A Participatory Design Approach to Develop a Web-Based Self-Care Program Supporting Early Rehabilitation among Patients after Total Laryngectomy

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Key Words
Laryngeal cancer · Total laryngectomy · Self-care · E-health · Usability testing · Participatory design approach

Abstract
Aim: 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 e-health 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 e-health (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, e-health 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 (fig. 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 e-health 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.

**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...
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’.
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.
7. Search for information about ‘Voice prosthesis’. Watch the demonstration video.
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?’

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].

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).

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

<table>
<thead>
<tr>
<th>Information on how to master treatment-related changes of physical function</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Difficulty eating</td>
<td>How to use tube feeding at home, on vacation.</td>
</tr>
<tr>
<td>2. Difficulty swallowing</td>
<td>What to do when having swallowing problems during/after (chemo)radiation.</td>
</tr>
<tr>
<td>3. Stiff neck, neck and shoulder pain</td>
<td>Get expert physiotherapist’s instructions/feedback.</td>
</tr>
<tr>
<td>4. Lymphedema in the head and neck area</td>
<td>Get expert lymphedema physiotherapist’s instructions/feedback.</td>
</tr>
<tr>
<td>5. Difficulty speaking</td>
<td>What to do when having speech difficulties during/after (chemo)radiation.</td>
</tr>
<tr>
<td>6. Tracheostomy and voice prosthesis care</td>
<td>How to choose and use the best adhesive stoma patches.</td>
</tr>
<tr>
<td>7. Psychosocial care</td>
<td>How to receive support from a health care professional, the partner, and/or family.</td>
</tr>
</tbody>
</table>

Phase II: System Design and Prototype Development

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.
rienced 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
<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ease of access</strong></td>
<td></td>
</tr>
<tr>
<td>Available</td>
<td>Unavailable</td>
</tr>
<tr>
<td>- at home (TLP*, ST#)</td>
<td>- for unmotivated TLP* and those without Internet (ST#)</td>
</tr>
<tr>
<td><strong>Ease of use</strong></td>
<td></td>
</tr>
<tr>
<td>Clear navigation, presentation of information</td>
<td>Unscreen navigation, presentation of information</td>
</tr>
<tr>
<td>- search functionality (TLP*)</td>
<td>- lack of orientation cues: no video start button;</td>
</tr>
<tr>
<td>- 'Read more' link (TLP*, ST#)</td>
<td>low-contrast (un)selected headings (TLP*, ST#);</td>
</tr>
<tr>
<td>- eligible for inexperienced Internet user (TLP*)</td>
<td>where to begin on home page (ST#);</td>
</tr>
<tr>
<td>- right color palette (TLP*); good voice-overs (ST#)</td>
<td>how to fill out workbook (TLP*, ST#)</td>
</tr>
<tr>
<td>- online step-by-step self-care information (TLP*)</td>
<td>- lack of overview ('Speech methods', 'Nutrition') (ST#)</td>
</tr>
<tr>
<td><strong>Design persuasiveness</strong></td>
<td></td>
</tr>
<tr>
<td>Design related to user values, needs</td>
<td>Design not related to user values, needs</td>
</tr>
<tr>
<td>- engaging multimedia/inspiring role models (TLP*, ST#)</td>
<td>- no need to watch same exercise video 3×/day (ST#)</td>
</tr>
<tr>
<td>- coping with functional changes after TL^ (TLP*)</td>
<td>- no 'Frequently Asked Questions' section (TLP*)</td>
</tr>
<tr>
<td><strong>Content quality</strong></td>
<td></td>
</tr>
<tr>
<td>Accuracy</td>
<td>Up-to-date, relevant information</td>
</tr>
<tr>
<td>- represents current view about self-care (TLP*, ST#)</td>
<td>Lack of up-to-date, relevant information</td>
</tr>
<tr>
<td>- reference sources are provided (ST#)</td>
<td>- unavailable brochure (ST#)</td>
</tr>
<tr>
<td>- consensus base</td>
<td>Information not based on theory, standard, or guideline</td>
</tr>
<tr>
<td>- gathered by expert team (TLP*, ST#)</td>
<td>- not all self-care advice reflects ST's point of view (ST#), e.g.,</td>
</tr>
<tr>
<td>- website with a professional look (ST#)</td>
<td>inadequate demonstration of electrolaryngeal speech (ST#)</td>
</tr>
<tr>
<td>- to support information provided by HCPs&quot; (ST#)</td>
<td></td>
</tr>
<tr>
<td>Completeness</td>
<td>Provision of sufficient information</td>
</tr>
<tr>
<td>- on 6 main self-care topics (TLP*, ST#)</td>
<td>Lack of sufficient information</td>
</tr>
<tr>
<td>- comprehensibility</td>
<td>- lack of 'Voice prosthesis leakage' animation (ST#)</td>
</tr>
<tr>
<td>Information is clear, understandable</td>
<td></td>
</tr>
<tr>
<td>- readable/comprehensible texts (TLP*)</td>
<td>Lack of clear, comprehensible information</td>
</tr>
<tr>
<td>Service quality</td>
<td></td>
</tr>
<tr>
<td>Perceived usefulness</td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td></td>
</tr>
<tr>
<td>- exercises/good nutritional status (ST#) are very important</td>
<td></td>
</tr>
<tr>
<td>- topics in 1st year after TL^ (TLP*)</td>
<td></td>
</tr>
<tr>
<td>- to help TLP* take ownership of care (TLP*, ST#)</td>
<td></td>
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<tr>
<td>- no waste of time doing the wrong things (ST#)</td>
<td></td>
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<tr>
<td>Drawbacks</td>
<td></td>
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<tr>
<td>- unavailable implementation protocol (ST#)</td>
<td></td>
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<tr>
<td>- website guidance needed: workload HCP&quot; (ST#)</td>
<td></td>
</tr>
<tr>
<td>- unknown role of HCP&quot;: coach, coordinator? (ST#)</td>
<td></td>
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<tr>
<td>- unpleasant role: 'Big Brother is watching' (ST#)</td>
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</table>
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, 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.

### 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 par-
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 e-health 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 e-health 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 has 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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Disclosure Statement

The authors declare that they have no conflict of interest.
References


