Eliciting Preferences for Clinical Follow-Up in Patients with Head and Neck Cancer Using Best-Worst Scaling

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A B S T R A C T

Objectives: There are no commonly accepted standards for monitoring patients treated for head and neck cancer. The aim of this study was to assess patients' preferences for different aspects of follow-up. **Methods:** A best-worst survey was conducted in a sample of head and neck cancer patients in clinical follow-up at the National Cancer Institute (Milan, Italy). Conditional logit regression with choice as the dependent variable was run to analyse the data. A covariate-adjusted analysis was performed in order to identify socio-demographic and clinical factors related to the selection of best-worst items. The participants were asked to report any difficulties encountered during the survey. **Results:** A total of 143 patients, predominantly male (74%) and with a mean age of 58 years were enrolled in the survey. The strongest positive preference was expressed for a hospital-based program of physical examinations with frequency decreasing over time. Conversely, the lowest valued item was not performing any positron emission tomography (PET) scan during follow-up. Patients

with high educational levels were more likely to value attending a primary care-based program and undergoing intensive radiological investigations. Other patient-specific variables significantly associated with the choice of items were employment and living status, time already spent in follow-up and number of treatments received. **Conclusions:** Overall, patients were more likely to choose an intensive follow-up scheme broadly consistent with the program currently administered by the hospital. There is little evidence of preference heterogeneity that might justify customized programs based on demographics. The best-worst scaling task appeared feasible for most participants.

Keywords: best-worst scaling, follow-up, head and neck cancer, patients' preferences.

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Introduction

Head and neck cancer (HNC) is the sixth most common cancer in the world with nearly 700,000 new diagnoses and 370,000 deaths reported each year [1,2]; incidence in Italy has been assessed at 7.7 cases per 100,000 [3]. HNC consists of a heterogeneous group of malignancies affecting several anatomical sites and with different prognoses [4]. The main risk factors are alcohol and tobacco abuse and, in recent years, the infection with human papilloma virus for cancers located in the oropharynx [1]. The risk of relapse is greater in the first 2 years after primary treatment, when an estimated 50% to 60% of patients develop locoregional recurrences or metastases [1]; lifetime risk of second primary cancers is around 10% to 20% (i.e., 2%–5% per year) [5]. Therefore, a follow-up program is essential shortly after the completion of treatment to identify potentially curable relapses. Nevertheless,

the optimal timing of visits and radiological assessments after treatment is debated by oncologists. Published recommendations are mostly informed by retrospective studies, expert opinions, and clinical practice rather than by randomized controlled trial–based evidence [2,5]. Until now, no consensus has been reached on the optimal follow-up modalities and timing in patients with HNC.

In addition to this clinical uncertainty, the patient's perspective has traditionally been neglected in designing cancer programs and elaborating clinical guidelines, although considering individual preferences might improve the feasibility, acceptability, and effectiveness of health care interventions [6]. This is part of a larger study evaluating the cost-effectiveness of different surveillance schemes in HNC (HETeCo, clinicaltrials.gov identifier NCT02262221). The present objective is to quantify preferences for post-treatment surveillance in a large sample of patients treated for primary HNC.

Methods

This study used best-worst scaling (BWS) to elicit patients' preferences for different aspects of follow-up after primary treatment for HNC.

Experimental Design

The best-worst (BW) choice experiment is a variant of the widely adopted binary choice experiment approach. As in traditional discrete choice experiments (DCEs), this method requires the identification of key characteristics (i.e., the attributes), each of which is split into two or more levels to create a series of scenarios described by different attribute-level combinations. Nevertheless, instead of selecting one scenario in a choice set of two or more, participants are asked to indicate which attribute-level they consider to be the "best" and which to be the "worst" (i.e., the BW pair) within each scenario. In other words, they choose "the pair that exhibits the largest perceptual difference on an underlying continuum of interest" [7,8]. There exist three types of BWS studies in the literature: the object case (case 1), the profile or attribute case (case 2), and the multiprofile case (case 3) [9]. The present study used the profile case in which participants are presented with a series of different scenarios to be evaluated one at a time.

Our analysis was limited to the process-related aspects of the follow-up [10], because clinical outcomes of post-treatment surveillance in HNC are still under debate in the scientific community. Relevant attributes and levels were established from literature review and expert opinion. We searched common databases (PubMed and EMBASE) using key terms such as "cancer" AND "follow up" AND "discrete choice experiment" (OR "best worst") in titles/abstracts to identify studies that assessed patients' preferences around post-treatment programs in oncology using stated preference methods. Interviews with six patients during routine

hospital visits were used to refine terminology and evaluate the comprehension and the acceptability of the BWS instrument.

After this preliminary work, we eventually identified four attributes: frequency and setting (hospital or mixed with primary care) of physical investigations, frequency of radiological assessments (magnetic resonance imaging [MRI]/computed tomography [CT] scans), frequency (and eligibility) of positron emission tomography (PET) scans, and telephone calls to monitor the occurrence of new symptoms. Levels were presented in order of increasing intensity (and resources consumption) for each attribute (Table 1). A balanced study design was adopted in which each study attribute ($K = 4$) had the same number of levels ($L_K = 3$). If an alternative contains K attributes, there are $K(K − 1) = 4(4 − 1) = 12$ possible BW pairs the participant can choose within each scenario. Because a full factorial design generating all possible attribute-level combinations ($3^4 = 81$ scenarios) was not feasible, a subset of 9 orthogonal scenarios (fractional factorial, main-effects design) was derived using the Hahn and Shapiro catalogue, Master Plan 3 [11]. The total number of BW pairs in the orthogonal design was 108 (12×9). This subgroup of selected scenarios preserved the properties of orthogonality (i.e., each attribute-level appears an equal number of times in combination with all other attribute-levels) and balance (i.e., each level within an attribute appears an equal number of times) [12,13].

Recruitment and Setting

Patients aged 18 years and older, with a diagnosis of HNC in any anatomical site (except for the skin) in the last 5 years, and who had completed any curative treatment at the National Cancer Institute (NCI) in Milan were eligible to participate. Patients were excluded if they were unable to comply with the study in the opinion of the clinical investigators, or if they could not provide their informed consent. Moreover, we excluded patients who underwent minor surgery for early stage cancer and subsequently did not attend a regular follow-up program in a multidisciplinary setting, that is, with the contemporary presence of the head and neck surgeon and the radiation and the medical oncologists. At the NCI, the routine follow-up program consists of outpatient visits every 2 to 3 months for the first 2 years after the end of treatment, then every 5 to 6 months for 3 more years. Radiological evaluations with MRI/CT scan are performed once 3 months after the end of treatment and then annually. PET is requested only in the case of doubtful imaging; no scheduled intervisit contact is planned during the follow-up period.

The study was described to a consecutive sample of eligible patients during a routine follow-up appointment. Patients were reassured that responses to the questionnaire would not affect the care they were receiving at the hospital [14]. Those who agreed to participate were asked to sign a consent form and then they received the survey. Sociodemographic and clinical information was collected for each study participant. The questionnaire included a short rationale for the study and an explanation of the task required. The study was approved by the NCI Ethical Committee in March 2015; the survey was subsequently administered between May and October of the same year.

Statistical Analysis

Data on patients' characteristics were summarized through descriptive statistics; categorical variables were presented as percentages, whereas continuous variables were presented as means and standard deviations (SDs). In regression analyses, missing demographic data were imputed using logical rules and information from related variables or, whenever this approach was not feasible, using the most common value (i.e., the mode) [15]. Missing BW responses were imputed with the items most

Table 1 – BWS attributes and levels.	
Attribute	**Level**
Frequency (and setting) of physical (and larynx/pharynx endoscopic) investigations	Every 2–3 mo for 3 y (primary care–based follow-up for 2 more years)
	Every 2–3 mo for 2 y, every 5–6 mo for 3 more years
	Every 2–3 mo for 5 y
Frequency of MRI/CT scans	Only at the occurrence of new symptoms
	One examination only at the beginning of follow-up (later only at occurrence of new symptoms)
	Once or twice a year
Frequency (and eligibility) of PET scans	No PET scan during follow-up
	Yearly PET scan only for high-risk patients (≥50 y and heavy smokers)
	Yearly PET scan for all patients
Telephone calls to monitor occurrence of new symptoms	No intervisit calls from the hospital
	Intervisit calls by the nurse
	Intervisit calls by the oncologist

CT, computed tomography; MRI, magnetic resonance imaging; PET, positron emission tomography.