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Review

Assessing head and neck cancer patient preferences and expectations: A systematic review

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ABSTRACT

Introduction: To enhance the value of care, interventions should aim at improving endpoints that matter to patients. The preferences of head and neck cancer patients regarding treatment outcomes are therefore a major topic for patient-centered research.
Methods: A systematic review (PROSPERO number CRD42016035692) was conducted by searching electronic databases (Medline, Embase, Cochrane, CINAHL) for articles evaluating patient or surrogate preferences in head and neck cancer. A qualitative review was performed but no quantitative synthesis.
Results: Of 817 references retrieved, 20 full-text articles were eventually included in the qualitative analysis Disease sites included mixed head and neck tumor sites, n = 9; larynx, n = 6; oropharynx/oral cavity, n = 5. Overall, patients prioritized survival over functional endpoints. However, preferences and utility scores varied greatly between patients and healthy subjects, and differences were less pronounced with spouses or healthcare providers. Findings from studies of laryngeal preservation are consistent and conclude that a subset of patients would be willing to compromise a certain amount of survival to avoid laryngectomy. On the other hand, studies of patients with oropharyngeal cancer are too heterogeneous to draw conclusions about acceptable functional trade-offs or priorities, and should be the focus of future research.
Conclusion: Future research surrounding head and neck cancer patients will most likely be clinically applicable if the questions are focused on well-defined patient groups and treatment options. Gathering reliable and valid quality-of-life data, designing patient preference studies that use reliable and generalizable methods, and using the results to develop decision aids for shared decision-making strategies are recommended going forward.

Introduction

Outcomes of patients with head and neck cancer have gradually improved over the past decades due to improved treatments and epidemiologic shifts [1,2]. Patient-reported outcomes (PROs) are increasingly collected more systematically in efforts to better understand the patients' perspectives on potential trade-offs between the likely effectiveness of a treatment and its side effects [3]. However, little attention has been given to head-and-neck cancer patient preferences other than those related to laryngeal preservation.

The evolution of radiotherapy techniques for the treatment of head and neck cancer has considerably reduced late toxicity, especially the incidence and severity of late xerostomia, by using parotid-sparing intensity-modulated radiotherapy (IMRT) [4]. Although the implementation of IMRT in the United States has been rapid, no randomized trials have been conducted in the United States to systematically compare radiation therapy techniques in terms of clinical outcomes or potential benefits. One barrier to the conduct of these trials was the perception that "the benefit was obvious" and that randomization was "unethical." Other

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countries have successfully demonstrated clinical benefit for patients with head and neck cancer: a small randomized controlled trial (RCT) conducted in the United Kingdom [4], a second small RCT from India [5,6], and three RCTs in nasopharyngeal cancer patients conducted in China [7–9]. Only three of these trials investigated patient reported outcomes as secondary endpoints [4,5,8].

The next generation of treatments for head and neck cancers includes new radiotherapy modalities, such as particle therapy, and the renewed use of surgery in the form of transoral robotic surgery (TORS). Initial reports indicate that particle therapy and TORS seem to provide durable tumor control of oropharyngeal cancer [10,11] with acceptable toxicity, but high-quality prospective, multicenter data are lacking. Although the authors of one retrospective uncontrolled comparison suggest that TORS could produce better functional outcomes than chemoradiation for oropharyngeal cancer [12], the respective values of new treatments relative to one another and to more established approaches needs to be assessed in a patient-centered manner.

Value in health care is currently defined as outcomes divided by costs, measured over the entire cycle of care [13]. The outcomes to be considered in the value framework have many components, and choosing the ones that matter the most to patients is a challenge [14]. Investigating patient preferences or priorities regarding treatment outcomes is an essential part of quantifying the value associated with various forms of treatment. We conducted a systematic review of the current evidence regarding the preferences and priorities of patients with head and neck cancer. Our aims were to summarize the current data, describe the knowledge gaps, and propose ways to improve research on patient priorities and foster shared decision-making between patients, caregivers, and providers.

Methods

Inclusion criteria and search

This systematic review was conducted in accordance with published guidelines [15] and was registered in the PROSPERO database (CRD42016035692). Pubmed, Medline, Embase, The Cochrane Registry, and the Cumulative Index of Nursing and Allied Health Literature (CINAHL) were searched for relevant articles. Inclusion criteria were: peer-reviewed articles focused exclusively on head and neck mucosal neoplasms (excluding esophageal and thyroid cancers or lymphoma); limited to localized disease; and, evaluated patient preferences/priorities or health utility by using a quantitative method. Keywords used included "patient preference", "patient priorities" and "head and neck cancers", as well as variations on these keywords and the different patient stated-preference methods [16], such as "rating", "ranking", "best-worst", "self-explicated", "value-based conjoint analysis", "rating-based conjoint analysis", "choice-based conjoint analysis", "take it or leave it", "tradeoff", and "trade-off". The full search equations used for the different databases are given in the Supplementary Materials. No restrictions on date or study design were applied. Review articles on outcomes-based research and value-based research in head and neck cancer were searched for additional references, although this search did not retrieve any new references. Abstracts and articles were assessed by one experienced head and neck radiation oncologist (PB), and checked by a second (SJF) and any disagreements were resolved by consensus.

Description of the studies included and methods used to assess patient preferences

The PRISMA flow diagram is presented in Fig. 1. Our search retrieved 817 references, including 238 duplicates and 81 conference proceedings; 442 references were excluded when analysis of the abstract revealed their irrelevance to the present study (major reasons: related to epidemiology/public health, reporting on outcomes but not on patient preference, focused on other disease sites such as thyroid gland or esophagus, review articles, and other reasons). Of the 56 full text articles evaluated, 36 were excluded for the reasons shown in Fig. 1, leaving 20 references for inclusion in the systematic review. The data collected for each study were dates of accrual, type of participants included, treatments studied, methods (instrument) used to assess preferences, mode of delivery (e.g. face to face interview or mail), timing of the assessment with respect to the delivery of treatment, and main results or study biases.

Among the 20 references included, nine evaluated preferences of patients with mixed head and neck cancer diagnoses, five focused on oral cavity or oropharyngeal cancers, and six focused on the issue of laryngeal preservation. Different stated-preference methods were used, and sometimes several methods were used in the same study. Two references were related to the same study but reported different statistical analyses, and so were both included [17,18]. The most commonly used methods were ranking/rating (10 studies), time tradeoff (7 studies), and standard gamble (2 studies). These methods are summarized briefly in Table 1 and described further in the Johns Hopkins white paper [16].

In terms of study participants, 13 studies involved patients with head and neck cancer; 8 studies, healthy subjects; 5 studies, caregivers or experts on head and neck cancer; 3 studies, patients with head and neck or pulmonary conditions other than cancer; and 1 study, spouses of patients with head and neck cancer. Eleven studies evaluated preferences in more than one group of participants. Regarding treatments, 12 studies were not comparative and mostly ranked patient outcomes, 7 studies compared preferences between surgery and radiotherapy, mostly with regard to laryngeal preservation, and 3 studies evaluated preferences between radiotherapy and concomitant chemoradiation. Nineteen studies were cross-sectional, and only one was longitudinal [19]. No formal assessment of the quality of the studies could be performed due to their design and the absence of an appropriate scale. Similarly, no quantitative synthesis could be performed owing to the heterogeneity of publication and type of results reported.

Results

Characteristics of the studies analyzed, including date of conduct, type of participants, treatments used or compared, methods of stated-preference assessment, timing with regard to treatment for head and neck cancer patients, and main results, are shown in Tables 2–4. Studies are grouped according to disease site: mixed head and neck tumor sites (Table 2), oral cavity and oropharyngeal cancers (Table 3), and laryngeal cancers (Table 4). Health states considered and utility values are reported in Table 5 for the studies that used such metrics. The major findings of these studies are summarized below.

Superiority of survival over functional endpoints

In all of the studies in which survival/cure was one of the endpoints that patients had to rate or rank, being cured and surviving consistently ranked at the top of the list [17,18,20–22]. Although this finding seems obvious, it nevertheless underscores the expectation that high survival rates are a prerequisite of any treatment that is being administered or is under development. Although in some instances, some patients accept a certain degree of tradeoff