

The development of a decision aid for patients with operable oropharyngeal carcinoma in the Netherlands – A mixed methods study

Anne N. Heirman^a, Richard Dirven^a, Lisette van der Molen^a, Willem H. Schreuder^a, Frank Hoebbers^b, Jimmie Honings^c, Abraham Al-Mamgani^d, Remco de Bree^e, Simone E.J. Eerenstein^f, Gyorgy B. Halmos^g, Michiel W.M. van den Brekel^{a,h,i,*}

^a Department of Head-and-Neck Oncology and Surgery, Netherlands Cancer Institute – Antoni van Leeuwenhoek, Amsterdam, the Netherlands

^b Department of Radiation Oncology (Mastro), GROW School for Oncology and Reproduction, Maastricht University Medical Centre, Maastricht, the Netherlands

^c Department of Otorhinolaryngology/Head and Neck Surgery, Radboud University Medical Center, Nijmegen, the Netherlands

^d Department of Radiation Oncology, The Netherlands Cancer Institute – Antoni van Leeuwenhoek, Amsterdam, the Netherlands

^e Department of Head and Neck Surgical Oncology, University Medical Center Utrecht, Utrecht, the Netherlands

^f Department of Otolaryngology/Head and Neck Surgery, Amsterdam University Medical Center, Amsterdam, the Netherlands

^g Department of Otolaryngology/Head and Neck Surgery, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands

^h Department of Maxillofacial Surgery, Amsterdam University Medical Center, Amsterdam, the Netherlands

ⁱ Amsterdam Center of Language and Communication, University of Amsterdam, Amsterdam, the Netherlands

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ABSTRACT

Objective: The aim of this project is to create an interactive online patient decision aid (PDA) for oropharyngeal cancer (OPSCC) patients, eligible for transoral (robotic) surgery with an ultimate goal to assist both physicians and patients in making treatment choices.

Materials and methods: Following the International Patient Decision Aid Standards, a mixed-methods approach was employed. The study involved semi-structured in-depth interviews with patients and physicians, thinking-out-loud sessions, and study-specific questionnaires. Thematic coding and analysis were conducted on verbatim transcriptions of audio-recorded interviews.

Results: The PDA drafts were evaluated by twenty OPSCC survivors and twenty multidisciplinary specialists. Significant revisions were made after phase 1 to enhance readability and reduce text, whilst incorporating videos and graphics. Following all phases, both patients and specialists rated the PDA as comprehensible, feasible, and a valuable addition to regular counseling.

Conclusion: This study showcases the development of a PDA for early stage oropharyngeal cancer patients considering surgery and radiotherapy options. The decision aid emphasizes the disparities in short- and long-term side effects between the two treatments. Patients and physicians found the decision aid to be understandable, user-friendly, and helpful for future patients. The PDA is available on <https://beslissamen.nl/>.

Introduction

There has recently been a shift in the epidemiology of oropharyngeal squamous cell carcinoma (OPSCC) in the Western world. Formerly, tobacco and alcohol were the main risk factors, but prevention campaigns have reduced their prevalence [1,2]. At the same time, human papillomavirus (HPV) has emerged as a new risk factor, causing a significant increase in the incidence of OPSCC [3,4]. HPV-related tumors are now responsible for most (70 %) OPSCCs in Europe [5]. HPV-positive early stage OPSCC patients, typically younger and healthier, are expected to

have excellent long-term survival. Nowadays the most applied treatment modalities for early-stage OPSCC are either radiotherapy to the oropharynx and neck, or transoral (robotic) surgery (TO(R)S) including a neck dissection if indicated. Single modality treatment is preferred for early-stage OPSCC to minimize morbidity and costs [6].

To date, retrospective studies have found no significant difference in survival and oncologic outcomes among these treatments [3,7]. Prospective data on long-term functional outcomes reveal similar quality of life (QoL) outcomes, but differences in toxicities [6,8]. But even with these new insights, patient and clinicians face the difficulty and

* Corresponding author at: Amsterdam Center of Language and Communication, University of Amsterdam, Spuistraat 134, 1000 BP Amsterdam, The Netherlands.
E-mail address: m.w.m.vandenbrekel@uva.nl (M.W.M. van den Brekel).

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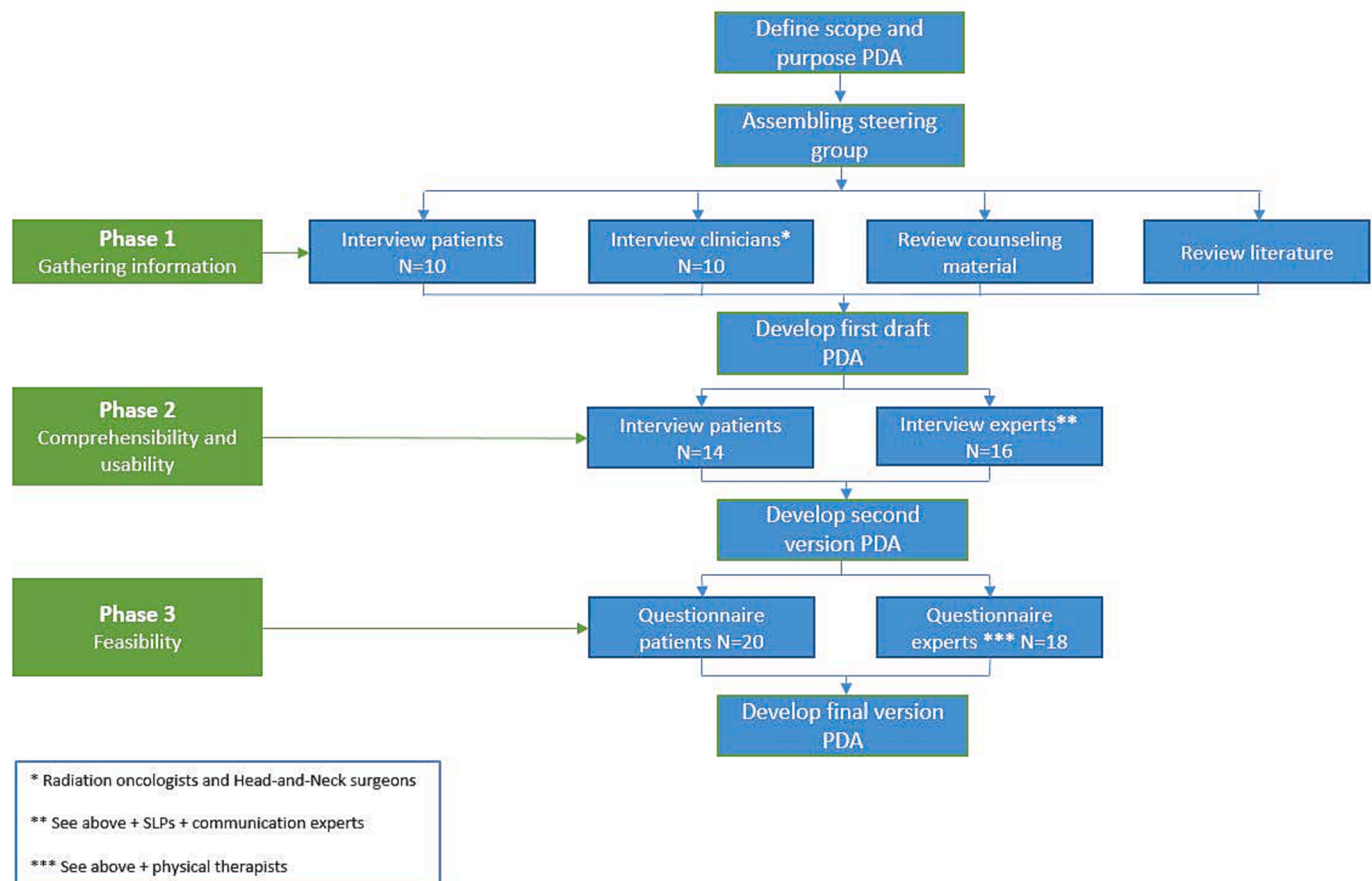


Fig. 1. Developmental phases Flowchart of all developmental phases following the IPDAS criteria. SLP = Speech-Language-Pathologist, IPDAS = International Patient Decision Aid Standard, PDA = Patient Decision Aid.

complexity of appropriate treatment selection to meet individual patient preferences. This emphasizes the importance of shared decision-making (SDM). Patient decision aids (PDAs) are interventions supporting patients in their decision-making process and have proven to be effective in making patients more knowledgeable, better informed, show insight in patient values and more accurate risk perception [9,10]. There are several existing PDAs for different cancer types. In Head-and-Neck Oncology there is a PDA for advanced laryngeal carcinoma developed in our center [11], and a PDA for oropharyngeal cancer from the United States [12]. Since patients' values, preferences but also treatment guidelines are dependent on country and culture, we decided to develop our own PDA for patients with early stage OPSCC that are eligible for curative treatment with either transoral (robotic) surgery or radiation therapy.

This study describes the assessment of the preferences and needs of early stage OPSCC patients and their healthcare providers, facing a single modality treatment choice, in The Netherlands. A PDA was developed, and its usability and feasibility was tested to make the PDA usable in daily practice.

Materials and methods

This is a multicenter study, based on the criteria for developing a PDA as set by the International Patient Decision Aids Standards (IPDAS) Collaboration [13,14], following the three development phases (see Fig. 1).

The scope of the PDA was determined by the research group, based on clinical experience and literature. The PDA was developed for patients with early stage OPSCC making a primary curative treatment

choice between radiation therapy and transoral (robotic) surgery (TO(R)S) with or without neck dissection (ND). The purpose of the PDA was to give an overview of the disease, treatment possibilities and side effects, and improve understanding.

The multicenter multidisciplinary steering group consisted out of the following disciplines: Radiation Oncology, Speech-and-Language Pathology, Head-and-Neck Oncology and Surgery, Physiotherapy and Rehabilitation. The role of this group was to review preliminary results and content, and provide guidance through all phases of the development process.

Phase 1 consisted of multiple steps. Most recent trials investigating primary surgery and radiation in early stage OPSCC were reviewed and compared with counseling materials. Furthermore, semi-structured in-depth interviews with patients and physicians from six head-and-neck centers were held to evaluate patients' decisional needs and the regular counseling process. Inclusions were stopped after reaching data saturation. All collected data was used to construct the first version of the PDA by a web designer with experience in developing decision aids.

In phase 2, the comprehensibility and usability of the PDA was alpha tested. This was done through interviews with patients and physicians, and thinking-out-loud sessions whilst showing the PDA. Afterwards everyone filled in a study-specific questionnaire with 35 statements regarding evaluation of the PDAs usability, comprehensibility, content, added value, design and satisfaction. All statements were positively framed and ranged from totally disagree (1) to totally agree (5). The questionnaire was followed by three open questions for feedback regarding points that participants liked, disliked, and suggestions for improvement. Ending with a ranking of the PDA ranging from 0 to 10, where a score ≥ 5.5 was a passing grade.

Table 1
Participant characteristics.

	Patients
Age (mean, range)	60 years (46–81)
Gender	7
Female	(35 %)13
Male	(65 %)
Education level	4
Primary	(20 %)7
Lower secondary	(35 %)5
Higher secondary	(25 %)4
University*	(20 %)
Tumor stage	13
I	(65 %)4
II	(20 %)
III	3 (15 %)
HPV	12
Positive	(60 %)
Negative	8 (40 %)
Treatment	12
RT	(60 %)1
TOS	(5 %)5
TORS + NDTO(R)	(25 %)2
S + PORT	(10 %)
Years since diagnosis (mean, range)	4 years (1 – 11)
Included per phase	N (%), N cumulative10
Phase 1	(50 %), 104
Phase 2	(20 %), 146
Phase 3	(30 %), 20
Experts	
Age (mean, range)	46 years (30 – 59)
Gender	10
Female	(50 %)10
Male	(50 %)
Specialty	7
RO	(35 %)7
HNS	(35 %)2
SLP	(10 %)2
PT	(10 %)2
CE	(10 %)
Work experience (mean, range)	14 years, (5 – 26)
PDA experience	4
None	(20 %)14
One	(70 %)2
Multiple	(10 %)
Included per phase**	N (%), N cumulative10
Phase 1	(50 %), 107
Phase 2	(35 %), 163
Phase 3	(15 %), 18

*Of which 1 patient obtained a doctorate. ** The numbers do not add up to 20 because one RO only participated in phase 1 and one SLP only participated in phase 2.
ND = neck dissection, RT = radiation therapy, TO(R)S = transoral (robotic) surgery, PORT = post-operative radiation therapy, RO = radiation-oncologist, HNS = Head-and-Neck surgeon, SLP = speech-and-language pathologist, PT = physiotherapist, CE = communication expert.

Phase 3, entailed a similar routine as phase 2, more focusing on the improvements and therefore feasibility. This was tested with the same method and tools as in phase 2.
Due to the Covid-19 pandemic, phase 2 and 3 were performed through video calls and questionnaires were sent via email or post as preferred by participant.

Recruitment and inclusion criteria

Previously treated patients were recruited by their treating physician and subsequently contacted by the researcher (A.H.). Patients needed to have been eligible for primary radiation therapy or TO(R)S with or

without a neck dissection. This was decided during the multidisciplinary team (MDT) meeting, taking into account the patient’s clinical profile, tumor stage and location, imaging results, and pathological examination. A crucial aspect was to minimize the risk of adjuvant treatment after surgery. OPSCC-treating physicians were recruited through peer networking. All participants signed informed consent.

Scope of the PDA

The PDA was developed for patients facing a single modality treatment choice. The Dutch oral cavity and oropharyngeal carcinoma guideline was published in 2014 and is therefore outdated (update expected to be published in 2023–2024). Involved centers have made their own guidelines based on literature, local resources (e.g. availability of TORS) and experiences. It was therefore decided not to limit inclusion criteria by tumor stage, but to follow the decision of the local MDTs whether a patient was suitable for unimodality treatment (radiation or TO(R)S). The PDA is meant for patients with stage I HPV + OPSCC and stage I-III HPV- OPSCC where primary tumors are resectable transorally and neck disease is very limited.

Data processing and statistics

All interviews (in depth, and thinking out-loud sessions) were performed by A.H., who had no treatment relationship with the patients. The interviews were audio-recorded, verbatim transcribed, and anonymized. Thematic coding was done using ATLAS.ti software (version 9.1). Thematic coding leads to the discovery of appropriate content for the decision aid focusing on the decision-making process, experiences around side effects of treatments, knowledge about the disease, (decisional) needs and opinions about the PDA. The results of the questionnaire were quantitative data and are displayed using means, ranges, and percentages.

Ethics

This study does not fall under the scope of the Medical Research Involving Human Subjects Act and was approved by the review board of the Netherlands Cancer Institute (IRBd18-030).

Results

Characteristics

All characteristics can be found in Table 1. Of all selected patients, two refused participation. All healthcare providers came from six different Dutch Head-and-Neck Centers and the medical Communication Experts (CE) from two Dutch universities.

Phase 1: Gathering information
Literature and Counseling materials.

We focused on randomized studies comparing radiation and surgery in early-stage OPSCC. The ‘ORATOR trial’ [15] and the ‘BEST OF’ trial [16] are both studies investigating the best treatment for this patient group. The ‘BEST OF’ trial is still ongoing. Results of the ‘ORATOR’ trial are analyzed and compared to our ‘inclusion criteria’ and used as background information. Preferably we wanted to use Dutch survival rates, but there were no reliable numbers available. After discussion with the steering group, it was decided that the survival numbers from the ‘ICON-S’ study are most accurate and therefore used in the PDA [17].

None of the interviewed Head-and-Neck Surgeons (HNS) used counseling materials during their consultations. Some of them use patients’ scans or drawings to clarify where the tumor is situated, and explain treatments. Radiation Oncologists (RO) did have flyers and brochures about radiation in the HN area, however, used them rarely.

Physicians.

Five HNS and five RO were included from four Dutch Head-and-Neck

Table 2
Themes observed in interviews.

Themes	Patients	Physicians
General results interview	(1) Fear of death (2) Overwhelmed by information (3) Want to start treatment as soon as possible	(1) Difficult to relay important information without giving too much information (2) Make clear that survival is relatively good (3) State treatment possibilities
Survival	(1) Most important, but since it is quite similar for both treatments it is not decisive in decision-making	(1) As far as we now know from research, both treatments give similar oncological outcomes
Side-effects	(1) Initially mostly focused on short-term side effects (2) After learning long-term side-effects they are viewed as most important for decision-making (3) Most feared is persistent swallowing problems (4) Most patients in hindsight missed information about dental problems, hair loss and risk of radiation after surgery	(1) Multimodality treatment gives more and more severe side effects, so unimodality treatment is preferred (2) Differences in the long term should be explained to patients for decision-making (3) Specialists mainly explain side-effects of their own treatment modality
Side-effects management	(1) Most focused on short-term side effects such as pain (painkillers) (2) Not familiar with the support options provided by paramedics and that this is also possible after completion of treatment	(1) Important to explain side effects and their management such as treatment by SLPs and dieticians

SLP = Speech-Language-Pathologists.

centers. Interviews lasted on average 26 min (range 22 – 35). All agreed that a PDA would be a valuable addition for the decision-making process in this group, and that the main goal should be to avoid multimodality

treatment to minimize treatment morbidity. There were different opinions regarding the occurrence of side effects and their severity (Table 2).

Patients

Ten patients were interviewed, which lasted on average 36.21 min (range 21.58–50.08). All patients initially stated that survival is the most important in decision-making, but after hearing survival is similar regardless of treatment modality, side-effects were mentioned as the leading factor in choosing treatment (See Table 2).

Prototype development PDA

The results of the selected literature, counseling materials and interviews were used to develop the first draft of the PDA. See Fig. 2.Fig. 3. Phase 2: Alpha testing of the Comprehensibility and usability

Experts

Sixteen experts evaluated the first draft, each focused mainly on their specialty (see Table 3). There was a discussion about HPV-status, and it was decided to make three versions of the PDA (HPV positive, negative, unknown) in which there would be different information regarding the etiology, risk factors, and survival. For HPV status ‘unknown’, survival numbers for HPV positive and negative are displayed. On a scale of 1 to 10 (worst to best, where ≥ 5.5 is sufficient) this draft of the PDA was rated 7.1 (median, range 6.0–7.5).

Patients

Fourteen patients went through the PDA during a thinking-out-loud session and completed a questionnaire. The PDA was rated as an easy-to-navigate website. They rated this draft a 7.9 (median, range 7.5–9.5).

Phase 3: Beta testing of the Feasibility.

Experts

Eighteen experts evaluated the last version of the PDA. Negative aspects were that the total duration to go through the PDA was rated as quite long (mean 21 min, range 12–45). Positive were the layout, structure of the website, and the addition of videos and graphs. All experts (n = 18) found the PDA feasible and a valuable addition to regular counseling. They rated this version of the PDA a 7.9 (median, range 7.5–8.5).

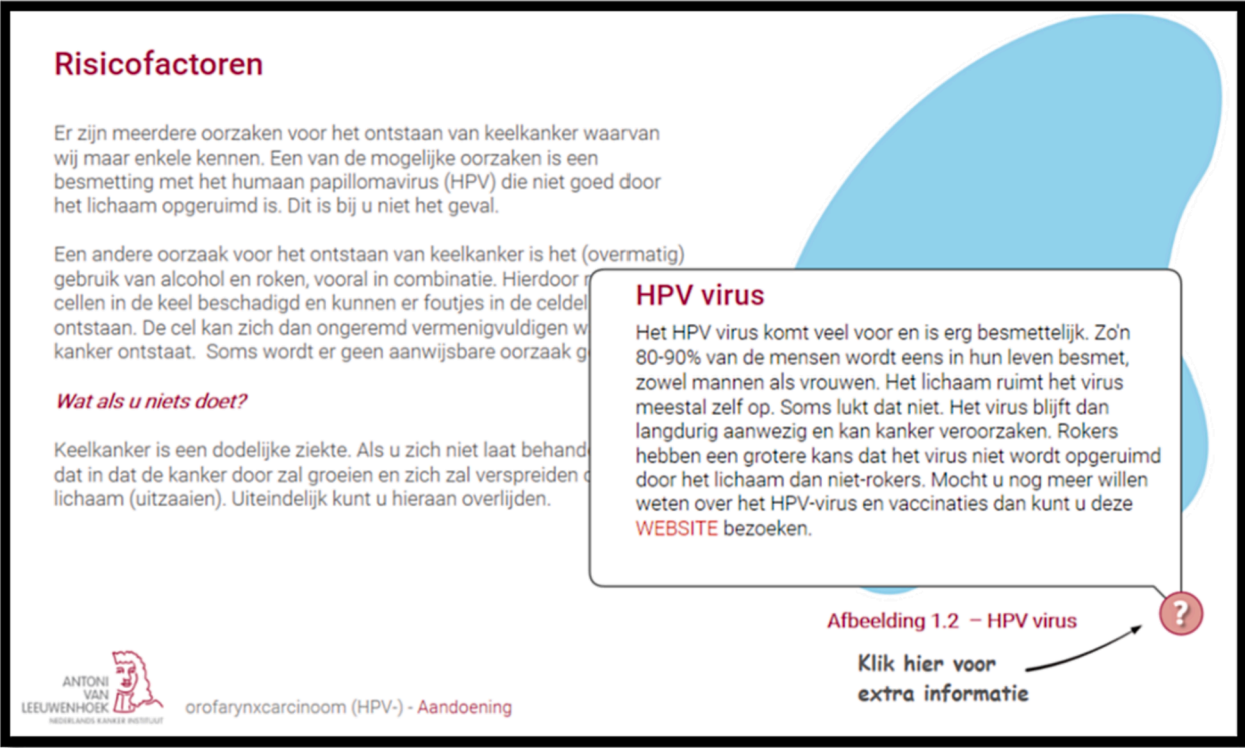


Fig. 2. First prototype of the PDA (in Dutch) Information about risk factors for developing OPSCC. It shows the additional information which appears when one clicks on the question mark in the right corner.



Fig. 3. Overview of used videos instead of text. A: Videos of the experiences of patients with radiation. There are also videos of patients surgically treated. B: Videos in which the consequences of the surgery are explained by a head-and-neck surgeon and a SLP. These videos are also available about radiation therapy and are explained by a radiation-oncologist and a SLP.

Patients

Twenty patients evaluated the final draft of the PDA. Patients reported that the time required to complete the final draft was appropriate (mean 37 min, range 15–60). All patients ($n = 20$) were satisfied with the feasibility and wished they had seen this PDA during counseling. They graded this version of the PDA with an 8.7 (median, range 8.0–10.0).

Final version of the PDA

The final version consists of several components, including a narrated slideshow that gives an overview of early stage OPSCC and its treatments along with their corresponding side effects. Additionally, there were side-by-side comparisons of the treatments, videos featuring physicians explaining treatments, side effects and their management, as well as videos of survivors detailing their personal experiences. The PDA also contained knowledge-based and personal value-based questions, as well as a printable worksheet where patients could record their answers and add additional questions to discuss with their physician. An appendix containing definitions of important terms was included, along with a page that provided patients with additional information, if needed.

The final version of the tool is available on <https://beslissamen.nl/>. This is a Dutch website that hosts multiple PDAs.

Discussion

This study outlines the development and feasibility testing of the first Dutch multidisciplinary PDA for patients with an early stage OPSCC) who are eligible for both treatment with radiation therapy or transoral (robotic) surgery with or without ND, as a single modality treatment with curative intent. Experts and patients perspectives were carefully considered during the development of this tool, which underwent extensive editing to ensure it was easy to understand, usable, feasible, and well-designed. With the incidence of OPSCC on the rise and a lack of consensus regarding radiation- versus surgery-based treatments, our PDA offers a helpful framework for newly diagnosed patients to make treatment decisions that align with their personal values but also increase their knowledge on the disease, treatment and possibilities.

Increasing attention is being given worldwide to the implementation of shared decision-making and associated tools; in the Netherlands this is an important topic in the vision document “Medical Specialist 2025” of the “Federation of Medical Specialists” [19]. Additionally, a campaign called “Start a Good Conversation” was launched in 2022, focusing on shared decision-making. This collaborative effort involves various organizations including the Federation of Medical Specialists, General Practitioners Association, Ministry of Public Health, Welfare and Sport, Dutch Association of Hospitals, Patients Federation, and Health Insurers

Table 3

Overview of the development of the PDA per phase, and quotes.

	Patients	Physicians	Quotes	Adjustments
Phase 1	<p>- Survival is the most important outcome</p> <p>- Side-effects should be the leading factor in choosing type of treatment</p> <p>- Receiving the diagnosis is overwhelming and stressful</p> <p>- Most received information was too extensive and complex</p> <p>- 70 % of the patients did not feel well informed after counseling</p> <p>- 50 % of the patients was not aware surgery could be a potential treatment</p>	<p>- All agreed that a PDA would be a valuable addition for the decision-making process</p> <p>- The main goal should be to avoid multimodality treatment to reduce treatment side effects</p>	<p>- HNS 2 (F, 51y): <i>"It is complex and difficult to determine which treatment is best for this group, also for us as physicians. You want to give the treatment that does the least harm, but up until now it remains unclear which treatment has least side-effects. Therefore, it is important to know patients' preferences and to inform them about both options, so that the patient, together with family or friends, and of course with our guidance, can make a choice in the treatment that suits him or her best."</i></p> <p>- RO 7 (F, 50y): <i>"My ultimate goal is to ensure that patients do not have to undergo multimodality treatment and therefore experience as few side effects as possible. With surgery, there is a potential risk for the need of adjuvant radiotherapy either to the neck or the primary site in case of inadequate margins or involvement of multiple lymph nodes or extra capsular spread. It is important that the patient is aware of this as part of treatment decision making."</i></p> <p>- Patient 7 (F, 62 years): <i>"When I received the diagnosis and</i></p>	<p>- The results of the literature search, counseling materials and interviews were used to develop the first draft of the PDA.</p> <p>- Simultaneously the first prototypes were designed.</p>

Table 3 (continued)

	Patients	Physicians	Quotes	Adjustments
Phase 2	<p>- 12/14 (86 %) stated there was too much text, which hampered focus and the use of the PDA</p> <p>- 8/14 (57 %) mentioned that the used level of language was too complex</p> <p>- All patients stated that more graphs and videos would make the decision aid easier and more accessible for everyone</p>	<p>CE: language level was too complex to be accessible to all. Also, the amount of text was too much, and the use of graphs and videos was too limited</p> <p>SLP: the amount of information was rated good, but more focus is needed on the management of potential side effects</p> <p>PT: information on nerve palsy after neck dissection is lacking</p> <p>HNS en RO: both wished to add more information regarding side effects and risks related to the treatment of the other specialty</p> <p>Overall: The decision aid should be adjusted for HPV status (positive, negative, and unknown)</p>	<p>information about treatments, I could not remember a thing that was said. All the appointments were on the same day, and everyone was using such difficult language. It was also because of the stress, but it was also just too much for me, and therefore I did not feel prepared for the treatment."</p> <p>- CE 1 (F, 54y): <i>"Unfortunately, medical terminology is still widely used during counseling. This is often complicated information and can create patient anxiety and therefore make them reluctant to ask questions. It is so important that treatments are explained in understandable language, and preferably visually assisted to improve intelligibility for every patient."</i></p>	<p>- Rewriting and concision of text (language level B1)[18]</p> <p>- Replacing text with graphics, animations and videos</p> <p>- Recording of videos in which survivors tell about their experiences</p> <p>- Information on nerve damage during a neck dissection was added</p>
Phase 3	<p>- The amount of time needed to finalize the final draft was in the right</p>	<p>- The videos are too long, and the possibility to be paused and</p>	<p>- HNS 8 (M, 61y): <i>"The goal of the decision aid should be to enable the</i></p>	<p>- Videos are shortened and can be paused and stopped</p>

(continued on next page)

Table 3 (continued)

Patients	Physicians	Quotes	Adjustments
proportion (mean 37 min, range 15–60)	exit the videos should be added	<i>patient to weigh and consider various aspects of the treatment.</i>	- Added the possibility to skip parts in the PDA (only for the general information about the disease)
- Patients who received RT as treatment stated they would like more information to be added on the potential side effects on dental status and loss of hair in the radiated area	- The total duration to go through the PDA was rated as quite long (mean 21 min, range 12–45)	<i>During my consultations I always discuss surgery and the associated quality of life. Is that acceptable for them, even if it is unsure? Then we will operate.</i>	- Added information about teeth extraction, hair loss in radiation field
- All patients (n = 20) were satisfied with the feasibility and wished they had seen this PDA during counseling		<i>Interestingly, patients often express that they prioritize quality of life. But controversially they can state they prioritize survival. Hopefully, by providing patients with a clearer understanding through the decision aid, they can make more informed choices”.</i>	- All text was recorded to create the opportunity to listen to the information and make the PDA more accessible
		- SLP. 2 (F, 36y): “Important is that patients know that we are here to support them in the side-effects that they will endure during and after treatment, but also what kind of side-effects they can expect.”	

PDA = Patient Decision Aid, RO = radiation-oncologist, HNS = Head-and-Neck surgeon, SLP = speech-and-language pathologist, PT = physiotherapist, CE = communication expert.

[20]. The campaign offers guidance for healthcare providers and patients to facilitate shared decision-making, as well as opportunities for collaborative development of decision aids and other tools.

In the Netherlands, multiple PDAs for several medical purposes have been developed, but for head-and-neck oncology only a PDA for advanced laryngeal carcinoma is available, of which the impact is still being studied [11]. One could state that decision aid tool development for head and neck cancer is falling behind compared to other oncological diseases [21–25].

We found that all patients were aware of radiation treatment, but not all were aware of the option of surgical treatment. This is quite interesting considering they were eligible for both, as judged by the multidisciplinary tumor board. It is unclear if both treatments were not discussed, or if patients have forgotten this information, referred to as ‘recall bias’ [26]. Important factors for decision-making for patients were clarity regarding equal survival numbers for these two treatments, focus on differences in short-term side-effects, but most important long-term side-effects. A research group from the Johns Hopkins hospital

developed an PDA for OPSCC patients and also found that patients primarily focus on survival. Most of their patients felt well informed by their physicians, whereas our patients felt overwhelmed and the used language was too technical and therefore too difficult [12,27]. Another PDA for OPSCC has been developed in Ontario [28]. They developed the PDA with healthy volunteers and focused on their treatment preference, showing a preference for TORS above radiation, based on the side-effects.

Our study reveals that both patients and physicians perceive the PDA as a valuable supplement to traditional counseling. However, notable distinctions arise between physicians and patients. Physicians tend to prefer offering extensive information, whilst patients express concerns about information overload. On the other hand, physicians report perceiving the time required to utilize the decision aid as relatively high, whereas patients rate it favorably. Once again, this underscores the importance of collaborative efforts between physicians and patients, particularly considering the substantial evidence indicating that patients and physicians prioritize different aspects of disease and treatment [29–31]. Physicians were satisfied with the results and most of all with the use of videos and graphics. For successful utilization, an effective implementation plan is crucial, particularly in determining how the PDA will be used: whether during counseling sessions with doctors, in collaboration with specialized nurses, or even in the comfort of one’s home.

Evaluation of patients’ preferences is a difficult task and is quite often overlooked or forborne in the era of national guidelines and results from multidisciplinary meetings in which strong emphasis is placed on survival outcomes. Furthermore, treatment choices can be highly dependent on the type of information provided during counseling. As physicians have limited consultation time, and physicians find it difficult to assess patients’ treatment preferences, levels of shared decision-making are low [32,33]. This might result in decision regret since patients are not aware of treatments and might undergo a treatment that is not fitting their preferences [34,35]. Tools like this PDA will be a perfect solution to bridge this gap.

Limitations

As a result of the COVID-19 pandemic, our study was limited to including patients solely from The Netherlands Cancer Institute. Additionally, the second and third phases had to be conducted remotely via phone or digital means, although the ideal scenario would have been in-person interactions. Literature comparing TORS and radiotherapy in this type of OPSCCs was scarce during the first phase of this study. A more recent study (which was not available during the development of this PDA) about long-term results of the ORATOR trial showed that swallowing difference between primary radiotherapy and TORS approaches persists but decreases over time [8]. It is worth noting that the educational level of the participating patients surpasses the average level in the Netherlands. Nevertheless, with the assistance of the patient society and communication experts, we ensured the accessibility of the PDA for individuals from diverse backgrounds, but at this moment only in Dutch. However, further testing on new patients presenting with early oropharyngeal cancer is yet to be conducted.

Conclusion

We developed a Dutch multidisciplinary patient decision aid focusing on treatment decisions for oropharyngeal tumors for whom primary transoral (robotic) surgery could be a curative treatment, following the quality criteria of IPDAS [36]. This web-based tool has shown to be feasible and an addition for regular counseling, as assessed by clinicians and OPSCC survivors.

To this end, a multicenter trial has started in 2022 comparing regular care to patients receiving the PDA (<https://www.kanker.nl>, trial 1339) to investigate the effect of using a PDA in daily practice on patient

knowledge and decisional conflict. Results are expected in 2026.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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