Head and Neck cancer patients’ preferences for individualized prognostic information: a focus group study

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Abstract

Background

Head and Neck cancer (HNC) is characterized by significant mortality and morbidity. Treatment is often invasive and interferes with vital functions, resulting in a delicate balance between survival benefit and deterioration in quality of life (QoL). Therefore, including prognostic information during patient counseling can be of great importance. The first aim of this study was to explore HNC patients’ preferences for receiving prognostic information. The second aim of this study was to explore patients’ views on “OncologIQ”, a prognostic model developed to estimate overall survival in newly diagnosed HNC patients.

Methods

We conducted a single center qualitative study by organizing five focus groups with HNC patients (n= 21) and their caregivers (n= 19), categorized in: 1) small laryngeal carcinomas treated with radiotherapy or laser, 2) extensive oral cavity procedures, 3) total laryngectomy, 4) chemoradiation, 5) other treatments. The interview guide consisted of two main topics: life-expectancy and the prognostic model OncologIQ. All focus groups were recorded, transcribed and coded. Themes were derived using content analysis.

Results

All patients found it important to receive information about their life-expectancy. While disclosing prognostic information in general terms like “the cancer is curable” gives enough reassurance for most patients, some also wanted numerical information like OncologIQ’s prognostic estimates. Overall, patients thought life-expectancy should not be discussed shortly after cancer diagnosis disclosure, as a certain time is needed to process the first shock. They had a stronger preference for receiving prognostic information in case of a poor prognosis. Prognostic information should also include information on the expected QoL. The pie chart was the most preferred chart for discussing survival rates.

Conclusions

HNC patients find it important to receive prognostic information. A tailor-made approach is necessary
to provide customized prognostic information. A clinical practice guideline was developed to support professionals in sharing prognostic information, aiming to improve shared decision making and patient-centered care.

Background

Head and Neck cancer (HNC) is an aggressive type of cancer characterized by significant mortality and morbidity (1-4). Treatment is often invasive and interferes with vital functions such as breathing, swallowing, and speech. In addition, patients often face psychosocial problems and experience body image dissatisfaction as a result of the mutilating procedures (2, 5). On the one hand physicians aim for cure and prolonging life, while on the other hand they strive for optimization of quality of life (QoL). This often results in a delicate balance between survival benefit and the functional, and psychosocial disabilities a patient is willing to accept after treatment. Therefore adequate counseling of patients including prognostic information can be of great importance. Previous research focused on whether or not to disclose the prognosis (6). More recently the focus has shifted more in-depth to what information to provide, and how to do this (6-8). This is in line with the increased attention for shared decision making (SDM). Patients need to be well-informed before they can be actively involved in treatment decisions (9, 10). As patients may not be able to make well-informed treatment decisions without understanding their prognosis, providing prognostic information is a key factor in SDM.

We recently published the results of a qualitative research, focusing on treatment discussions among HNC patients and their doctors. We found that in only 6% of the consultations doctors provided quantitative prognostic information, by discussing numbers, such as percentages. In 94% qualitative prognostic information was provided, by using words such as “curable” and “good prospect” (11). The current study is the second step in our qualitative research by exploring HNC patients’ preferences and views on receiving prognostic information. Relatively little attention has been paid to this topic. Some cancer patients want to know everything, while others are overwhelmed by too much information. Furthermore, each patient group has its own characteristics and preferences. For example, patients with breast cancer are considered to have high information needs (12). To our knowledge, there are no studies published that explore HNC patients’ views on receiving quantitative prognostic information. Therefore, research is needed on what these patients want to know about their prognosis and in which manner they wish this information to be conveyed to enable better counseling and patient-centered care.

Physicians are often unable to forecast an individual’s life-expectancy and tend to overestimate survival (13, 14). This can lead to concerns of being proved inaccurate and therefore reluctance to discuss the prognosis (15). Survival rates of cancer are traditionally based on the TNM-classification of the tumor. These are however general estimates of a heterogeneous group of
patients and not tailored to an individual’s prospect. Prognostic models that include patient specific predictors, like age and co-morbidity, could help doctors to provide a more individual prognosis. Our department developed a prognostic model, named ‘OncologIQ’ (see figure 1) (16-18). This model calculates an individual estimation of the remaining life-span of newly diagnosed HNC patients. It gives a 1 to 10-year survival prediction, combining the TNM-classification with patient-specific predictors, such as age, sex, and co-morbidity (16-18). This model could support doctors with prognostication during patient encounters, by providing more accurate estimates of their survival. However, it remains unclear if, how, and when this prognostic information should be shared with HNC patients? Furthermore, how should one visualize the individual survival estimates and in which manner should healthcare providers explain the results? While more prognostic models are developed, there is a dearth of evidence on the impact of the use of such models in clinical practice(19), and to what level patients appreciate and understand the information provided (20). Our study fills this gap by exploring patients thoughts on OncologIQ.

The aim of the current study was to explore 1) HNC patients’ preferences for receiving prognostic information, 2) and their views on the prognostic model OncologIQ. By examining patients’ views on these topics, we can optimize counseling between physicians and patients. In addition, a clinical practice guideline on how to use OncologIQ for individualized prognostic counseling was developed.

Methods
We conducted a single center qualitative study by organizing five focus groups with HNC patients and their caregivers between December 2016 and February 2017, aiming to explore their preferences for receiving prognostic information on life-expectancy. Methods and results are described using the Consolidated Criteria for Reporting Qualitative Research (COREQ) (21).

Definition of prognosis
In this study we refer to the concept of prognosis from two different angles:
Qualitative information: general terms like ‘the cancer is curable’
Quantitative information: numbers or percentages, like survival rates.

Research team & reflexivity
The research team consisted of three investigators. M.P.J. Offerman (MO), PhD, is a psychologist and has several years of experience with focus group research. The second investigator, A. Hoesseini (AH), MD, is a physician and PhD candidate. The third investigator, E.A.C. Dronkers (ED), MD, is also a physician and PhD candidate. MO and AH conducted the focus groups. There was no relationship established with the participants prior to the beginning of the study. Treating physicians were not allowed to attend the focus groups, so participants would not feel reluctant to share their thoughts.

Study design
This study was approved by the ethics committee of the Erasmus Medical Center (MEC-2013-052). Purposive sampling was used by dividing patients in five treatment groups: 1) small laryngeal carcinomas treated with radiotherapy or laser, 2) extensive oral cavity procedures, 3) total laryngectomy, 4) chemoradiation, 5) other treatments. In this way, we selected patients who had a shared experience and thus were more likely to feel understood by each other. Participants were consecutively selected by AH if they had undergone treatment for HNC in the Erasmus MC Cancer Institute, six to 18 months before selection. Caregivers were encouraged to accompany patients. See figure 2 for the patients selection criteria and exclusion criteria. In total 21 patients gave their informed consent and participated. All focus groups were held in the same conference room in the Erasmus MC Cancer Institute. Two volunteers were present during each focus group to welcome the patients. The volunteers did not know the patients and did not actively participate in the focus groups.

**Interview guide**

An interview guide was made prior to the start of the focus groups (see supplementary material). The main topics were 1) life-expectancy, and 2) the prognostic model OncologIQ. Each topic was first briefly introduced by AH and MO using a PowerPoint presentation. Subsequently closed-ended questions, using small cards, were answered by patients themselves. This enabled patients to react individually without being affected by the opinion of the other participants. Thereafter open-ended questions were asked to stimulate the group discussion, and caregivers were also encouraged to participate. The interview guide and presentation were adjusted once after the first focus group. In this focus group we introduced quantitative terms like “5-year survival” directly after discussing life-expectancy in qualitative terms such as “curable”. This resulted in confusion among patients and caregivers. They interpreted the 5-year survival rate as “being told you only have five more years left to live” or confused it with the 5-year follow-up after the diagnosis. Therefore, we decided to introduce life-expectancy in qualitative terms more extensively before the break and introduce quantitative terms like “5-years survival” after the break in the next focus groups. We also added one quantitative question on whether the physician should use a chart when explaining survival rates. After these adjustments no problems were encountered in focus group two until five, and therefore no further adjustments were made. All focus groups were digitally recorded. The mean duration of the focus groups was 2 hours and 7 minutes. Researcher notes were made during each focus group. The focus groups were transcribed by AH and one of our volunteers.

**Data analysis**

Two researchers (AH and MO) coded all transcripts and discussed the coding for each group until consensus was reached. Themes were derived from the coded data by AH and MO individually. These themes were discussed and if necessary rearranged, starting with one focus group, and adding the
others one by one. When there was no agreement on the themes or on the matching of quotations with the themes, consensus was reached after an in-depth discussion. After discussing the fourth focus group, no new themes were identified and therefore data saturation occurred. The next step was verification of the results by the third researcher (ED). She was given parts of coded transcripts and was asked to match them with the identified themes, and if deemed necessary suggest new themes or codes. No new themes were identified by ED, however some (sub)themes were rearranged. Finally, one quotation per (sub)theme was chosen jointly to include in the results section. NVivo 12 was used to manage the data. The participants did not provide feedback on the findings.

Results

Participants

Table 1 shows an overview of the number of patients and caregivers in each focus group, and patient characteristics. In total 17 patients (81%) were accompanied by their caregiver(s). In 15/17 of the cases (88.2%) this was a partner. One patient took a sibling with her and one patient was accompanied by both his partner and two children. Education level was categorized according to the International Standard Classification of Education(22, 23).

1) Life-expectancy

After the introduction of the main topic life-expectancy, we first asked patients to what extent they found it important to receive information about their life-expectancy in general (see also attachment 1). All patients found that important: thirteen patients (62%) answered “very important”, the remaining eight (38%) answered “somewhat important”. In total three themes and 12 subthemes were derived from the transcripts (see table 2).

------------- insert table 2 here ------------------

2) The prognostic model OncologIQ

Table 3 gives an overview of the themes that were derived from the discussions on OncologIQ. In
addition, several recommendations were shared. Table 4 shows several visual formats of communication and patients’ preferences for the selected charts. The pie chart was the most preferred chart. All patients in focus group two until five (n = 15) preferred the combination of verbal explanation of survival rates and a visual presentation with a chart, over a verbal explanation solely. This was deemed easier to understand.

Discussion
To our knowledge, this is the first study offering in-depth understanding of HNC patients’ preferences for disclosure of prognostic information, and the use of a prognostic model during treatment decision consultations.

1) Life-expectancy
Understanding the concept & using a tailor-made approach
While all patients considered it important to receive information about their prognosis, only some of them wanted to receive this in a specific quantitative manner, like 5-year survival rates. This is in line with previous research among patients with advanced or incurable cancer (24, 25). The majority of patients wanted to receive prognostic information from their doctor in general terms, like ‘your cancer can be well treated’. This kind of qualitative information would give these patients enough reassurance for the first moment. Even though doctors generally use the concept 5-year survival rate, participants often did not understand this concept or confused it with other terms, for example chances of cure, and thought it had a negative connotation. Overall, little is known about patients’ awareness, and understanding of prognosis(6). Previous research stressed that in some cases cancer patients misunderstand or fail to absorb the information given, cannot recall the status of their disease and often overestimate their survival chances (6, 26-28).

The need for receiving prognostic information was dependent on different circumstances. This means that sharing prognostic information requires a tailor-made approach. Patients had a stronger preference for quantitative information like months or survival rates, in the hypothetical case of cancer recurrence and/or a poor prognosis. This kind of information would enable them to weigh whether undergoing a second treatment to prolong survival would be worth the ‘costs’.

Prognostic information is not a standalone concept according to patients and caregivers. Patients also expressed the need for prognostic information about their expected quality of life, since this would be
of significant importance in the decision-making process. Fried et al. asked 226 patients with a limited life expectancy whether they would choose a treatment with survival, but with severe functional or cognitive impairment. 74.4% of patients answered they would not accept severe functional impairment and 88.8% would not accept cognitive impairment, and thus rather face death (29). However, more recent research by Blanchard et al. among HNC patients showed that they overall prioritize survival over functional endpoints (30).

In case patients want to receive quantitative information, what would be the right timing to share this? Our focus group results suggest that the right timing and phasing are of key importance. It seems that life-expectancy should be best discussed after the conversation in which the cancer diagnosis is given. According to most patients and their caregivers, it would be too stressful to discuss this all at once.

It also depends on personal preferences whether a patient wants to receive prognostic information. While on the one hand some patients gain an increased sense of control by receiving more information about their disease and prognosis, others want to receive very little information. The latter group often wants the doctor to take control and is not interested in the details on treatment or prognosis. Receiving unwanted prognostic information could destroy hope and therefore patients’ needs should be explored beforehand (31), instead of bluntly confronting them with unwanted information.

Who should take the initiative in exploring prognostic information needs? While some patients will take the lead, others aren’t capable or don’t want to. Therefore, according to the participants, the healthcare provider should be the one to introduce the topic, while the patient is given the opportunity to decide whether he or she wants to receive the information. During a qualitative research among advanced cancer patients by Clayton et al. most patients and caregivers said a physician should offer to discuss the prognosis, if the option to decline the information was also provided (32).

**Communication skills professional**

According to our participants, doctors should be honest while discussing the prognosis without taking away hope, and tailor prognostic information after exploring patients’ needs. The importance of being realistic and honest while maintaining hope is also identified in previous literature on patients with advanced or incurable cancer (33-36). For example, Kutner et al. found that while 100% of patients in their survey wanted honesty from clinicians, 91% also wanted them to be optimistic (33). Balancing
between honesty while disclosing prognosis and maintaining hope can be a challenging task for healthcare providers (35, 37).

2) The prognostic model OncologIQ

Some patients would appreciate counseling with OncologIQ as they thought it was clear and more personalized, while others were in doubt. Some patients didn’t want counseling with OncologIQ at all because of the need to maintain some ambiguity about the future. This need to maintain ambiguity about outcomes, is also identified in previous research among advanced or incurable cancer patients (25, 31, 34). Ambiguity could help to maintain hope and avoids a blunt confrontation with the facts. Participants shared several recommendations to improve the model. In three focus groups caregivers were concerned that the monthly health insurance premium would rise, if the insurance companies would also have access to an individuals’ prognostic estimate. Questions on this topic should be considered when using a prognostic model for counseling.

OncologIQ could take away physicians reluctance to discuss the prognosis and reduce ambiguity in case of conflicting opinions among healthcare professionals by providing individual estimates. Previous research showed physicians’ willingness to use prognostic models in end-of-life care, aiming to improve prognostic confidence (15). It also enabled physicians’ to take a more directive role in specific cases where the expected prognosis significantly differs from patients’ expectations, and it reduced ambiguity in case of conflicting opinions about prognosis among colleagues (15).

Visual formats of communication

Prognosis can be presented in various formats. While previous research showed that most persons find numbers and 100-person diagrams easiest to understand (38, 39), the HNC patients in this study preferred the pie chart. The pie chart was a favorite because they thought it was clear at a glance (see table 4) and less confronting than some of the other formats. The 100-person diagram was considered too confronting by both patients and caregivers. This is in line with previous research that explored this by using a 100-faces diagram (39). In addition, Davey et al. stated that the survival graph was considered negative, since it showed the constantly increasing mortality. In the current study, patients’ thoughts on the survival graph were also mostly negative. They found it too mathematical, since on must first must interpret the X- and Y-axis. Davey et al. also tested cancer patients’ understanding of the survival graph: only six out of 26 patients correctly interpreted the graph (39). Patients’ preferences to combine verbal explanation with visual information when discussing prognosis over a verbal explanation solely is also reported in previous research on this topic (40). Furthermore, it is unclear as to what extent patients understand the uncertainty around prognostic models’ estimates (41). Presenting data uncertainty is difficult and there is no consensus
about the optimal way to communicate different types of uncertainty (41, 42).

**Practice implications:** a guideline for individualized prognostic counseling.

Based on the results of this study a clinical practice guideline was developed that includes basic steps for sharing individualized prognostic information (see figure 3). While our earlier published guideline for professional communication focuses on general aspects of sharing prognostic information with HNC patients (11), this guideline specifically focuses on how to share the information provided by the prognostic model OncologIQ. It could also be used for other similar prognostic models in HNC.

**Strengths and limitations**

One must first listen to patients’ preferences and needs, to be able to provide patient-centered care. The use of a qualitative methodology provided us with rich data on HNC patients’ preferences on these vital but unexplored topics. In addition, we included a representative sample of our patient population by selecting patients consecutively. However, it is difficult to make assumptions on its generalizability. This study focused on patients with HNC in the curative setting. Since each setting has its own concerns, the generalizability of these results to the incurable setting is not desirable. Also, our results may be different in other, non-Western, cultures or countries. The presence of family members or other caregivers adds complexity to prognostic discussions since they may have different information needs (43). We purposely chose to include caregivers in the focus groups, as they are also present during the treatment decision consultation.

**Future perspectives**

The results of the current study have been used to improve OncologIQ. Currently the prognostic model has been updated. In the first place because of the improvement of survival of HNC patients in the past years (44). The second aim of the update was to test whether adding new prognostic factors, like smoking or alcohol consumption, would improve model performance. Also a visual format for patients has been developed, including a pie chart of the 5-year survival rate. The next step will be to evaluate the clinical impact of OncologIQ in a prospective clinical trial with sequential cohorts. The primary outcome of this trial is decisional conflict among HNC patients. The impact of the use of OncologIQ in our multidisciplinary tumor board meetings will also be investigated by evaluating treatment proposals and healthcare providers therapeutic confidence scores with and without the use of the model.

Another future aim would be to develop a prognostic model that includes both survival and quality of life for HNC patients. Despite not addressing this future prospective during the focus groups, several patients stressed the importance of combining both survival and quality of life, rather than focusing solely on survival. Due to the implementation of our Healthcare Monitor we will be able
to meet this need in the future (45). With this monitor we are collecting electronically patient reported outcomes (ePRO) on physical and psychosocial functioning from intake until the last follow-up visit since 2013. In the first place this is done to improve patient care and counseling, although these data could also be used for research purposes.

Conclusions
This study is first in examining HNC patients’ preferences for disclosure of prognostic information, and the use of a prognostic model. Overall, the findings of the current study highlight the importance of exploring patients’ thoughts and needs, in order to enhance patient-centered care. While disclosing prognostic information in general terms like “the cancer is curable” gives enough reassurance for most patients, some also wanted numerical information like OncologIQ’s prognostic estimates. A tailor-made approach is necessary to provide this prognostic information in a customized manner. A clinical practice guideline was developed to support the healthcare professional in sharing individualized prognostic information, aiming to improve shared decision making.

Abbreviations

| Abbreviation | Definition                                      |
|--------------|------------------------------------------------|
| HNC          | Head and Neck cancer                           |
| QoL          | Quality of Life                                |
| SDM          | Shared Decision Making                         |
| COREQ        | Consolidated Criteria for Reporting Qualitative Research |
| ePRO         | Electronically Patient Reported Outcomes       |

Declarations

**Ethics approval and consent to participate:** This study was approved by the ethics committee of the Erasmus Medical Center (MEC-2013-052). Although no identifying information is used, the study participants provided informed consent in the form of verbal agreement at the beginning of each focus group interview. In addition, all patients signed an informed consent form.

**Consent for publication:** Not applicable.

**Availability of data and materials:** The datasets generated and/or analyzed during the current study are not publicly available due to the qualitative content of the dataset. The full dataset could contain information that might compromise research participants’ privacy and/or their conditions of consent. The data that support the findings of this study may be available on reasonable request from the corresponding author [AH].

**Competing interests:** The authors declare that they have no competing interests.

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commercial, or not-for-profit sectors.

**Authors’ contributions:** AH and MO served as co-principle investigators and conceived the study. AH recruited study participants and transcribed the data. AH and MO conducted the focus groups and analyzed and interpreted the data. AH took primary responsibility for writing the manuscript. ED contributed to data analysis, data interpretation and manuscript revision. AS, JH, RBJ contributed to the study design and critically revised the manuscript. All authors commented on the drafts and approved the final draft. AH is the corresponding author (a.hoesseini@erasmusmc.nl).

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Monitor for routine symptom monitoring of head and neck oncology patients.

Unpublished results (submitted 2019).

Tables
Due to technical limitations, tables are only available as a download in the supplemental files section.

Figures

Figure 1
An example of OncologIQ’s estimates, as presented during the focus groups.
Patient selection procedure. Exclusion criteria were: aged 80 years or older; histology of a carcinoma in situ; Korsakoff syndrome or dementia; severe alcohol and/or drugs abuse; possible recurrent or metastatic disease; recent hospitalization; simultaneous tumor outside of the head and neck region.
Figure 3

Clinical practice guideline for individualized prognostic counseling. *Keep the following in mind: do not to discuss life-expectancy in the same consult in which the cancer diagnosis is discussed but hereafter.

Supplementary Files
This is a list of supplementary files associated with this preprint. Click to download.

additional file 1_supplementary material.docx
Table 1.jpg
additional file 2_tables 2 & 3.docx
Table 4.jpg