

# Communication of prognosis in head and neck cancer patients; a descriptive qualitative analysis

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## ABSTRACT

In shared decision making it is important to adequately, timely and actively involve patients in treatment decisions. Sharing prognostic information can be of key importance. This study describes whether and how prognostic information on life expectancy is included during communication on diagnosis and treatment plans between physicians and head and neck (H&N) oncologic patients in different phases of disease. A descriptive, qualitative study was performed of n=23 audiotaped physician-patient conversations in which both palliative and curative treatment options were discussed and questions on prognosis were expected. Verbatim transcribed consultations were systematically analyzed. A distinction was made between prognostic information that was provided a) quantitatively: by giving numerical probability estimates, such as percentages or years or b) qualitatively: through the use of words such as 'most likely' or 'highly improbable'. In all consultations, H&N surgeons provided some prognostic information. In 5.9% of the provided prognostic information, a quantitative method was used. In 94.1% prognostic information was provided qualitatively, using six identified approaches. H&N surgeons possibly affect patients' perception of prognostic content with two identified communication styles: directive (more physician-centered) and affective (more patient-centered). This study is first in providing examples of how H&N surgeons communicate with their patients regarding prognosis in all stages of disease. They often exclude specific prognostic information. The study outcomes can be used as a first step in developing a guideline for sharing prognostic information in H&N oncologic patients, in order enable the process of shared decision making.

## INTRODUCTION

During the last decade patient centered communication and patient involvement in treatment decisions has become an important approach in clinical care.<sup>1</sup> The shared decision making approach (SDM) is considered to be a central component of treatment decision consultations.<sup>2</sup> Patients need to be well-informed in order to be able to be actively involved in treatment decisions.<sup>3</sup> Prognostic information may be a valuable factor in considering treatment options.<sup>4</sup> Besides content, the communication style within the professional setting is also important, especially since patients tend to remember only 20-60% of the information provided by their physician.<sup>5,7-8</sup> Furthermore, when patients do not fully understand their illness, prognosis and treatment options and physicians do not sufficiently elicit patients' values, this can worsen their physical and psychological suffering.<sup>9</sup>

The SDM approach is getting more attention in treatment decision consultations with head and neck (H&N) cancer patients.<sup>10</sup> The 5-year survival rates of H&N cancer remain around 50%.<sup>11</sup> Also, the commonly used treatment modalities are associated with high morbidity and impact on quality of life.<sup>12</sup> Especially in the case of treatment options with a direct impact on important functions, involving swallowing, taste or speech, there might be a difficult trade-off between life expectation or cure and quality of life. Therefore prognosis, morbidity and quality of life of H&N cancer patients can be significant topics in doctor-patient communication, especially in consultations during which treatment options are discussed.

However, communication on prognosis is difficult. Many physicians experience this particular task as distressing.<sup>13-15</sup> They avoid conversations addressing prognosis for many reasons, most frequently due to uncertainty about the actual prognosis or how to communicate this. Other reasons are lack of training, insufficient time to attend to the patient's emotional needs, and fear of a negative impact on the patient.<sup>14,16</sup> As a result, some physicians discuss prognosis in vague or in optimistic terms, avoid the topic unless the patient insists, or mainly focus the discussion on treatment options. Estimates of prognosis provided by physicians are also often overly optimistic when compared to actual or predicted outcomes.<sup>17-19</sup> On the other hand, interpretation of prognostic information by patients may range from unrealistic optimism to the belief that one will be the patient who experiences the bad outcome described.<sup>20</sup>

The way physicians provide prognostic information is of vital importance. Some rely on qualitative statements (e.g. *"I think he is unlikely to survive"*), whereas others use quantitative or numeric expressions (e.g. *"80% of patients in this situation do not survive"*).<sup>21</sup> Likewise, the framing of prognostic information, either positive or negative, might be different

among physicians (e.g. *“the chance of survival is 20%”* versus *“the chance that you’ll die will be 80%”*). Lastly, physician communication style can differ, either being directive (e.g. telling the patient what to do) or affective (e.g. autonomy supportive).<sup>22</sup> Research has shown that providing sufficient quantitative information allows patients to make fully informed decisions in contrast to providing solely qualitative information.<sup>4,21,23</sup> Also, giving numeric expressions of prognosis improves the accuracy of patients’ risk perceptions and the comfort with feeling informed.<sup>23</sup>

Most research in the field of communication of prognosis in cancer care focuses on end of life or palliative care. This is also the case for H&N cancer.<sup>24-26</sup> However, improving prognostic understanding is important during all stages of disease. The literature lacks information on communication of prognosis in H&N cancer patients, especially on those with curative treatment options.

This study’s primary purpose is to investigate whether prognostic information on life expectancy is included during communication on diagnosis and treatment plans between physicians and H&N oncologic patients in all phases of the disease. We also want to describe the communication style displayed by physicians as this can affect patients’ perceptions of prognostic content.

## METHODS

We performed a qualitative single-center descriptive study based on audio-taped real physician-patient consultations in which treatment options were discussed and questions on prognosis were to be expected. A qualitative approach is most suitable for in depth investigating health care issues in context and for taking into account interaction, behavior, and perceptions within groups.<sup>27</sup>

### Consultations

In this study, n=31 patients were approached to record the consultation with their physician. Patients were eligible if they received a treatment proposal for their recently diagnosed H&N cancer, regardless of the phase (curative/palliative) of their disease. Patients were recruited at the out-patient clinic of the Erasmus MC Cancer Institute and received oral and written counselling about this study by an independent researcher before entering the consultation with their physician. Written informed consent was obtained following guidelines of the Medical Ethical Committee. N=23 patients gave their consent and the consultations between them and n=7 physicians were digitally recorded. Eight patients

declined participation in this study due to privacy reasons. The seven physicians were all H&N cancer surgeons with relevant experience varying between 5 and 30 years.

### **Definition of prognostic information**

Prognosis was defined as life expectancy, survival and the prospect of cure as anticipated from the usual course of disease. We made a distinction between prognostic information that was provided quantitatively by giving numerical probability estimates such as percentages or years or qualitatively through use of words or phrases such as 'most likely', 'frequent' or 'highly improbable'.

### **Analytic procedures**

All verbatim transcribed consultations were analyzed by three independent researchers (ED, MB and MO) using a constant comparative technique.<sup>28</sup> Two researchers (ED and MO) who were trained in this technique, initially made independent assessments of the first 7 consultations separately, assuring that all audiotaped H&N surgeons were included at least once. Both researchers detected prognostic information provided by H&N surgeons and wrote short descriptions of the different phrases used to share prognostic information (quantitatively or qualitatively). All highlighted passages have been reviewed and discussed in detail by the researchers in order to reach consensus. In the next assessment saturation of the qualitative study approach was reached after discussing 13 more consultations. No additional prognostic content besides the known qualitative and quantitative approaches regarding prognosis could be identified. Apart from the method of providing prognostic information, the communication style or professional attitude of H&N surgeons that can affect patients' perception of prognostic content, was described. We made a distinction between directive and affective communication styles. The directive communication style is more physician-centered, while the affective communication style is more supportive and patient-centered.<sup>21,23</sup> A third researcher (MB) verified the results by coding n=7 transcribed consultations that were randomly selected.

At the end of this procedure, the researchers found a few examples that were classified differently by each researcher. After an in-depth discussion, consensus was reached. The results were subsequently rationalized into a coding frame that was applied to all transcripts, using NVivo qualitative software (version 10). Furthermore, the primary initiator of the discussion about prognosis in each consultation was documented, either being the patient, the caregiver or the H&N surgeon. Also the time used to communicate the prognosis in the consultation was recorded.

## RESULTS

### Characteristics of participants and consultations

Twenty three patients participated in this study, with an average age of 68 years. Most patients (87%) received a curative treatment plan (Table 1).

Mean total duration of consultations was 14 minutes and 21 seconds (SD 9 minutes 1 second). The mean time used for discussing a quantitative prognosis was 38 seconds (SD 35 seconds), accounting for 4.4% of the consultations. H&N surgeons were the primary initiators in 58% of discussions about prognosis, patients in 18% and caregivers in 24%.

### Provision of prognostic information

In all n=23 consultations, H&N surgeons provided some prognostic information. We found a total of n=222 quotations containing prognostic information. In seven interviews, n=13 quotations (5.9%) demonstrating a quantitative method using clear numerical probabilities were identified. An example of this method:

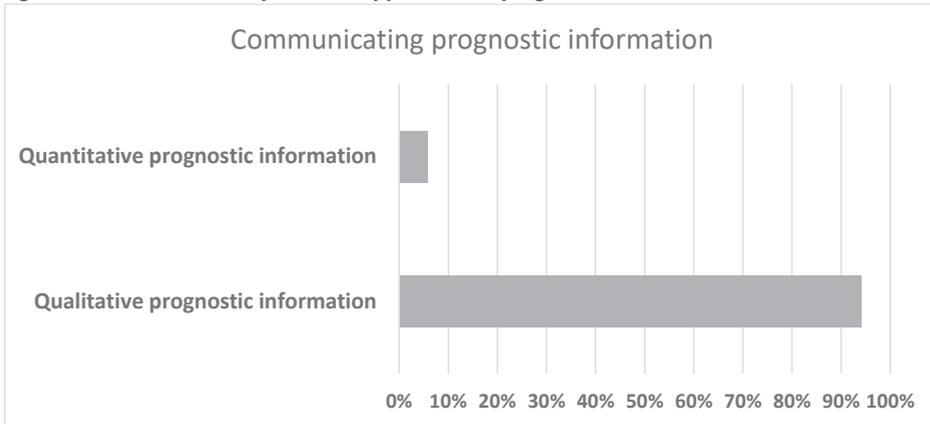
*H&N surgeon:*

*“ You can say that the probability of you living for one more year is not big. That chance that you will live to 90 is considerably smaller. If I had to predict, I would say that you have a 30% to 40% more chance compared to those in your age group who presently get nothing. Not 0 though if it was at 0 we would not do anything.”*

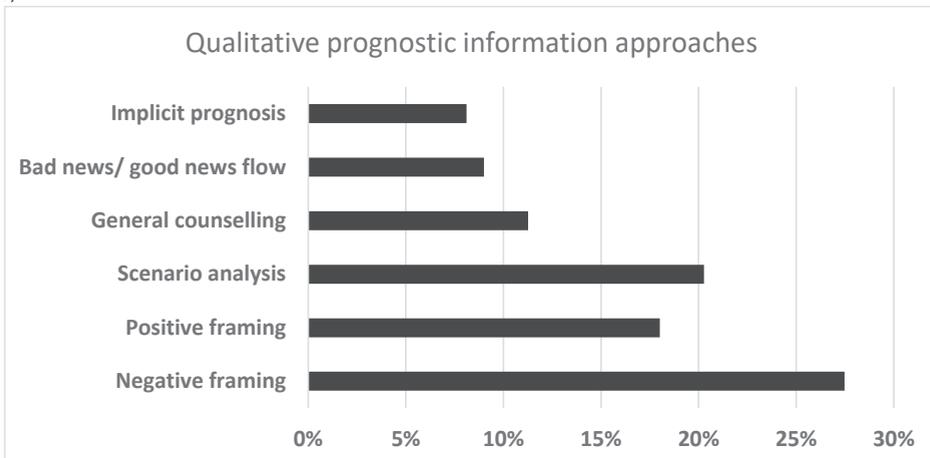
In all n=23 consultations, prognosis of the disease and its treatment was provided in a qualitative manner (n=209 quotations, 94.1%) (Figure 1a) In 30% of the interviews quantitative and qualitative methods were combined to deliver the prognostic message. In case of a qualitative method H&N surgeons varied communication approaches to share the prognostic content. We identified six different qualitative prognostic communication approaches: 1) bad news / good news flow (9%), 2) positive framing (18%), 3) negative framing (28%), 4) implicit prognosis (8%), 5) general counselling (11%) and 6) scenario analysis (20%) (Figure 1b). Examples are shown in Table 2.

**Table 1. Patient characteristics**

	Number of patients	% of total number of patients
Men	17	74%
Women	6	26%
<i>Age (years):</i>		
50-59	6	26%
60-69	9	39%
70-79	5	22%
>80	3	13%
<i>Intention of treatment:</i>		
Curative	20	87%
Palliative	3	13%

**Figure 1. Quantitative and qualitative approaches of prognostic information**

a)



b)

The '*bad news / good news flow*' approach is characterized by good news and bad news being used in an alternating order resulting in possible uncertainty about the prognostic tendency of the provided information: positive or negative? (example 1, Table 2)

In the '*positive framing*' approach the positive aspects of prognosis are emphasized (example 2, Table 2) The negative aspects regarding prognosis are underlined in the '*negative framing*' approach (example 3, Table 2). The use of an '*implicit prognosis*' approach (example 4, Table 2) is illustrative for a qualitative method of providing prognostic information. An approximation or ambiguous description of prognosis of the individual patient is used, thus implicitly providing prognostic information without being specific. An example of this method:

**Table 2. Identified prognostic communication approaches used by physicians.****Approach 1) Bad news good news flow:**

*Example: "The last time I saw you, you were not looking well. That is the reason for the scan and ultrasound. The tongue looks good and the throat is also completely fine, only in the scan there is still a small lymph node visible in the neck."*

**Approach 2) Positive framing:**

*Example: "Now luckily for you radiation treatment only will probably be enough"*

**Approach 3) Negative framing:**

*Example: "You see the only thing I can do is a big operation with a lot of risk and a small chance of success and I do not think that that is realistic as we are then making you worse than you are now. The risk are.. that there are huge blood vessels...you may become paralyzed on one side...you will end up in a wheel chair and a nursing home."*

**Approach 4) Implicit prognosis:**

*Example: "Now that means that, yes, your life expectancy through this has naturally changed slightly. Look, for you is has become like heads or tails either you will survive or you will not. However if you look at it with a group of patients then there will obviously be a few patients that will indeed pass away because of this problem... that is exactly what is happening now."*

**Approach 5) General counselling:**

*Example: "You have stopped smoking right? Yes thankfully, as that is very important...as that gives you a greater chance of getting back into the good group, as we know that people that continue to smoke have worse expectancies."*

**Approach 6) Scenario analysis:**

*Example: "Another option is not a curative treatment. You can decide only to radiate but that will be to keep the tumor under control, reduce symptoms and slow it down. However because of the tongue tumor we do not expect you to survive."*

*H&N surgeon:*

*“Now that means that... yes... your life expectancy through this has naturally changed slightly. Look, for you is has become like heads or tails; either you will survive or you will not. However if you look at it with a group of patients then there will obviously be a few patients that will indeed pass away because of this problem... that is exactly what is happening now.”*

In the ‘*general counselling*’ approach general information about the course disease or treatment in a general population with regard to prognosis is given. The final qualitative approach that could be identified is ‘*scenario analysis*’ (example 6, Table 2). Prognostic information on a ‘what if’ scene is provided. In this situation general conditions are outlined that could be the case for the individual patient.

### **Examples of different communication styles displayed by physicians**

H&N surgeons possibly affect patients’ perception of prognostic content with two identified communication styles: directive (more physician-centered) and affective (more

patient-centered). Several examples of the directive communication style were found (Table 3), such as the paternalistic professional attitude and the use of medical jargon during patient-physician communication.

**Table 3. Examples of directive communication style**

Example 1 – Paternalistic professional attitude:

H&N surgeon: *“In the meantime many things have been set in motion for you...I had already requested the surgery and there is already a date planned for you.”*

Example 2 – Use of medical jargon:

H&N surgeon: *“Yes it is now at the T3 stage so the protocol will without a doubt say PORT.”*

In the first example, the H&N surgeon has already decided – with best intentions – which treatment option is the best for the patient. The second example shows the use of medical jargon which can lead to one-way communication in which patients might feel by-passed.

We found examples of the more patient-centered affective communication style that were characterized by giving hope or by a compassionate tone of voice. Diminutive words were used along with the affective communication style. Those words appeared to alleviate the harsh message, but could also be misleading when serious subjects such as ‘tumor’ or ‘treatment plan’ were discussed (Table 4). In example 1, the physician supports the patient to take part in the decision process. In example 2, the physician is trying to provide hope to the patient. Finally, example 3 illustrates the use of diminutive words as discussed above.

**Table 4. Examples of affective communication style**

Example 1 – Patient empowering professional attitude:

H&N surgeon: *“So we think that yes we can consider the radiation treatment. If this is what you want... as you are naturally the boss... if we say something and you do not want that, that is also fine. It is your life.”*

Example 2 – Giving hope:

H&N surgeon: *“One abnormality yes but again it could be a false alarm.”*

Example 3 – Use of diminutive words and euphemisms:

H&N surgeon: *“Yes...the X-ray was naturally not made for nothing as there are some small problems with your lungs...and...”*

Patient: *“Of course, I coughed up blood.”*

## DISCUSSION

To our knowledge, this study is first in describing whether and how prognostic information is included during communication on diagnosis and treatment plans between H&N surgeons and their H&N oncologic patient in all phases of disease. Research has shown that providing sufficient quantitative information on life-expectancy allows patients to

make fully informed decisions.<sup>2, 21, 23</sup> In this study our qualitative analysis revealed that only 5.9% of the provided prognostic information included in the treatment and decision consultations was given quantitatively. In the majority of cases (94.1%) a variety of qualitative methods was used. Positive and negative framing were mostly used (46%). The same prognostic content could be interpreted differently using these framing approaches. With positive framing patients might interpret the information unrealistically optimistic and with negative framing patients might believe that they will be the ones with the bad outcome. A combination of these two approaches is found in the 'bad news / good news flow' (9%), where good and bad news are used in an alternating order, potentially resulting in insecurity about the prognostic tendency of the provided information: "am I going to be all right or not?". The same might happen with a 'general counselling' approach (11%) or 'scenario analysis' approach (20%) where the prognostic information is general and not tailor-made to the patients specific situation. The 'implicit prognosis' approach was seen in the minority (8%) of the qualitative approaches, while being closest to the prognostic value of the explicit quantitative approach.

Overall, we found that different communication approaches were used during one encounter in a rapid alternating order. Given the fact that patients tend to remember only 20-60% of the information provided by their physician, they may feel so overwhelmed by the amount of information, one can question if they adapted the useful part.<sup>8</sup>

Why is an explicit quantitative prognostic communication strategy being used in a minority of the cases? Given the 4.4% of the total time of conversations that H&N surgeons communicate prognostic information in numerical probabilities, there might be a reluctance to do so.

First, this could be due to a lack of reliable prognostic information, which is in agreement with earlier research. Prognostic judgments by physicians tend to be inaccurate and optimistically biased.<sup>18-19</sup> In H&N oncology, estimation of prognosis is based on the American Joint Committee on Cancer (AJCC) TNM staging classification. This objective and accurate tool is used to predict prognosis for an entire population of patients. However, it is ineffective for predicting outcomes in an individual patient, not taking into account the role of other tumor factors and important patient characteristics such as comorbidity or tobacco use.<sup>19, 29</sup> In order to improve predictions, prognostic models for H&N oncologic patients are developed based on multivariate survival analyses of large datasets.<sup>30-32</sup> These tools could help physicians with patient counselling and deciding on treatment options.

Secondly, it will take time and effort to identify patients' preferences about receiving prognostic information. Literature shows that patients desire accurate estimates of prognosis

in order to allow them to make decisions that are consistent with their values.<sup>5, 33-34</sup> On the other hand, patients desire, above all, to maintain hope for their situations, or do not want to receive information about their prognosis at all.<sup>5, 35-36</sup> That 'management of hope' permits the physician to take some liberties with prognostic estimates. Obviously, there is some tension between these two views and as mentioned before the majority of available studies focus on patients in the palliative phase of their disease.<sup>33-36</sup> As we used a qualitative study design, no deductions could be made about predisposing factors that could predict patient preferences on wanting prognostic information or not.

Furthermore, the right timing of sharing prognostic information is key. This is part of the professional attitude each physician possesses and the relationship built with the patient. However it is difficult for physicians to predict patients' values or preferences.<sup>37</sup> There is no consensus in literature on this topic. One study reported that 84% of patients with metastatic disease wanted to discuss treatment goals and options when first diagnosed, and only 59% wanted to discuss survival at that time.<sup>5</sup> Another study showed that common sense or intuition should guide physicians when to raise prognostic discussions.<sup>6</sup> Patients preferred their doctors to raise the topic of prognosis early on, as not to question the timing of raising it themselves. Physicians see communicating prognosis as a process rather than a conversation triggered by certain circumstances, such as upon diagnosis.<sup>25</sup> Literature shows that younger and more educated patients are associated with wanting a high level of prognostic information.<sup>38-40</sup> Caregivers favored full patient involvement in decision making, while patients were divided between wanting autonomy and a more passive approach.<sup>24</sup>

Finally, professional communication skills explain the limited use of explicit prognostic communication. Communication styles may differ and might affect patients' perception of the prognostic content. Most studies emphasize the importance of the communication style as frequently as the content.<sup>5-7</sup> This is underlined by our findings on professional attitude. For physicians, it sometimes seemed to be a struggle finding the right words and tone of voice. Accurate information is preferred, as long as it is not delivered bluntly or with too much hard factual or detailed information.<sup>5-7</sup> It is reasonable that physicians try to offer hope to cancer patients. However, a realistic perspective, including a small amount of 'negative' information about the course of disease, can help patients gain a more balanced perception of their prognosis and subsequently experience less anxiety and distress.<sup>33, 39, 41</sup> In confirmation with literature, patients favor information conveyed in a compassionate and empathic manner.<sup>42</sup> Patients prefer information given in a digestible manner using appropriate language, avoiding medical jargon.<sup>43</sup> In addition, information may need to be repeated on different occasions to meet patient's individual needs and to

prevent the 'one-way-process' of overwhelming the patient with information and different communication strategies.<sup>44</sup>

### Strengths and limitations

The major strength of this study is that it gives a unique insight behind closed doors. Insight is gained in otherwise private consultations between H&N surgeons and their patients. Another strength is that we included patients with all stages of disease. At the same time this is a limitation of the study because life expectancy and therefore prognosis is inevitably worse in patients in the palliative phase of disease. As patients volunteered to partake in this study it is possible that the results of this study represent the more 'engaged' patients and caregivers; those who are interested in prognosis and quality of life, and present a participating attitude during the consultation. Additionally bias could be introduced as physicians are aware their conversations are registered. Despite these limitations, the study results add to an underexposed subject and enabled us to better understand communication of prognosis in patients with H&N cancer.

## PRACTICE IMPLICATIONS

Based on our results and discussion of the topic, we prepared first steps for a guideline for sharing prognostic information in H&N oncology practice (Table 5). These suggested steps are meant as a stimulus to encourage sharing prognostic communication in a clinical setting. We recommend to provide written information on treatment options to assist patients and caregivers with retaining information and to overcome the 'one-way-process' whereby a physician provides a large amount of information to patients.<sup>45</sup> Additionally, the presence of a case manager or an additional visit to an oncology nurse could be of added value to both patient as H&N surgeon. This is an easy accessible professional who can take some more time with the patient in order to clarify and confirm the physician's message.

**Table 5. Guideline for sharing prognostic information in H&N oncology practice.**

Step 1: Explore patient preferences on receiving prognostic information
Step 2: Assure there is accurate or as personal as possible information on the prognosis of the individual patient
Step 3: Initiate a conversation about life expectancy
Step 4: Use prognostic information in an empathic, honest and digestible way
Step 5: Avoid use of a directive communication style; yet give a realistic perspective of prognosis
Step 6: Recognize prognostic communication as a process and if needed repeat information on different occasions

## CONCLUSION

This study is first in providing examples of how H&N surgeons communicate with their patients regarding prognosis in all stages of disease. Understanding the difficulties of communicating prognosis will take us a step further into our strive for patient-centered counselling and shared decision making. This study points out that specific quantitative prognostic information is often not included in communication between H&N oncologic surgeons and their patients and different qualitative methods are used instead. Doctors should be aware of both their communication approach for discussing prognosis and their communication as this might affect patients' understanding and perception of information provided. Prognostic models can contribute to knowledge and thus enhance patient empowerment and make shared decision possible.

### Future research

With this study we add to an underexposed subject of research on prognostic communication in head and neck oncologic patients. However there is a need for creating patient-preference studies, starting research on the efficacy of our suggested approach of prognostic communication and developing decision aids for patients and caregivers. In our clinic we have started a study based on focus group methodology to discover patient preferences in prognostic communication. There is limited data on effective teaching methods to promote long-term change of communication skills. Research should focus on whether feedback is an essential element and how best to incorporate decision aids into conversations. Finally, development of reliable, internally and externally validated sophisticated prognostic models is needed to support physicians in providing tailor-made prognostic information to their patients.

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