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A PARTICIPATORY DESIGN APPROACH TO DEVELOP A WEB-BASED SELF-CARE PROGRAM SUPPORTING EARLY REHABILITATION AMONG PATIENTS AFTER TOTAL LARYNGECTOMY

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ABSTRACT

Objective

The aim of this study was to develop a web-based self-care program for patients after total laryngectomy according to a participatory design approach.

Methods

We conducted a needs assessment with laryngectomees ($n=9$) and their partners ($n=3$) by means of a focus group interview. In 4 focus group sessions, a requirement plan was formulated by a team of health care professionals ($n=10$) and translated into a prototype. An eHealth application was built including illustrated information on functional changes after total laryngectomy as well as video demonstrations of skills and exercises. Usability of the prototype was tested by end users ($n=4$) and expert users ($n=10$). Interviews were held to elicit the intention to use and the desired implementation strategy.

Results

Six main self-care topics were identified: (1) nutrition, (2) tracheostomy care, (3) voice prosthesis care, (4) speech rehabilitation, (5) smell rehabilitation, and (6) mobility of head, neck, and shoulder muscles. Expert users expressed concerns regarding tailored exercises, indicated a positive intent to implement the intervention in routine care, and expressed a need for guidance when implementing the intervention. End users and expert users appreciated the content completeness and multimedia-based information built into the application.

Conclusion

The participatory design is a valuable approach to develop a self-care program to help meet users' needs.

INTRODUCTION

Following total laryngectomy, patients can encounter challenges while returning home [1,2]. Changes in altered airway, swallowing, taste, loss of voice and nasal function, difficulties in neck and shoulder movement, and social embarrassment have a profound effect on a patient's quality of life [3,4].

Self-management skill training is a critical element of rehabilitation, and is necessary in order to encourage patients to learn and apply new self-care skills [5]. The information and support needs of laryngectomees during the transition from hospital to home are extensive [6]. Meeting these needs is a complex task for health care professionals [7]. Providing eHealth (using information and communication technology, especially the Internet, to improve health care [8]) has the potential to be (cost-)effective, to improve quality of life, and to have beneficial effects on health literacy, decision-making, health care participation, psychological well-being, and physical activity levels [9,10]. Alongside usual care for laryngectomees, eHealth offers an innovative approach to promote self-care education [11] and has great potential to enhance recovery, improving hospital-to-home transition, accessibility of supportive care [12], and reintegration into the community [2]. However, to our knowledge there are no web-based self-care programs for patients after total laryngectomy.

The overall aim of this study was to develop and test the usability of a web-based self-care program for laryngectomees by means of a participatory design approach. To be effective in empowering patients' engagement, it is important to carefully match the program to their specific needs [13]. Expert and end user usability testing is essential to ensure that patients' needs are met and that patients are able to navigate the website appropriately and efficiently [14,15]. To anticipate potential adoption problems, it is important to include all stakeholders, such as health care professionals, during the entire developmental phase. In the present study, a 3-phase development life cycle method (Figure 1) was employed, incorporating end users' input with the expertise of health care professionals [16-19].

Recently, more attention has been paid to the development of eHealth technologies based on participatory development, co-design, and user-centered persuasive design techniques [13,17-19]. A participatory design approach to develop a web-based self-care program is rather new and has not often been put into practice in speech pathology and phoniatrics. There is thus a need for scientific studies reporting on the operationalization of these novel approaches in practice. The findings presented here may inform others designing or evaluating web-based self-care programs using a participatory design approach.

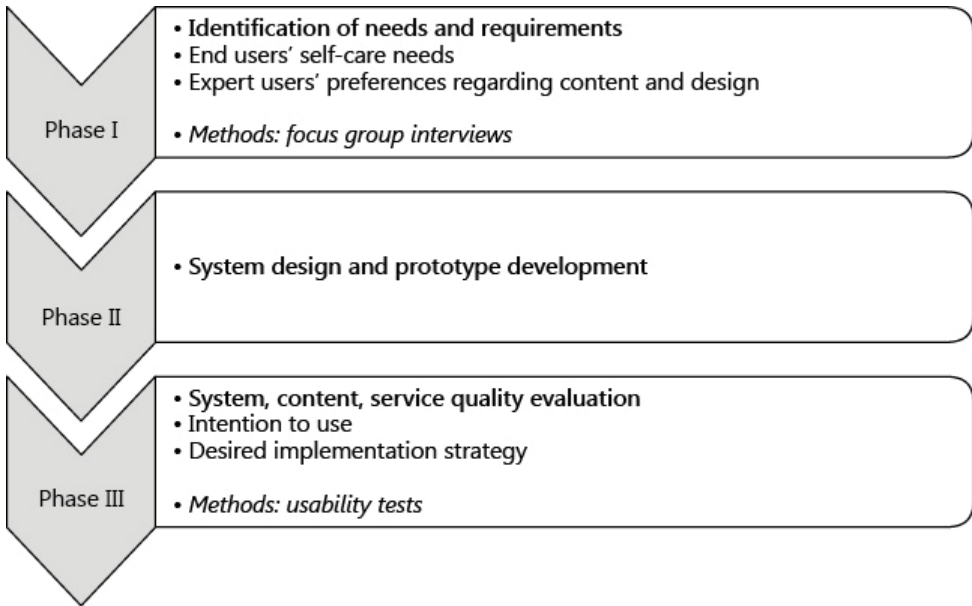


Figure 1. A 3-phase life-cycle method

PHASE I: IDENTIFICATION OF NEEDS AND REQUIREMENTS

METHODS

Patients' self-care needs after total laryngectomy

A focus group interview was held with patients ($n=9$, mean age 64.4 years, 6 male and 3 female) and their partners. Patients were recruited from the Dutch Patient Society for Laryngectomees [20]. The mean time elapsed since total laryngectomy was 11.6 years (SD 8.0, range 2-22). The interview lasted 120 min, was held at the VU University Medical Center (VUmc), Amsterdam, The Netherlands, and was conducted by 2 moderators following a topic guide (Table 1). In part 1 of the interview, needs regarding the management of illness and treatment side effects at home and perspectives regarding the future self-care program were identified. In part 2, the findings were presented to the participants in order to reflect on these and provide additional input [21].

Table 1. Interview topic guides*Focus group questions**(patients after total laryngectomy and partners)*

1. 'What kind of self-care information and education was received after total laryngectomy?'
2. 'What was helpful and what was missing?'
3. 'What are the most important self-care information topics you need towards managing your illness and treatment side effects at home?'

*Focus group questions**(health care professionals)*

1. 'What do you find to be the biggest challenge in providing self-care information and education?'
2. 'Which problems do you currently encounter providing self-care support?'
3. 'What are the most important self-care topics concerning total laryngectomy you provide?'

Think-out-loud tasks during end user and expert user usability evaluation

Information search tasks

1. Search for information about the purpose of the web-based program, and how to use the program.
2. Search for information about 'Maintaining a healthy weight and maintaining physical fitness'.
3. Search for information about 'Esophageal speech'. Watch the demonstration video.

Cognitive tasks

4. Log into the private website (speech therapists). Navigate to your workbook, choose and perform exercise.
5. Indicate that you performed the exercise ('done'). Check your most recent update.
6. Watch the 'Jaw exercises' instruction video. Perform the 'Jaw exercises' (speech therapists).
7. Search for information about 'Voice prosthesis'.
Watch the demonstration video 'How to clean your voice prosthesis' (speech therapists).
8. Log out (speech therapists).

*Exit interview questions**(patients after total laryngectomy and speech therapists)*

1. 'Do you consider yourself a potential user of the program?'
2. 'How and when should this self-care program be implemented within care as usual?'

Health care professionals' preferences regarding content and design

To gain better insight into health care professionals' requirements, we conducted 4 focus group interviews. Three male and 7 female health care professionals were recruited from a multidisciplinary expert team at the VUmc. The sample comprised 2 head and neck surgeons, 1 oncology nurse, 3 speech therapists, 1 physiotherapist, 1 dietician, 1 psychologist, and 1 medical social worker. The health care professionals on average had a working experience with total laryngectomy patients of 15 years (range 6-26). The interviews lasted 1 h, were held between April and August 2011, and were led by a moderator (I.C.C.) following a topic guide (Table 1).

Data Analysis

Field notes and meeting minutes of the focus group interviews with patients and their partners and with health care professionals were analyzed by 1 coder using thematic analysis.

RESULTS

Patients' self-care needs after total laryngectomy

Patients indicated that an online self-care program could be helpful and was expected to enable the delivery of trustworthy and up-to-date information about functional changes after total laryngectomy and of self-care strategies. Patients indicated that a self-care program should include video demonstrations of self-care skills and exercises for head, neck, and shoulder muscles, as well as exercises to reduce lymphedema. They emphasized that the program should send out a positive message. Patients and their partners identified 2 broad themes to be included in an online self-care program: (1) information on how to master treatment-related changes of physical function and (2) information on how to manage emotions. Six subthemes were identified under the physical function theme: (1) difficulty eating, (2) difficulty swallowing, (3) stiff neck and neck and shoulder pain, (4) lymphedema in the head and neck area, (5) difficulty speaking, and (6) tracheostomy and voice prosthesis care. One subtheme was identified under the theme managing emotions: psychosocial care (Table 2).

Table 2. Overview of end users' self-care needs

<i>Information on how to master treatment-related changes of physical function</i>	
1. Difficulty eating	How to use tube feeding at home, on vacation What to do when having taste problems What to do when having chewing problems How to make nutritional, tasteful meals
2. Difficulty swallowing	What to do when having swallowing problems during/after (chemo)radiation What to do when having a dry mouth What to do when having too much saliva
3. Stiff neck, neck and shoulder pain	Get expert physiotherapist's instructions/feedback How to perform flexibility exercises
4. Lymphedema in the head and neck area	Get expert lymphedema physiotherapist's instructions/feedback How to perform exercises for the head and neck area to reduce lymphedema
5. Difficulty speaking	What to do when having speech difficulties during/after (chemo)radiation How to gain insight on speech rehabilitation options after total laryngectomy How to inform the partner about speech rehabilitation after total laryngectomy
6. Tracheostomy and voice prosthesis care	How to choose and use the best adhesive stoma patches How to cope with thick mucus How to cough after total laryngectomy How to perform skin care around the tracheostomy [during (chemo)radiation] How to perform inner cannula care How to perform stoma care How to clean the voice prosthesis
<i>Information on how to manage emotions</i>	
7. Psychosocial care	How to receive support from a health care professional, the partner, and/or family

Health care professionals' preferences regarding content and design

The health care professionals had strong ideas about concepts that should be incorporated into the self-care program. Despite thorough hospital discharge preparation, they indicated that patients still feel challenged in finding support and information on self-care at home. According to the health care professionals, the program should be developed as a support tool for problem-solving at home (troubleshooting) and to provide self-care information and education. The health care professionals suggested adding the subtheme 'smelling' to the theme 'physical functioning' to provide information about the possible relation of taste problems to smelling due to the absence of nasal airflow.

PHASE II: SYSTEM DESIGN AND PROTOTYPE DEVELOPMENT

5

METHODS

A prototype of 'In Tune without Cords' was created based on the needs assessment results. During prototype development, the team met regularly to provide feedback on several prototype versions.

RESULTS

Figure 2 provides details on the content of the 'In Tune without Cords' prototype.

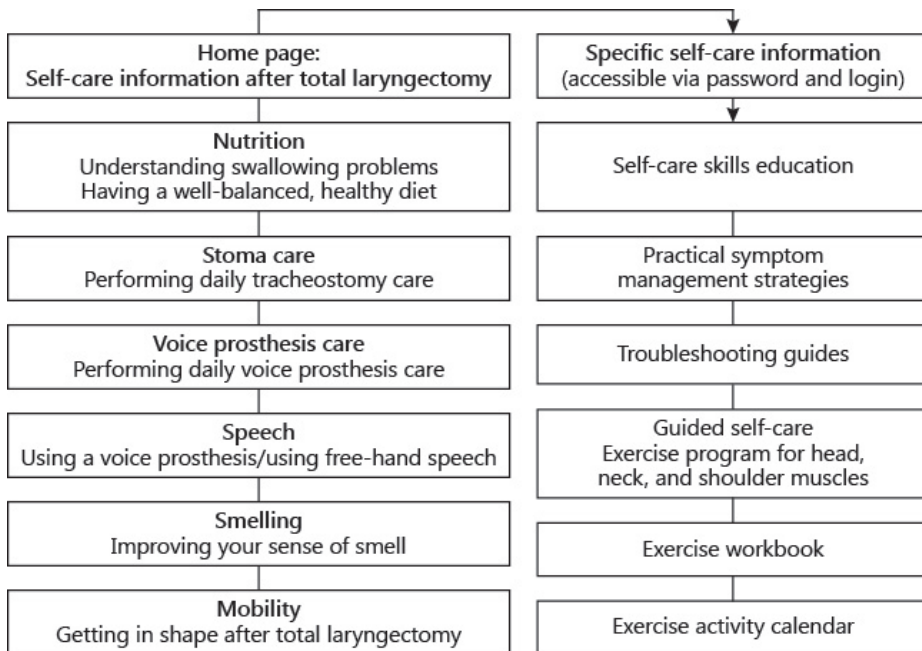


Figure 2. Overview of the website content

PHASE III: SYSTEM, CONTENT, AND SERVICE QUALITY EVALUATION

METHODS

End User Testing

Usability evaluations were conducted with end users (patients; $n=4$; 3 male and 1 female) recruited from the Dutch Patient Society for Laryngectomees [20] ($n=3$) and from the VUmc outpatient clinic ($n=1$). The patients had an average age of 63 years (SD 8.2, range 51-69). The mean time elapsed since total laryngectomy was 15.5 years (SD 10, range 1-24). The patients were asked to familiarize themselves with the 'In Tune without Cords' website and conducted a series of tasks while 'thinking out loud'. Task incompleteness was monitored. To elicit the intention to use and the desired implementation strategy, interviews were held (Table 1). The usability evaluations were held at the VUmc, lasted between 36 and 80 min (mean 59.2, SD 20.7), and were recorded using Morae™ software and transcribed verbatim.

Expert User Testing

Expert usability evaluations were conducted with a sample of 1 male and 9 female speech therapists recruited from 5 university medical centers. We asked speech therapists to participate as they play a vital role in pre- and postoperative care. The speech therapists on average had 16 years of working experience with laryngectomees (SD 7.9, range 1-26). They were asked to 'walk through' the application guided by scenarios and patients' user tasks. All expert-based usability evaluations were conducted in pairs. The interviews were held to elicit the intention to use and refer as well as the expert users' desired implementation strategy (Table 1). The expert usability evaluations were held at the speech therapists' workplace, lasted between 29 and 76 min (mean 62.8, SD 19.1), and were recorded using Morae software and transcribed verbatim.

Data Analysis

In analyzing the usability evaluations, we made use of transcripts supported by Morae recordings. The transcripts were coded by 2 coders who independently selected citations using a coding scheme concerning system quality (ease of use), content quality (usefulness and relevance), and service quality (the process of care provided) [22-25]. Next, the 2 coders met to discuss their findings and to resolve differences. They developed a framework in which (sub)themes were defined. After coding, the raw data were examined again to ensure that all data were reflected in the coding [26]. Quotes, which we included in this manuscript, were translated from Dutch into English and anonymized. Finally, statistics for task incompleteness rates were computed.

RESULTS

System Quality

The laryngectomees and speech therapists appreciated the ease of access of 'In Tune without Cords' by its availability from home. The speech therapists emphasized that 'In Tune without Cords' would not be suitable for those without Internet access and those unmotivated (Table 3). Through clear navigation and presentation of information, the system was deemed easy to use even for inexperienced Internet users. The patients valued the efficient search functionality to find specific self-care information. The 'Read more' link to dose the information provided was appreciated. An unclear navigation aspect mentioned was a lack of orientation cues, not making the user's location on the site apparent. Video start buttons and instructions on how to fill out workbooks were reported to be missing. The speech therapists reported the theme 'Nutrition' to consist of too many subthemes. The patients and speech therapists both appreciated the use of engaging multimedia. The patients who acted in the demonstration videos were indicated to be seen as inspiring role models. The patients reported they valued the application as a helpful tool to learn how to cope with the functional changes: 'This would really be helpful. After surgery I had to figure it out all by myself.' According to the speech therapists, having to perform all exercises for a long period of time and to watch the same video repeatedly seemed excessive.

Content Quality

The patients and speech therapists indicated that 'In Tune without Cords' provides an accurate online source of relevant information and represents current views about self-care (Table 3). Inaccurate elements, such as usage of a photo of an old-fashioned stoma cover, were also mentioned. According to the speech therapists, some videos needed editing: 'You hear a voice telling you something about leakage and how you can monitor it. At the same time the ENT surgeon is doing completely different things.' According to the speech therapists, 'In Tune without Cords' could support the information provided by health care professionals: 'It may happen that health care professionals forget to provide all information to patients'. Texts were evaluated by patients as easy to read as well as complete: 'All you need to know about self-care after total laryngectomy'. The information provided was reported to be comprehensible. Negative comments of speech therapists were mainly on self-care information not reflecting their ideas. Furthermore, they reported that electrolaryngeal speech was demonstrated inadequately and that a 'voice prosthesis leakage animation' was missing.

Service Quality

The speech therapists indicated that offering head and neck exercises and informing on how to obtain good nutritional status could be beneficial (Table 3). Both patients and speech therapists reported that 'In Tune without Cords' would help patients to take ownership of care. The

speech therapists indicated that the skills are being properly demonstrated utilizing videos: 'It could help laryngectomees not to waste time doing the wrong things'. Negative comments of speech therapists were mainly on the unavailability of an implementation protocol and on an unclear job description: would they have to act as a guide or a coach, or would they be acting as a 'Big Brother watching'? The speech therapists valued the provision of coaching by telephone or email. Online 24/7 support was valued by the patients. They expected that this could lead to increased confidence and reassurance as well as an increased ability to acquire self-care information at their own pace and to recognize minor symptoms early. Both patients and speech therapists stated that 'In Tune without Cords' could also be used to advise informal caregivers and health care professionals unfamiliar with total laryngectomy. Negative comments were reported by speech therapists having doubts regarding tailored exercises: 'I wish I could compile an individualized list of exercises to recommend to my patients' and regarding exercise performance quality. To enable monitoring of exercise performance quality, 1 patient suggested the introduction of Skype; to monitor quantity, the use of check marks was suggested by patients and speech therapists.

End Users' Task Completion

Three users needed help with information search task 1 (Table 1). All patients were able to complete tasks 2 and 3 and the first cognitive task. One participant needed help navigating and filling out his workbook (task 4). None of the patients could complete cognitive task 5. The participants said they were hindered by unclear reference information.

Intention to Use and Refer

Overall, all intended to use and refer to 'In Tune without Cords' when available. According to some patients and speech therapists, 'In Tune without Cords' should be introduced at intake, i.e. *before* total laryngectomy. Others preferred to introduce it *after* total laryngectomy, i.e. before hospital discharge, serving as a starting point for follow-up care. The speech therapists considered themselves to be most suitable to introduce 'In Tune without Cords', because of their involvement in pre-rehabilitation.

Prototype Modification

Clear navigation instructions were added to the menu (e.g. 'You are on the public website'). When clicked on, the color of the heading text changed, making the user's location on the site apparent. Considering the theme 'Nutrition', the text amount on a webpage was re-sized, and meaningful subheadings were used. New animations and video demonstrations were implemented in the prototype. Due to financial and time restraints, we were unable to develop a 'Frequently Asked Questions' section and a 'Voice prosthesis leakage animation' and to edit the electrolaryngeal speech video.

Table 3. End user and expert user usability evaluation

Strengths	Weaknesses
System quality	
<i>Ease of access</i>	
Available	Unavailable
– at home (TLP*, ST#)	– for unmotivated TLP* and those without Internet (ST#)
<i>Ease of use</i>	
Clear navigation, presentation of information	Unclear navigation, presentation of information
– search functionality (TLP*)	– lack of orientation cues: no video start button;
– ‘Read more’ link (TLP*, ST#)	– low-contrast (un)selected headings (TLP*, ST#);
– eligible for inexperienced Internet user (TLP*)	– where to begin on home page (ST#);
– right color palette (TLP*); good voice-overs (ST#)	– how to fill out workbook (TLP*, ST#)
– online step-by-step self-care information (TLP*)	– lack of overview (‘Speech methods’, ‘Nutrition’) (ST#)
<i>Design persuasiveness</i>	
Design related to user values, needs	Design not related to user values, needs
– engaging multimedia/inspiring role models (TLP*, ST#)	– no need to watch same exercise video 3x/day (ST#)
– coping with functional changes after TL [^] (TLP*)	– no ‘Frequently Asked Questions’ section (TLP*)
	– unable to load exercise performance pie chart (ST#)
Content quality	
<i>Accuracy</i>	
Up-to-date, relevant information	Lack of up-to-date, relevant information
– represents current view about self-care (TLP*, ST#)	– unavailable brochure (ST#)
– reference sources are provided (ST#)	– old-fashioned stoma cover (TLP*, ST#)
	– voice prosthesis videos need editing (ST#)
<i>Consensus based</i>	
Standard-, theory-, or guideline-based information	Information not based on theory, standard, or guideline
– gathered by expert team (TLP*, ST#)	– not all self-care advice reflects STs’ point of view (ST#), e.g., inadequate demonstration of electrolaryngeal speech (ST#)
– website with a professional look (ST#)	
– to support information provided by HCPs” (ST#)	
<i>Completeness</i>	
Provision of sufficient information	Lack of sufficient information
– on 6 main self-care topics (TLP*, ST#)	– lack of ‘Voice prosthesis leakage’ animation (ST#)
<i>Comprehensibility</i>	
Information is clear, understandable	Lack of clear, comprehensible information
– readable/comprehensible texts (TLP*)	– dietician needs to clarify nutritional information (ST#)

Table 3. End user and expert user usability evaluation
(continued)

Service quality	
<i>Perceived usefulness</i>	
Benefits	Drawbacks
<ul style="list-style-type: none"> – exercises/good nutritional status (ST#) are very important topics in 1st year after TL[^] (TLP*) – to help TLP* take ownership of care (TLP*, ST#) – no waste of time doing the wrong things (ST#) 	<ul style="list-style-type: none"> – unavailable implementation protocol (ST#) – website guidance needed: workload HCP" (ST#) – unknown role of HCP": coach, coordinator? (ST#) – unpleasant role: 'Big Brother is watching' (ST#)
<i>Operationalization</i>	
Provision of prompt services; ability to give feedback or provide coaching	Lack of prompt services; not being able to give or get feedback or provide coaching
<ul style="list-style-type: none"> – by telephone or email (ST#); get (online) 24/7 guidance, support, reassurance, increased confidence when leaving hospital after TL[^] (TLP*) – acquire self-care information at own pace (TLP*) – less need to have (hospital) meetings (TLP*, ST#) – early recognition of minor symptoms (TLP*) – on exercise performance <i>quantity</i> (ST#) – to remind TLP* to perform self-care (TLP*, ST#) – partnership between TLP* and HCP" (ST#) – to inform informal caregiver/care professional unfamiliar with TL[^] (TLP*, ST#) 	<ul style="list-style-type: none"> – by phone: TLP* may not use phone, because of speech problems (TLP*) – doubts on level of exercise tailoring (ST#) – some exercise programs target treatment phase (e.g. during radiation) and not specific symptoms (ST#) – on exercise performance <i>quality</i> (ST#): suggest developing chat version or Skype with webcam (TLP*) – on exercise performance <i>quantity</i>: suggest to use check marks ('done' = ✓) (TLP*, ST#)
<p>TLP* = patient after total laryngectomy (end user); ST# = speech therapist (expert user); TL[^] = total laryngectomy; HCP" = health care professional.</p>	

DISCUSSION

The purpose of this study was to develop and test the usability of 'In Tune without Cords', aiming to support laryngectomees in their rehabilitation process. The participatory design approach used was fruitful. This approach resulted in more insight into patients' self-care needs and in high levels of satisfaction among patients and speech therapists in the usability tests. While a couple of (web-based) interventions to promote self-management in head and neck cancer patients have been developed [27,28], 'In Tune without Cords' is the first web-based intervention to support laryngectomees, hereby fulfilling the reported need for a web-based self-care program [2]. Affecting motivation, skill building, and behavioral change demands instructional strategies that move beyond text on a screen. Multimedia can be particularly appropriate when an intervention includes motor skill building [29] and is expected to address patients' self-care needs in a better way.

The needs and requirement assessments provided a good basis for informing the content and design of 'In Tune without Cords'. In line with others [1,2], our study revealed that patients experience challenges in their rehabilitation process related to physical changes, in relation to psychological concerns [30], and with regard to integrating their new situation into their everyday life. Because of its low priority, 'Information how to manage emotions' was not included. Possibly, 'In Tune without Cords' could be linked to the website of the Dutch Patient Society for Laryngectomees [20], which provides a list of peer support groups or individuals willing to serve as contacts, as well as to an existing eHealth intervention available in the Netherlands targeting anxiety and depression in head and neck cancer patients [31].

Usability studies enable developers to discover problems with the web-based program, to explore end users' experiences, and minimize the likelihood of end users having difficulties using the system [32]. The importance of usability tests for eliciting detailed information on user interaction has been demonstrated in several studies [33,16]. Usability studies typically involve 5-7 end users [34], since a sample of 5 end users reveals 85% of the problems [35]. Therefore, the sample of 14 users (4 laryngectomees and 10 speech therapists) in the present study was sufficient.

The study results did not show a clear position regarding by whom and when 'In Tune without Cords' should be introduced. According to some, it should be introduced *before* total laryngectomy, while others stated that it should be introduced *after*. A survey among head and neck cancer patients showed that patients were satisfied with pretreatment information, while a better preparation for the long-term effects on functioning and quality of life was suggested as an improvement [36]. Minimal evidence exists on how best to prepare patients for chronic treatment side effects, despite it being recommended as good clinical practice [37]. Further research is needed to identify the proper timing of implementation.

A limitation of this study is that only one multidisciplinary expert team was formed to gain insight into health care professionals' perceived content requirements. Substantial differences between expert teams may exist, and care should be taken to consider different perceptions [38]. However, pairs of experts from 5 university medical centers performed the usability evaluations

in order to tailor the content of the application. Strengths of this study are the stakeholders' engagement, co-creation with users [19], and focus on the next phase in the development process by inquiring factors that either impede or facilitate the implementation of this eHealth application in clinical practice.

The refined prototype of 'In Tune without Cords' will be used in a feasibility study. A feasibility study is needed to provide more insight into actual uptake before studying (cost-)effectiveness. When the program have been proven to be (cost-)effective, the next step will be its sustainable implementation in current clinical practice.

CONCLUSION

The participatory design is a valuable approach to develop a self-care program to help meet users' needs. The findings from this study were used to refine the prototype of 'In Tune without Cords'.

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