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## **Needs and preferences of patients with head and neck cancer in integrated care**

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**Brief running title:** Patients' needs and preferences in integrated care

**Key words:** Head and neck cancer; Multidisciplinary care; Integrated care; Patient' needs and preferences; Patient-Centered Care

## **Abstract**

**Objectives:** Incorporation of patients' perspectives in daily practice is necessary to adapt care to users' needs. However, information on patients' needs and preferences for integrated care is lacking. The aim was to explore these needs and preferences, taking patients with head and neck cancer (HNC) as example, to adapt current integrated care to be more patient-centered.

**Design:** Semi-structured interviews were held with current and former patients and chairmen of patient associations. Relevant needs and preferences were identified and categorized using the eight-dimension Picker model of patient-centered care.

**Setting:** Integrated HNC in the Netherlands.

**Participants:** HNC-patients and chairmen of two Dutch HNC-patient associations.

**Main outcome measures:** Patients' needs and preferences of integrated HNC care categorized according the Picker model.

**Results:** A total of 34 themes of needs and preferences were identified, by 14 HNC-patients or their delegates, using the Picker dimensions. Themes often emerged were: personalization of healthcare regarding patients values, clear insight into the healthcare process at organizational level, use of personalized communication, education and information that meets patients requirements, adequate involvement of allied health professionals for physical support, more attention to the impact of HNC and its treatment, adequate involvement of family and friends, adequate general practitioner involvement in the after care, and waiting time reduction.

**Conclusions:** Monitoring the identified themes in integrated HNC care, fitting in the Picker model, will enable us to respond better to the needs and preferences of patients and patient-centered care in oncological care can be enhanced.

## Introduction

Head and Neck Cancer (HNC) is the sixth most common cause of cancer worldwide<sup>1</sup>. HNC and its treatment has significantly impact on a patient's well-being as HNCs grow relatively quickly in an anatomically and functionally complex area<sup>2,3</sup>. Patients often experience problems with speech, swallowing, and physical disfiguration due to treatment<sup>4-7</sup>. In addition, they often suffer from psychological disorders, such as depression and anxiety, and social problems, such as relationship difficulties with their partner and family members, and loss of work<sup>8-10</sup>. Therefore, HNC care is complex, requiring medical specialists and allied health professionals to collaborate throughout the entire healthcare process from the diagnostic phase until the surveillance phase. A strategy for better coordination of services across the entire care continuum with optimal alignment and collaboration of all disciplines is required<sup>11</sup>.

Nowadays, providing patient-centered care is an essential component of high quality integrated care<sup>12</sup>. Responding to the needs and preferences of patients for the delivery of healthcare is an important aspect of current healthcare policy worldwide<sup>13,14</sup>. It leads to positive clinical outcomes, for example better survival<sup>13</sup> or physical and emotional recovery<sup>15</sup>, and increased patient satisfaction<sup>16</sup>. Increased patient satisfaction might result in a better adherence to treatment recommendations and increase quality of life<sup>17</sup>.

Patient-centered care has been defined as “care which is responsive to consumer needs, values and preferences; integrated and coordinated; relieves physical discomfort; provides emotional support; allows for the involvement of family and friends; and supports the provision of information, communication and education to enable patients to understand and make informed decisions about their care”<sup>12</sup>. Also, this definition points out that patient-centered care is relevant during the entire healthcare process. However, until now, information on patients' needs and preferences for integrated cancer HNC care is lacking.

We aimed to identify all possible needs and preferences of Dutch HNC-patients' in integrated care to obtain tools to make current integrated HNC care more patient-centered.

By identifying those themes of healthcare where improvement regarding patient-centeredness is necessary, optimizing integrated care for patients with HNC is possible.

## **Materials and methods**

### *Study design*

In this exploratory study, semi-structured interviews were held until data saturation (the point at which no new information was mentioned in interviews<sup>18</sup>) was reached with current and former patients and the chairmen of two HNC patient associations. The aim of the interviews was to identify all possible needs and preferences of HNC-patients, to discuss these explored needs and preferences in a group meeting with all participants and to check if new items came forward. The Medical Ethical Committee (CMO) of the region Arnhem–Nijmegen assessed the study and declared that ethical approval was not necessary. The study is in agreement with the COREQ checklist.

### *Setting*

In the Netherlands, where approximately 3000 patients are yearly diagnosed with HNC, HNC care is centralized in 14 hospitals: eight Head and Neck Oncology Centres (HNOCs) and six affiliated centres<sup>19</sup>. The affiliated centres have committed themselves to using the same treatment protocols as the related HNOc. There are two Dutch patient associations: 'Stichting Klankbord' and 'NSVG'. Currently, they collaborate in one Dutch patient association 'Patiëntenvereniging Hoofd-hals'.

### *Participants*

Research shows that 13–15 interviewees are usually sufficient to reach data saturation<sup>18</sup>. Therefore, each of the 14 hospitals and both Dutch patient associations were asked to select one or two patients using the following inclusion criteria: the patient was diagnosed with

HNC, was treated with a curative or palliative intention, and had the capacity to overview his own healthcare process. In addition, the two chairmen of both patient associations were asked to participate (Table 1). Participants were approached either by telephone or email, depending on their ability to talk clearly on the phone. This was followed up by a letter or email to confirm their participation and a request to sign an informed consent form. A total of 12 patients and the two chairmen participated in the semi-structured interviews either by telephone ( $n = 8$ ) or in person ( $n = 6$ ). One of the two chairmen is a former HNC-patient. There was no relationship with the patients, only one chairman of a patient organization was part of the steering committee of a project where the study was part of.

#### *Data collection*

An expert panel developed a structured interview guide (Appendix 1). The interview guide contained open-ended questions and optional questions to deepen each topic. The interview guide contained four sections, referring to the referral, the diagnostic, treatment, and follow-up phases of HNC care. In each section, similar questions were asked emphasising the received healthcare in the specific phase. Questions focused on the needs and preferences, involvement of and communication among the different healthcare providers, strong and weak points of the received healthcare, and points for current healthcare improvement. The interview (lasting 30–45 minutes conducted by the first researcher (female, MSc Biomedical sciences, PhD student, experience for interviewing obtained in her master, 1<sup>st</sup> author)) was fixed regarding the sections, each interview started with the referral and ended with the follow-up phase. Within a section, the questions were flexible depending on the answers of the interviewee. The pilot for the interview was done with the first and the last author (female, senior researcher, experience with qualitative research). Patients did not receive questions in advance and were not informed about the use of the framework to analyze the data using the eight-dimensions Picker model.

## *Analysis*

A deductive approach was used with the eight-dimensions Picker model as a basis for our analyzes (Table 2). This model contains dimensions regarding patient-centeredness of care and served as a theoretical framework for the analyzes of the interviews<sup>20,21</sup>. The model embodies the conviction that all patients deserve high-quality patient-centered care. The eight dimensions appear important and relevant in several European countries and in the USA<sup>22,23</sup>. Expressed needs and preferences were categorized into Picker dimensions using the following four steps. Step 1: marking expressed needs and preferences with codes. Step 2: categorizing codes dealing with the same subject into similar items. Step 3: categorizing items dealing with the same topic into similar themes, and step 4: categorizing themes into the Picker dimensions. For step 1, interviews were recorded using an audio recording device, transcribed verbatim and qualitatively analyzed using ATLAS.ti (version 7). To enhance the reliability and validity, coding was done by two researchers: the first and third author (female, BSc Medicine, inexperienced). The first four interviews were coded open ended independently by both researchers<sup>24</sup>. Hereafter, codes were compared and discussed until consensus was reached. One concept coding tree was made, e.g. axial coding, that was used to provide some support for the remaining interviews and to stimulate the researchers to keep the same focus<sup>24</sup>. In addition, both researchers could add, remove or move codes of the coding tree. Codes of the last ten independently coded interviews were compared and discussed until consensus was reached. Hereafter, the coding tree was finalized and the following steps were taken. Step 2-4 were done by the same two researchers. Disagreement was discussed between the two researchers and if needed classified with the last author (female, PhD) until consensus was reached. We aimed to fit all themes into the Picker dimensions, new dimensions were proposed if codes would not fit.

## **Results**

All invited patients and chairmen participated in the study (Table 1). A total of 34 themes of needs and preferences were analyzed (Table 3 and Figure 1) and all were categorized into

the Picker dimensions. All needs and preferences were discussed and approved in a group meeting with all participants. For a comprehensive and clear overview of the results, beneath we give a summary of most often mentioned themes in each domain with an explanation.

#### *Respect for patient-centered values*

The most important two themes that the interviewees mentioned regarding patient-centered values, was the expectation for personalized care regarding their individual values and assertiveness. Personalized care was expressed by the interviewees as listening to the patient, taking the patient seriously, and incorporating the patient's wishes into the healthcare process. In order to deliver personalized healthcare, interviewees mention that it is important that patients are assertive. For more assertive patients, it is easier to express their issues and questions, resulting in better care adapted to the needs of the patient.

#### *Coordination and integration of care*

An important aspect mentioned in this domain was the relevance of the healthcare process at the organizational level being clear. It was pointed out that this would increase the confidence of the patient in the healthcare provided, which might reduce their feeling of being ill.

In addition, involvement of allied health professionals, including oncology nurses, and peers at the right time in the healthcare process, according to the patient's needs, was also noted as being valuable. For example, the first patient does not prefer the involvement of a dietician, a second patient prefers the involvement of a dietician right after the diagnosis to give all available information about nutrition specified for their health process, and a third patient prefers the involvement of a dietician just before start of the treatment to give the most important information that is relevant at that time point and the rest of the information can follow on a later time point.

### *Information, communication, and education*

Important themes mentioned by the interviewees were the requirements for communication, information and education, and training of healthcare providers. Requirements mentioned by the interviewees were, clear, honest, complete and repeated informational and communication. This can increase trust in the healthcare provided and reduce possible feelings of uncertainty and doubt. Interviewees also pointed out that healthcare providers should be trained very well. This includes sufficient knowledge about HNC, the ability to communicate, as well as the skills and attitudes of doctors and nurses.

### *Physical comfort*

Interviewees mentioned that the involvement of the physiotherapist and speech therapist should be in line with patients' preferences, also the amount of support during the aftercare that should be provided. In addition, interviewees mentioned the restrictions and disadvantages of devices. More high quality devices will increase the motivation of patients to sport and go out again.

### *Emotional support and alleviation of fear and anxiety*

An important aspect of care mentioned by the interviewees was the involvement of psychological support at patient's preference, given by a psychologist but also by any allied health professional. In addition, interviewees mentioned that more attention should be given to the major impact of HNC and its treatment. Furthermore, emotional support from the general practitioner (GP) during aftercare was mentioned as being highly important since the support from the healthcare providers from the hospital will decrease. Less or no involvement might result in fear and feeling of helplessness of the patient.

### *Involvement of family and friends*

Support from family and friends was mentioned as highly important. Even, they concluded that a good partner or carer makes the allied health professionals less relevant in this situation. Furthermore, interviewees mentioned the involvement of family as an important issue. Especially regarding children: how do you involve children?

### *Transition and continuity of care*

An aspect that often emerged, according to the interviewees, was the 'gap' between the hospital and the home situation. The interviewees considered it important to better organize the transfer to reduce this void. To better organize the transfer, it is important to include the GP in the healthcare transfer, particularly, the GP should be well informed about the medical condition of the patient to prevent that a patient needs to inform the GP him/herself. In addition, the cooperation of the allied health professionals and the hospital is crucial. This includes knowledge of each other's discipline and reduction of repetition of care processes, which can increase trust in healthcare and might ensure optimal recovery.

### *Access to care*

The most important aspect in this domain concerned the delay between the visit to the GP or the dentist and the first appointment at a specialized hospital. This was caused either by the GP, dentist, or the general hospital, or by the patients themselves. Therefore, it is important to increase the knowledge about HNC to decrease the first delay. Secondly, they noted that there is an urgent need to reduce waiting times in the hospital, particularly prior to the start of treatment. On the other hand, they indicated that the waiting time between two treatments might result in a better recovery.

## Discussion

This study identifies a total of 34 themes of patients' needs and preferences, categorized according to the eight-dimension Picker model regarding patient-centeredness of care, for current integrated HNC care. The main themes emerging from the interviews were the personalized care regarding patient values (Respect for patient-centered values), a clear healthcare process at an organizational level (Coordination and integration of care), personalized communication and information that meets requirements (Information, communication, and education), involvement of allied health professionals for physical support (Physical support), more attention to the impact of HNC and its treatment (Emotional support), adequate support from family and friends making support from allied health professionals less necessary (Involvement of family and friends), adequate involvement of the GP in the after care (Transition and continuity), and reduction of waiting times prior to the start of the treatment (Access to care).

Unique for this study is that it demonstrates needs and preferences of HNC-patients over the entire healthcare process from the diagnostic phase until the surveillance phase. In addition, it demonstrates the relevance of both patient-centered care and integrated care for HNC-patients; two important aspects of healthcare published previously<sup>12,15,25</sup>. After analyzes of the interviews we identified many themes that fitted easily into the Picker dimensions of patient-centered care. For example, the need for personalized communication, the need for more attention to the impact of HNC and identified conditions to optimize transfer from the hospital to the home situation. In addition, needs and preferences for healthcare delivered by both medical specialists and allied health professionals emerged in the interviews. For example, the expertise and professionalism of doctors and the doctor-patient relationship are needs and preferences that refer to the medical specialist. Personalized involvement of allied health professionals for physical and emotional problems are examples of needs and preferences that refer to the allied health professional. However, personal preferences of the patient should not interfere with the best possible healthcare as described in evidence based

guidelines. The task of a(n allied) health professional is to deliver evidence based practice by incorporating best available evidence, clinicians' judgement and patient values and preferences. Herewith, the healthcare can be both personal based and evidence based<sup>26</sup>.

#### *Suggestions for daily practice*

Patients in our study expect an active involvement of GP's at referral, during transfer, and for emotional support in the aftercare. GPs' engagement can be increased by involving them in the multidisciplinary team meetings before determining the treatment<sup>27</sup> and before discharge of the patient<sup>28</sup>. In the last case, a patient-specific follow-up plan can be developed together with the GP, the specialist and the patient. Other initiatives exist to give the right support to GP's to develop their own role and to provide the best care for patients with cancer.

Examples of these initiatives are the Macmillan Cancer support in the UK or Oncological Networks in the Netherlands<sup>29</sup>. Moreover, multimedia campaigns as The Make Sense campaign can increase the awareness and knowledge of both patients, health professionals (including GPs) and society regarding head and neck cancer symptoms and subsequently drive earlier presentation, diagnosis and referral<sup>30</sup>. Therefore, it is important that more people know that this campaign exists.

#### *Strengths and limitations*

The selection of patients from across the spectrum of Dutch hospitals, and the inclusion of representatives from the patients associations, are strengths of this study. The aim of this explorative study was to identify all possible needs and preferences of HNC patients and not to give a representative set of their needs and preferences. Therefore, only data saturation was needed, which we indeed reached with our 14 patients<sup>18</sup>. A disadvantage might be that we only included patients, diagnosed with an oral cavity carcinoma or laryngeal carcinoma. However, most cancer treatments, independent of the type of HNC cancer, follow similar health care processes. Therefore, we think that most expressed needs and preferences for

HNC care are relevant for both the included and not included HNC cancer types. In addition, the included two tumor types represents 55% of the patient population in the Netherlands.

### Conclusions

Patients' needs and preferences for integrated oncological care were identified to obtain tools to make current care more patient-centered. Knowing the patients needs and preferences helps to improve healthcare accordingly. The next step is to quantify the expressed needs and preferences among a representative population, to explore to what extent the needs and preferences are met in practice and which has the highest priority.

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**Figure 1. Quotations expressed by current and former HNC-patients and the chairmen of two HNC-patient associations for each Picker dimension.**

## **Appendix 1 - Interview guide**

### **General information**

Name:

Age:

Diagnosis:

Year of diagnosis:

Type of treatment:

### **A. Received health care**

For each contact moment (A1 to A7) we focused on the following questions:

- What involved this process? How did it look like?
- How was the experience with the process? What went well, what could have been better? Why?
- Were allied health professionals involved in the process? was the involvement of allied health professionals as you preferred? If yes, why? If not, why?
- What would be any improvement for the process?

A1. before referral to specialized hospital?(GP and/or peripheral hospital)

A2. at first appointment in the specialized hospital?

A3. during diagnosis?

A4. at the consult that the treatment plan was discussed?

A5. during preparation of the treatment?

A6. during treatment?

A7. during the follow-up phase?

## **B. Specific organizational aspects in the received health care**

For each organizational aspects (B1 to B3) we focused, beside specific questions/topics, on the following questions:

- How did you experience the process?
- Was it as expected?
- What could have been better?

### **B1. Communication**

- Was there one contact person? Did you prefer that?
- Was communication clear about appointments, parking, with health professionals etc.?

### **B2. Information**

- Did you understood everything?
- Was the information enough?
- Was information given in the right format?
- Was family involved if you preferred?
- Were peers involved if you preferred?
- Was information repeated?

### **B3. Organization and coordination**

- Clear were you were expected?
- Waiting times
- Enough time for you as a patient

### **B4. Transfer to GP**

## **C. Overall experience**

- What was your best experience?
- What was your worst experience? And what improvement would you suggest?
- What would you suggest for future health?

<b>Table 1. Characteristics of participating patients.</b>					
	Age, years	Sex (n)	Type of tumor (n)	Type of treatment	Year of diagnosis
Patient 1	67	Male	Larynx	Operation & radiotherapy	2009
Patient 2	52	Male	Larynx	Operation & radiotherapy	2008
Patient 3	56	Female	Larynx	Operation & chemoradiation	2004
Patient 4	59	Male	Oral cavity	Operation	2013
Patient 5	60	Male	Oral cavity	Operation & radiotherapy	2011
Patient 6	66	Female	Larynx	Operation & radiotherapy	2004
Patient 7	58	Female	Oral cavity	Operation	2011
Patient 8	67	Female	Larynx	Operation & radiotherapy	2009
Patient 9	56	Female	Larynx	Operation & radiotherapy	2011
Patient 10	58	Male	Oral cavity	Chemoradiation	2012
Patient 11	65	Male	Oral cavity	Operation & radiotherapy	2005
Patient 12	50	Female	Oral cavity	Operation & radiotherapy	2009
Chairman 1	58	Male	Larynx	Operation & radiotherapy	1997
Chairman 2	69	Male	x	x	x

Table 2. Definition of the eight Picker dimensions translated to the Dutch situation.	
Picker dimensions	Definition of each dimension
1. Respect for patient-centered values	An awareness of quality-of-life issues, involvement in decision-making, dignity, and attention to patient's needs and autonomy
2. Coordination and integration of care	Care across clinical, ancillary, and support services and in the context of receiving front-line care
3. Information, communication, and education	On clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care, and health promotion by healthcare providers or patients themselves
4. Physical comfort	Pain management, help with activities of daily living, and clean and comfortable surroundings
5. Emotional support and alleviation of fear and anxiety	Support with issues such as clinical status, prognosis, and the impact of illness on patients, their families, and their finances
6. Involvement of family and friends	Involving family and friends in decision-making and awareness and accommodation of their needs as caregivers
7. Transition and continuity of care	Information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions
8. Access to care	Attention to time spent waiting for admission, diagnostics, treatment(s) or time between appointments in the hospital and with allied health professionals

Table 3. Expressed needs and preferences categorized into the Picker dimensions.		
Domains	Themes	Corresponding items
1. Respect for patient-centered values	– Personalized care regarding patient values	Healthcare providers should listen to the patient, take the patient seriously, and incorporate the patient's wishes into the treatment plan. In addition, they should give the patient the feeling that there is enough time and attention for the patient.
	– Assertiveness relevant in personal healthcare	Assertiveness of the patient is relevant to deliver personalized healthcare. Patients can come with their own questions towards healthcare professionals and can indicate better what they prefer. The amount of assertiveness required depends on the attitude of the healthcare professional.
	– Emotional support towards inability to speak	It is important to support the patient who has lost the ability to speak. For patients it is very frightening and frustrating to realize and to experience the loss of voice.
	– Hospital facilities	A clinic with a warm atmosphere results in calmness. In addition, a hospital room adapted to patients wishes is preferred.
	– Doctor–patient relationship	Integrity and mutual respect are necessary for a good doctor–patient relation.
	– Disease physically demanding as a single	More attention should be given to single persons in order to cope with the physical barriers, especially in the first phase of recovery.
2. Coordination and integration of care	– Clarity about healthcare process	The healthcare path should be clear regarding what the patient can expect, this means that each step that will be taken in the diagnostic phase will be clear. This is also expected of the treatment (especially regarding the operation).
	– Personalized involvement of allied health professionals	Involve allied healthcare professionals before or after the treatment, depending on patients' preferences and the advice of the healthcare professional. However, there should always be an option to meet the allied healthcare professional.
	– Availability of a contact person	Patients need to have one known person available in the multidisciplinary integrated healthcare team who can answer questions and address health-related issues. The contact person should be often available.
	– Involvement of oncology nurse and peers as personal experts	It is important to involve peers as personal experts, they are valuable for the patient on multiple timepoints. In addition, involving oncology nurses might result in time saving during the consult with the doctor, also, it is described as a more personal contact.
	– Personalized involvement of peers	Involve peers before or after the treatment, depending on patients' preferences and the advice of the healthcare professional. Nevertheless, the healthcare professional should always offer the option to meet a peer.
	– Personalized diagnostic phase	Adjust the number of diagnostic appointments one after the other according patients' preferences and combine medical consultations.
	– Home care for both patient and partner	Besides support for the patient, home care should be directed towards the partner as well.
3. Information, communication, and education	– Communication, information, and education meets requirements	Communication, information and education should be clear, honest, complete, and be repeated. It is acceptable to tell uncertainties about the healthcare process, as long as the information is clear. Information on the internet should be of good quality.

