



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

Emilie A.C. Dronkers*, Arta Hoesseini, Maarten F. de Boer, Marinella P.J. Offerman

Department of Otorhinolaryngology and Head and Neck Oncology, Erasmus University Medical Center Cancer Institute, Rotterdam, The Netherlands

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ABSTRACT

Objectives: 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.

Methods: 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'.

Results: 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).

Conclusion: 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 [1]. The shared decision making approach (SDM) is considered to be a central component of treatment decision consultations [2]. Patients need to be well-informed in order to be able to be actively involved in treatment decisions [3]. Prognostic information may be a valuable factor in considering treatment options [4]. 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 [5,7,8]. 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 [9].

The SDM approach is getting more attention in treatment decision consultations with head and neck (H&N) cancer patients [10]. The 5-

year survival rates of H&N cancer remain around 50% [11]. Also, the commonly used treatment modalities are associated with high morbidity and impact on quality of life [12]. 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 [13–15]. 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 [14,16]. As a result, some physicians discuss prognosis in vague or in optimistic terms, avoid the topic unless the patient insists, or mainly

* Corresponding author at: Dr. Molewaterplein 40, 3015 GD, room NT-216, Rotterdam, The Netherlands.

E-mail address: e.dronkers@erasmusmc.nl (E.A.C. Dronkers).

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focus the discussion on treatment options. Estimates of prognosis provided by physicians are also often overly optimistic when compared to actual or predicted outcomes [17–19]. 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 [20].

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*”) [21]. 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) [22]. Research has shown that providing sufficient quantitative information allows patients to make fully informed decisions in contrast to providing solely qualitative information [4,21,23]. Also, giving numeric expressions of prognosis improves the accuracy of patients’ risk perceptions and the comfort with feeling informed [23].

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 [24–26]. 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 [27].

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 [28]. 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 [21,23]. 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 (see Table 1).

Mean total duration of consultations was 14 min and 21 s (SD 9 min 1 s). The mean time used for discussing a quantitative prognosis was 38 s (SD 35 s), 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

Table 1
Patient characteristics.

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

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