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Preferences for disclosure of disease related information among thoracic cancer patients

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ABSTRACT

Objective: Cancer patients in developed countries increasingly express a preference for more detailed information and involvement in decisions about their care. However, data is sparse and conflicting on preferences of ethnic minorities and immigrants. We aimed to identify preferences for illness related information and correlates with clinical characteristics among patients with thoracic cancers.
Methods: Two hundred and fifty two consecutive cancer patients seen at the Thoracic Oncology Unit, Sheba Medical Center, Israel, participated in the study. Prior to their first oncologist visit, patients completed a questionnaire eliciting their preferences for disclosure of illness related information – full, partial or none – as well as additional demographic information.
Results: Eighty four percent of subjects requested full disclosure of disease related information including bad news. Patient age, gender, marital status, birth country, immigration status and smoking status were not associated with disclosure preferences. Patients who refused complete-disclosure were more likely to have metastatic disease with a 2.72 odds ratio (95% confidence interval 1.29–5.74).
Conclusions: Most Israeli thoracic cancer patients request full disclosure of illness related information. This preference seems more significantly correlated to disease stage than demographic characteristics.

1. Introduction

The increasing preference of cancer patients in Western countries to be fully informed about their diagnosis and involved in treatment decisions is well documented [1–3]. However, this desire for information may not be true for all cultural groups [4–6]. Studies from non-Western countries often show an inclination toward family centered decision making with a large proportion requesting non-disclosure of disease related information [5–7]. Contrary to expectations, some studies have shown that patients uninformed of their cancer diagnosis may have better outcomes. For example, in a cohort of gastrointestinal cancer patients in Iran, 52% were unaware of diagnosis, and when compared to informed patients, experienced a better physical, social and emotional quality of life [5].

As migration is increasing worldwide, physicians need to embrace the concept of cultural competence. Limited studies of migrant populations to developed countries suggest that migrants may prefer non-disclosure of prognostic information [6,8]. However, results are conflicting with a more recent Australian study reporting that migrant patients, and not Anglo-Australian patients, desired to be better informed of their disease [9]. Israel, a country established through waves of migration from Europe, Asia America and Africa houses a very ethnically heterogenous population, with approximately 60% being immigrants [10]. In Israel, one Jerusalem-based study found that 92% of patients preferred complete disclosure, with those declining more likely to be identified as religious. The effect of ethnicity was not explored [11].

In the current study, we aimed to evaluate the effect of clinical and demographic characteristics, including ethnicity, on patient preference for disclosure of disease related information. As patient preferences have been shown to vary by cancer type [2], we limited our investigation to thoracic cancer patients, in which ethnic minorities and immigrants are over-represented [12,13].

2. Materials and methods

Two hundred and fifty two consecutive cancer patients presenting to the Thoracic Oncology Unit, Sheba Medical Center,

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Israel, participated in the study. Prior to their first consultation with an Oncologist, patients independently completed a written questionnaire comprising demographic and clinical data. Preference for disclosure was assessed through a single closed-ended question – "Would you like all disease related information to be communicated to you directly, including bad news?", and a selection between all, partial or none. Information regarding cancer diagnosis, TNM staging and Eastern Cooperative Oncology Group performance status (ECOG PS) was obtained from subjects' clinical charts.

Demographic variables recorded included sex, age, marital status, having children and country of birth. Smoking history was categorized as past, current or never. Past smokers had quit smoking more than one year before the relevant clinic visit. Never smokers smoked less than 100 cigarettes lifelong. Clinical variables were first degree familial cancer history, a history of a previous personal cancer other than the current thoracic cancer, ECOG PS and the presence of metastatic disease.

The primary outcome was preference for disclosure of disease related information, categorized as complete (all information) or incomplete (partial or none). To determine significant differences in independent variables t-tests and χ^2 tests were used as indicated. A univariate analysis was used to estimate odds ratio (OR) for each independent variable. All tests of significance were two-sided, with a $p < 0.05$ considered as significant. Confidence intervals (CI) were reported at the 95% significance level. All analyses were conducted with a standard statistical package (SPSS 20.0, SPSS, Chicago, IL).

3. Results

Of 252 patients completing the survey, 56% were male, with a mean age of 65.4 (SD 11.9) years. The majority (86.9%) were diagnosed with non-small cell lung cancer (NSCLC), 8.3% with small cell lung cancer (SCLC) and 4.8% with other thoracic malignancies – carcinoid, cancer of the thymus and cancer of unknown primary. With regard to country of birth, 39.3% were native Israelis, with the remainder immigrating from Europe, Asia, Africa and the Americas. Population characteristics are provided in Table 1.

Two hundred and thirteen (84.2%) subjects requested complete disclosure of cancer related information. Of the 39 remaining patients, 20 (7.9%) requested partial disclosure and 14 (5.6%) preferred to remain completely uninformed. The characteristics of subjects requesting complete and selective disclosure are demonstrated in Table 2. Only a diagnosis of metastatic disease was associated with a refusal of complete information with an odds ratio (OR) of 2.72 (95% CI, 1.29–5.74). Patient's age, sex, marital status, number of children, smoking history, ECOG PS and personal or familial history of cancer, did not influence the patient's information disclosure preference. While we did not find significant differences in country of birth or immigration status, patients originating from Africa compared to Israeli natives, tended to prefer a more selective disclosure of information with a suggestive OR of 2.50 (95% CI, 0.88–7.12).

Table 1
Population characteristics.

Characteristic	No.	%
Age		
<65	117	46.4
≥65	135	53.6
Gender		
Female	110	43.7
Male	142	56.3
Birth country		
Israel	99	39.3
Europe	32	12.7
Former USSR	45	17.9
Africa	24	9.5
Asia	47	18.7
Americas	5	2.0
Married		
No	73	29.0
Yes	179	71.0
Children		
No	20	7.9
Yes	232	92.1
Smoking status		
Never	65	25.8
Past	94	37.3
Current	86	34.1
Cancer type		
NSCLC	219	86.9
SCLC	21	8.3
Other	12	4.8
Metastatic		
No	121	48.0
Yes	131	52.0
Personal cancer history		
No	43	17.1
Yes	209	82.9
First degree familial cancer history		
No	209	82.9
Yes	43	17.1
ECOG PS		
0–2	225	89.3
3–4	27	10.7

USSR, Union of Soviet Socialist Republics; ECOG PS, Eastern Cooperative Oncology Group performance status.

4. Discussion

The results from the current study indicate that the large majority of thoracic cancer patients want to be completely informed about their disease. This is consistent with previous reports [2,3,8] and is similar to the 92% rate reported in Jerusalem over a decade ago [11]. However, to our knowledge, this is the first local study to compare attitudes of patients from multiple ethnic backgrounds. We found an equally high desire for information among migrant patients compared to natives. Data on this subject is limited; often inferred from the more traditional conceptualizations of non-Western attitudes to patient autonomy and empirically based on small sample qualitative studies [6,9,14,15]. While most have suggested that migrants may prefer approaches entailing limited disclosure, more recent studies conducted in Western countries such as Australia [9] and America [15] have countered this traditional assumption.

Our population was limited to patients with thoracic cancers, most of them lung cancer patients. As a whole, lung cancer patients have not been involved in many information disclosure preference studies. In line with our findings, one Belgian study of 128 patients with advanced lung cancer reported 97% of subjects requesting to be fully informed [16]. Patients with lung cancer have higher levels of perceived cancer-related stigma compared to other malignancies. Specifically, active or previous smoking is correlated with higher levels of guilt and shame and a belief that past behavior contributed to their cancer [17]. Currently, we did not identify an association between smoking status and information preference.

Demographic characteristics were not associated with the preference for information disclosure in our study. While previous studies have found age, sex and education to affect patient preferences for communication strategies [18,19], it seems that the more simplistic request to be kept well informed is more ubiquitous. Of