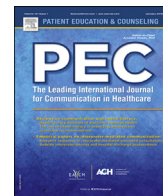




Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



The relationship between role preferences in decision-making and level of psychological distress in patients with head and neck cancer

Joe Jabbour^{a,b,*}, Haryana M. Dhillon^{c,d}, Heather L. Shepherd^{c,d}, Puma Sundaresan^{b,f},
Chris Milross^{b,e}, Jonathan R. Clark^{b,g,h}

^a St Vincent's Hospital, Sydney, NSW, Australia

^b Central Clinical School, University of Sydney, NSW, Australia

^c Psycho-Oncology Cooperative Research Group (POCOG), School of Psychology, The University of Sydney, Camperdown, NSW, Australia

^d Centre for Medical Psychology & Evidence-Based Decision-making, The University of Sydney, Camperdown, NSW, Australia

^e Department of Radiation Oncology and Medical Services, Chris O'Brien Lifecare, Camperdown, NSW, Australia

^f Crown Princess Mary Cancer Centre, Westmead Hospital, Westmead, NSW, Australia

^g Sydney Head and Neck Cancer Institute, Chris O'Brien Lifecare, Camperdown, NSW, Australia

^h South West Clinical School, University of New South Wales, NSW, Australia

ARTICLE INFO

Article history:

Received 15 February 2018

Received in revised form 20 April 2018

Accepted 27 May 2018

Keywords:

Decision-making experience

Decision-making preference

Psychological distress

Head and neck cancer

ABSTRACT

Objective: Is there a relationship between decision-making preferences and psychological distress?

Methods: Patients who had received treatment for head and neck cancer (HNC) at four institutions within NSW, Australia were invited to complete a single questionnaire.

Results: Five hundred and ninety-seven patients completed the questionnaire. The majority of patients (308, 54%) preferred shared decision making. Significant predictors of a preference towards active decision making were education level (OR 2.1 for tertiary, $p < 0.001$), primary cancer site (OR 1.9 for thyroid compared to salivary gland, $p = 0.024$) and gender (OR 1.4 for female, $p = 0.028$). Mean psychological distress score on Kessler 6 (K6) was 9 (Range: 0–28). Significant predictors of psychological distress were age ($p < 0.001$), gender ($p < 0.001$), primary site ($p < 0.01$), and decision preference ($p < 0.01$).

Conclusion: HNC patients who are either tertiary educated or female are more likely to prefer active involvement in decision-making. Psychological distress is more likely in patients actively involved in decision making, younger patients, and in females.

Practice implications: Patients experienced paternalistic decision-making, but most preferred active or a shared approach. Clinicians need to be aware of potential for psychological distress in active decision-makers and refer patients for psychosocial support.

© 2018 Published by Elsevier B.V.

1. Introduction

Head and neck cancer (HNC) represents more than ten different primary tumour sites, with many possible types of cancer (pathology) within each. The treatment decisions are often complex because of the functional morbidity associated with radical surgery and high-dose radiotherapy, the main forms of HNC treatment. These decisions have a significant impact on a patient's body image, psychological wellbeing, productivity, and lifestyle [1–4]. Whilst the importance of these decisions is undisputed, at

present, there is little to guide clinicians regarding how active patients want to be in the decision-making process.

The role patients with cancer prefer to play when making decisions about treatment decision making is variable [5–8]. Patients preference for involvement may range between those preferring to decide their own treatment, to those who prefer to leave treatment decisions to their medical team, largely as patients report lacking the specialized knowledge needed to make treatment decisions [9]. The Control Preferences Scale developed by Degner and Sloan, pioneered assessment of the role patients prefer in decision-making [10]. In a meta-analysis measuring treatment decision-making roles in 3491 cancer patients, 26% preferred active involvement, 49% collaborative, and 25% passive [11]. Furthermore, the roles patients reported experiencing were: 30% active, 34% collaborative, and 26% passive. Moreover, 61% of patients reported achieving their preferred role in treatment decision-making [11].

* Corresponding author at: St Vincent's Hospital Sydney, Darlinghurst, NSW, 2010, Australia.

E-mail address: joejabbour@icloud.com (J. Jabbour).

<https://doi.org/10.1016/j.pec.2018.05.023>

0738-3991/© 2018 Published by Elsevier B.V.

Decisions people with cancer make commonly have an important impact on their body image and the lifestyle factors that can arise as part of their disease and its treatment [12]. Currently, there is a shift towards patient-centred care and a focus on an exchange of information, in a two way interactive process known as shared decision-making, between the physician and patient or their advocate [13]. Despite differing attitudes to individual patient decision-making, the emphasis should be on understanding and catering to patient-specific information needs.

Beliefs persist that patients are unable to take part in treatment decision-making due to the complexity of the information on which such decisions are based. Treatment for HNC encompasses a range of options including operations, radiation therapy, and/or chemotherapy requiring decoding of a large amount of information with potential to overwhelm patients. Despite verbal consultations and participation in multidisciplinary team meetings, patients may find the treatment plan difficult to remember and understand [14].

Thus, individuals may hold differing attitudes towards treatment decision making requiring information to be tailored patients' specific information needs. Here we report the secondary analysis of a survey of information needs of HNC patients, the HNC Patient Education and Support Needs survey [15]. We aimed to investigate the relationship between decision-making preferences and psychological distress in HNC patients.

2. Methods

The data analysed in this study was taken from a cross-sectional survey of 597 patients who had participated in the HNC Patient Education and Support Needs survey [15]. The 28-item, cross-sectional survey was completed by patients treated for HNC at one of four institutions in New South Wales, Australia (Chris O'Brien Lifehouse, Liverpool, Westmead, and Wollongong hospitals). It incorporated the adapted Kessler Psychological Distress Scale and questions assessing information quality, quantity, and format [16]. Multi-site ethical approval was obtained from a single Human Research Ethics Committee (LNR/14/LPOOL/465).

We investigated whether age, gender, educational level, primary cancer site and level of psychological distress predicted decision-making experience and decision-making preference. Educational level was categorised by highest level of schooling completed: (i) School certificate (Year 10 equivalent) or less; (ii) Higher School Certificate (Year 12); (iii) TAFE certificate/diploma; (iv) University – Undergraduate Degree; and (v) Postgraduate qualifications – Masters Degree/PhD. Educational level categories were dichotomised into tertiary (responses iv & v) and non-tertiary (responses i-iii). Primary cancer site was classified into 4 groups: i) Oral cavity (cheek, floor of mouth, gum, lip, oral not otherwise specified, palate, tongue); ii) salivary (major salivary glands, parotid, and skin), iii) thyroid; and, iv) others (unknown primary, soft palate, base of tongue, tonsil, larynx + hypopharynx, sinus – sinus, maxilla, & nasal cavity, and not specified).

Decision-making experience was assessed using an adapted version of the Control Preferences Scale (CPS) used in other studies [6]. The adapted CPS involved reversing the order of the patient responses (passive role, collaborative role and active role instead of active role, collaborative role and passive role) to the question "Who made the decision regarding treatment? (Please tick one statement only):

- The doctor made the decision using all that is known about the treatments;
- The doctor made the decision but strongly considered my opinion;
- The doctor and I made the decision together on an equal basis;

- I made the decision, but strongly considered the doctor's opinion; or
- I made the decision using all I knew or have learned about the treatments." [17]

Decision-making preference scores were simplified into three categories by combining the first two passive preference options, last two active preference options and the shared preference alone: passive (I prefer the doctors to make the decisions about my treatment and don't want too much information), shared (I would like the doctor and myself to make the decision together on an equal basis) and active preference (I would like to be strongly involved in decisions about my cancer treatment) [18].

To measure psychological distress we used the K6, adapted from the Kessler Psychological distress scale (K10), which included the following items addressing feeling worthless, depressed, hopeless, effort, restless, and nervous [19,20]. The K6 used a 5 point Likert scale with the following categorical scale: 1 (none of the time); 2 (a little of the time); 3 (some of the time); 4 (most of the time); and, 5 (all of the time) and has been validated to measure psychological distress [16]. The sum of the 6 items was calculated and the K6 total score (maximum 30) was used as an indicator of psychological distress. In the Australian National Survey of Mental Health and Wellbeing, a score of 0–5 is indicative of no or low psychological distress, 6–11 indicates moderate distress, 12–19 indicates high psychological distress, and a score of 20 or more very high distress [21,22].

2.1. Statistical analysis

Statistical analysis was performed using Stata version 12.0 SE (StataCorp LP, College Station, Texas). All statistics were 2-sided and $P < .05$ was considered statistically significant. The associations between variables was assessed with the Chi-square test. Ordinal logistic regression was used to determine odds ratios for different variables as predictors of decision-making preference. Linear regression was used to determine predictors of psychological distress (total K6).

3. Results

3.1. Demographics

A total of 597 patients completed the questionnaire. The median age was 62 (range 21–94 years) with slightly more females (313) than males (284). Table 1 lists the demographics of the participants.

3.2. Decision-making experience

Two hundred and eighty-nine (51%) patients reported their doctor making the treatment decision, followed by 188 (33%) patients who reported experiencing shared decision-making, and 92 (16%) who reported making the treatment decision alone.

3.3. Decision-making preference

The majority of patients (308, 54%) indicated a preference for shared treatment decisions, followed by 242 (42%) patients preferring active involvement, and 24 (4%) patients a passive role. Significant univariate predictors of active decision-making preference were education level (OR = 2.1 for tertiary [95% CI 1.40–3.11] $p < 0.001$), primary cancer site (OR = 1.9 for thyroid compared to salivary gland [95% CI 1.09–3.31] $p = 0.024$), and gender (OR = 1.4 for female [95% CI 1.03–1.95], $p = 0.028$). Age was not a significant predictor of decision preference ($p = 0.77$).

Download English Version:

<https://daneshyari.com/en/article/8958230>

Download Persian Version:

<https://daneshyari.com/article/8958230>

[Daneshyari.com](https://daneshyari.com)