validation of the translation

Based on the feedback from the pilot study participants regarding the language of the module, two changes were made to the wording of the module (Table 1). The word 'self-conscious' ('*Itsetietoinen*' in Finnish), which was used in four of the 14 translated scales, was reported by several participants to be confusing and leaving room for interpretation. Based on this response, the word was changed to a synonym, 'vaivaantunut', which has a more negative connotation than the original translation. This term was changed in all four scales to clarify the intention behind the question. In addition, one question was rephrased based on a suggestion from one participant, making the question easier to understand. Otherwise, no further linguistic deficiencies were reported by the pilot study participants, in either wording or phrasing for instructions, questions, or answer options in the newly translated FACE-Q Head and Neck Cancer Module.

Pilot study

A total of 51 patients filling the inclusion criteria were identified and approached. Twenty-one (41%) of the approached patients returned the filled-out survey package with the newly translated FACE-Q Head

Table 1. Implemented language changes to the Finnish FACE-Q Head and Neck Cancer Module.

Item / Scale	The original English version	The Finnish version used in the pilot study	Pilot study comments	The Final Finnish version
Speaking	It is difficult to understand my speech.	<i>Puhettani on vaikea ymmärtää</i>	A suggestion from one pilot study participant, that made the Finnish version of the question more comprehensible.	<i>Puheestani on vaikea saada selvää</i>
Drooling distress	I am <u>self-conscious</u> about drooling.	<i>Olen <u>itsetietoinen</u> kuolan valumisen takia.</i>	The word 'self-conscious' was described as confusing in Finnish and was changed to a better Finnish synonym.	<i>Olen <u>vaivaantunut</u> kuolan valumisen takia.</i>
Appearance distress	I am <u>self-conscious</u> about how my face looks.	<i>Olen <u>itsetietoinen</u> siitä, miltä kasvoni näyttävät.</i>	The word 'self-conscious' was described as confusing in Finnish and was changed to a better Finnish synonym.	<i>Olen <u>vaivaantunut</u> siitä, miltä kasvoni näyttävät.</i>
Eating distress	I am <u>self-conscious</u> about how I look when I eat.	<i>Olen <u>itsetietoinen</u> siitä, miltä näytän syödessäni.</i>	The word 'self-conscious' was described as confusing in Finnish and was changed to a better Finnish synonym.	<i>Olen <u>vaivaantunut</u> siitä, miltä näytän syödessäni.</i>
Smiling distress	I am <u>self-conscious</u> about my smile.	<i>Olen <u>itsetietoinen</u> hymystäni.</i>	The word 'self-conscious' was described as confusing in Finnish and was changed to a better Finnish synonym.	<i>Olen <u>vaivaantunut</u> hymystäni.</i>

Table 2. Characteristics of the pilot study patients (N = 21).

Patient ID	Age (Years)	Sex (M/F)	Cancer locus	Time since surgery (Years)	Smoker (Yes/No)
1	69	M	Tonsil	3	No
2	71	F	Floor of mouth	4	No
3	77	M	Soft palate	2	No
4	64	M	Mobile tongue	3	Not known
5	68	M	Floor of mouth	3	No
6	51	F	Mobile tongue	3	Not known
7	58	M	Mobile tongue	1	Yes
8	55	F	Soft palate	1	No
9	68	M	Upper jaw	3	No
10	60	F	Mobile tongue	2	Yes
11	75	F	Tongue base	2	No
12	59	F	Tongue base	3	No
13	89	M	Mobile tongue	3	No
14	57	M	Mobile tongue	3	No
15	67	F	Mobile tongue	3	Yes
16	70	M	Tongue base	3	No
17	63	M	Subtotal tongue	3	No
18	53	M	Subtotal tongue	2	No
19	66	M	Subtotal tongue	2	No
20	71	F	Subtotal tongue	2	No
21	48	F	Upper jaw	2	No

and Neck Cancer Module. The median age of the participants at the time of the pilot study was 66 years, with a range of 48–89 years, and the median time since reconstructive surgery was 3 years, ranging from 1 to 4 years (Table 2).

The median scores obtained from this pilot study, along with the cohort mean scores from the original validation study are presented in Table 3 [13]. In all items, except the 'Cancer Worry' item, a higher score indicated a better outcome. A higher score in the 'Cancer Worry' item suggested more distress, which was considered a worse outcome.

Discussion

The importance of understanding the impact of surgical treatments on the patient's health-related quality of life is increasingly valued [23, 24]. For patients with HNC, the potential effects the disease and its treatment may have on their functionality, appearance and psychosocial well-being are considerable and should not be underestimated. Understanding this impact is crucial for guiding supportive interventions and potentially improving the existing treatment options. In this study, a linguistically validated Finnish version of the FACE-Q Head and Neck Cancer Module was produced, a PROM

specifically designed for the evaluation of the health-related quality of life of HNC patients [13].

Minimal adjustments to the phrasing and wording of the module were needed throughout the translation process of the original module into the first version of the Finnish module. This easy adaptation of the questionnaire into Finnish illustrates the benefits of the forward translation being performed by medical professionals familiar with the subject matter, fluent in the original language and native speakers of the target language. Awareness of the target population, in particular the difference between medical terminology and common language, is also key [25]. In line with this, the recruited patients broadly represented the target population, in terms of both age and gender, with nearly equal representation of men and women. The input gathered from the participants, invited to provide feedback on the module language, led to the identification of two language-related issues in the phrasing of the module that were not detected during the translation process, emphasising the importance of conducting a pilot study during the translation process.

The general scores for the domains assessing facial functionality, facial appearance and psychosocial distress were consistently in the upper end of the 0 to 100 scale. The results observed in our pilot study population were higher for most of the items within these domains,

Table 3. Median scores from the pilot study and cohort mean scores from the original FACE-Q Head and Neck Cancer Module validation study for both the function and the distress scales [13].

	Pilot study		Original validation study
	Median score	Score range (minimum-maximum)	Cohort mean score [13]
Function scales			
Appearance	89	50–100	64.7
Eating and drinking	57	29–100	52.4
Oral competence	75	41–100	55.7
Salivation	62	33–100	46.9
Smiling	88	34–100	58.8
Speaking	50	0–100	47.7
Swallowing	73	0–100	53.1
Distress scales			
Appearance distress	75	41–100	64.74
Drizzling distress	100	0–100	73.2
Eating distress	50	0–100	61.4
Smiling distress	78	31–100	71.2
Speaking distress	63	25–100	62.8
Cancer worry	29	0–55	31.5
Information	89	35–100	Not available

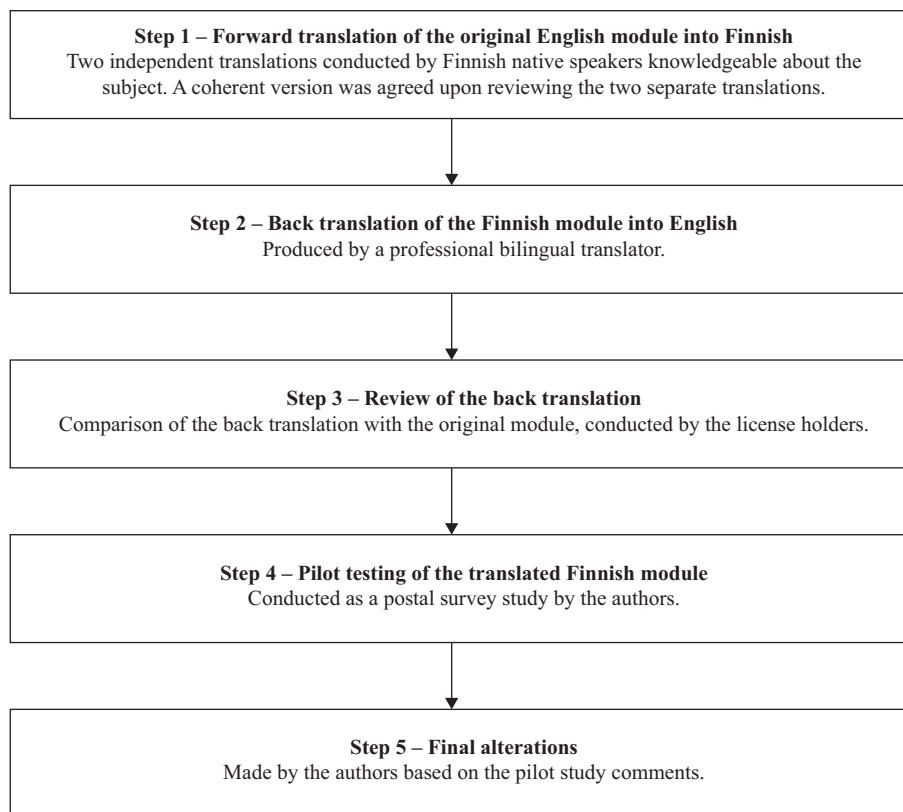


Figure 1. Flow chart showing the translation process behind the Finnish FACE-Q Head and Neck Cancer Module.

compared to the results obtained in the original validation study conducted with 219 US patients [13]. However, the small size of our study group prevented us from conducting any statistical comparison. This trend was noticeable in scales evaluating facial appearance, smiling, oral competence and swallowing [13]. In particular, the pilot study participants reported less distress related to smiling, appearance and drooling [13]. On the contrary, the pilot study participants expressed more distress regarding eating than the participants in the original validation study [13]. The apparent differences between the two studies are most likely caused by differences in population size and patient characteristics, rather than deficiencies in the translation. Our pilot study included a small population, with most patients having cancer located in various parts of the tongue. The impact of surgery on facial appearance and functionality in this area may be comparatively lower than in regions such as the jaw, a patient group, which was more extensively represented in the original validation study [13]. In line with this, scales assessing functionality more dependent on the tongue, for example, eating, speaking, and drinking, displayed results more aligned with each other. No notable differences in cancer worry or speaking distress were observed between the pilot study and the validation study participants [13].

The number of participants in our study group, although insufficient for statistical analyses or results comparison, can still be considered sufficient for the purpose of this study [26]. In addition, the pilot study patients had undergone resections and reconstructions of variable extent and localisation, reducing the generalisability of our results. However, this patient diversity can also be considered a strength of our study, as it allowed for the testing of the module's comprehensibility and relevance across a broad spectrum of patients in terms of both age and gender, representing the typical patient population at our institution. Another limitation of our study is the use of a postal survey format. However, to mitigate this, a separate

section on each page of the module was included, following each scale, for patients to comment on linguistic challenges and suggest alternative phrasings. Although conducting interviews with the pilot study participants might have brought additional insights into the module language, the fact that most participants identified the same deficiencies in items within the same scales, suggests that this method was effective at highlighting the most significant issues in the translation. These issues were then addressed before the final formatting of the Finnish FACE-Q Head and Neck Module.

In conclusion, the newly translated and linguistically validated Finnish version of the FACE-Q Head and Neck Cancer Module translated well into Finnish and showed results that were in line with the results obtained from the original validation study [13]. Further research is needed to better evaluate the performance and behaviour of the module within the Finnish population. The Finnish FACE-Q Head and Neck Cancer Module is available free of charge at the Q-Portfolio Website [17].

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Authors' contributions

All authors contributed to the conception and design of the study. LV, AL, PL and PH conducted the translation process of the Finnish FACE-Q Head and Neck Cancer Module. LV, IBH and AH collected and analyzed the pilot study data. LV drafted the first version of the manuscript. All authors contributed to and approved the final version of the manuscript.

Disclosure statement

The authors declared no potential conflicts of interest with respect to the research, authorship, or publication of this article.

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