RESEARCH ARTICLE

Truth-telling in Oncology: Egyptian Patients' Attitudes and Preferences

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Abstract

Objective: Truth-telling in oncology is a major challenge, particularly in the absence of disclosure protocols in Egypt and the lack of Egyptian studies examining patients' preferences regarding cancer disclosure. This study aimed to reveal the preferences of patients seeking care at the National Cancer Institute – Cairo University regarding disclosing cancer diagnosis and the type and amount of information to be told. **Methods:** This cross-sectional study was conducted on 200 patients selected consecutively from those attending the outpatient clinics of the National Cancer Institute – Cairo University. Face-to-face interviews were performed with the patients according to a structured questionnaire. The questionnaire consisted of five parts: socio-demographic characteristics, knowledge about cancer disease, attitudes towards cancer disease, experience during the disclosure of the diagnosis, and preferences regarding disclosure of cancer diagnosis. **Results:** Most patients (89.5%) preferred to know the diagnosis. Of them, 94.4% wished to know from the physician. No agreement was found between most patients' preferences and physicians' practice. On multivariate logistic regression analysis, patients' education was the only significant predictor of the preference to know the diagnosis (OR = 5.298, 95% CI = 1.258 - 22.301, P = 0.023). **Conclusion:** Patients have a great desire to know the diagnosis and other information related to treatment and prognosis.

Keywords: Cancer disclosure- Bad news- Patients' preferences- Disclosure session

Introduction

In a medical setting, bad news refers to any information that significantly and negatively alters patients' perceptions of their future. Nobody likes delivering bad news; nevertheless, physicians and other healthcare professionals are compelled to do so (Alrukban et al., 2014).

The more serious and life-threatening a condition, the greater the importance of communication when delivering bad news. The effectiveness of bad news communication appears to be strongly linked to psychological adjustment, coping with treatment, outcomes, anxiety, and depression (Kaiser and Klocker, 2013).

While some established recommendations exist in the form of protocols or guidelines for effectively communicating bad news in a variety of countries, growing evidence indicates that disclosing bad news is a purely cultural issue influenced by an individual's social perceptions and preferences, and the recommendations applicable to one culture should not be applied blindly to another (Rabow and McPhee, 2000; Hollis et al., 2013).

Cancer diagnosis is a life-changing event. It is frequently seen as extremely stressful by patients, leading to anxiety, shock, sadness, withdrawal, and unresolved denial (Chittem et al., 2013). Physicians play a crucial

role in determining the overall well-being of a patient. The physicians' attitude toward the patients will be reflected on their management which may determine the patient's prognosis (Deepak et al., 2021).

Worldwide, the information provided to cancer patients continues to be a source of debate due to significant cultural variations. While most physicians in western nations reveal the diagnosis, the attitude is different in eastern countries. However, even in nations where disclosure of the diagnosis is now the norm, the attitude was the opposite a few decades ago. This demonstrates how the disclosure problem may evolve over time (Naji et al., 2015).

In Egypt, patients are frequently shielded from such knowledge. Family caregivers demonstrate a variable degree of negative attitude toward cancer diagnosis disclosure and may impede communication with cancer patients. According to an Egyptian study, Egyptian physicians prefer cancer diagnosis disclosure to family caregivers, while a minority prefer disclosure to patients (El Ghazali, 1997). Additionally, a recent study reports that approximately half of the physicians agree that patients would be psychologically damaged by knowing cancer diagnosis (Deepak et al., 2021).

These traditional paternalistic models of patient

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care have given way to more emphasis on patient empowerment, autonomy, and shared decision-making. Egypt lacks culture-based guidelines for disclosing cancer diagnosis. Furthermore, the literature lacks Egyptian studies examining patients' preferences regarding cancer disclosure. Only physicians' preferences were explored in a study conducted more than twenty years ago (El Ghazali, 1997).

This study aimed to explore Egyptian patients' preferences regarding cancer diagnosis and the type and amount of information they need to know in one of the largest cancer hospitals in Egypt.

Materials and Methods

This cross-sectional study was conducted from December 2020 to May 2021. The inclusion criteria were patients with a confirmed cancer diagnosis attending the outpatient clinics of the National Cancer Institute – Cairo University. Exclusion criteria were patients less than 18 years of age, bedridden patients, physical or cognitive difficulties affecting participation, and refusal to participate. To avoid selection bias, we used a representative sample of all cancer patients who visited the National Cancer Institute (NCI).

Tool

An interview questionnaire was used. The questionnaire was designed based on a literature review. It consisted of five parts: socio-demographic characteristics, knowledge about cancer disease, attitudes towards cancer disease, actual experience during the disclosure of the diagnosis, and preferences regarding disclosure of cancer diagnosis. The questions were closed-ended, to which the patients responded yes or no for most items, except for some items which included the "I don't know" or "not applicable" option.

Field-work

The researcher attended the National Cancer Institute (NCI) outpatient clinics from 9 am to 2 pm, two days weekly. The researcher conducted face-to-face interviews with patients according to the structured questionnaire. At each interview, the researcher introduced himself to each patient and told them the purpose of the study to obtain their approval and cooperation. Data confidentiality was ensured to gain the trust and confidence of the participants.

Validity and internal consistency

To examine the content validity of every sentence and phrasing of the questionnaires, the draft was given to three independent experts to assess whether it represented the principles intended to test and to decide its readability and consistency. Also, a pilot study was performed to determine the tool usability and clarity. It also helped to predict the time required for the questionnaire. In addition, internal consistency was tested using the Kuder-Richardson-21 test (KR-21) for patients' answers, and it showed moderate to good internal consistency.

Sample size calculation

The sample size was calculated using epi-info software version 7.2 based on an expected disclosure preference of 85% for patients (Zekri et al., 2016). The margin of error and confidence level were adjusted at 5% and 95%, respectively.

Ethical considerations

An approval from the research ethics committee at the National Cancer Institute – Cairo University was obtained (approval number: 201-617-064). Also, informed consent was obtained from all participantsa. All data were kept confidential.

Statistical analysis

Data management and statistical analysis were done using SPSS version 25 (IBM, Armonk, New York, United States). Quantitative variables were summarized as means and standard deviations. Time since diagnosis, a quantitative variable for which normal distribution would not be assumed, was summarized as median and range. Categorical data were summarized using numbers and percentages. Disclosure preferences of patients were compared according to different variables using independent t-test for numerical data and Chi-square or Fisher's exact test for other categorical data. The agreement was tested using the Kappa measure of agreement. All statistical tests were two-sided. P values less than 0.05 were considered significant.

Results

Patients' socio-demographic and general characteristics

As shown in Table 1, the mean age of the patients was 50 ±13 years. The sex distribution showed a slight female predominance relative to males; 58% and 42%, respectively. Regarding education, approximately half of the patients were illiterate (52.5%). Twenty percent of the patients were educated till the primary or secondary school levels; 12.5% and 7.5%, respectively. Almost one-quarter of the patients had a diploma degree (23.5%). University graduates were a minority (4.0%). Most of the studied patients had no employment (72%). About two-thirds of patients were married (67.5%). More than half of the patients were from rural areas (57%). Regarding cancer sites, GIT and gynecological malignancies were the most frequent and represented 28.0% and 22.0%, respectively, while lung cancer was the least frequent diagnosis (4.0%). About one-quarter of the patients (22%) had metastasis. The median time since diagnosis was 5 years, ranging from 7 days to 9 years.

Patients' knowledge and attitude

Approximately one-quarter of the patients (24.5%) knew information about cancer. About half of the patients believed that cancer is a serious disease (52%). Two-thirds believed that there is a cancer therapy (67.0%). Most patients believed that cancer patients are not rejected in the community (88.5%). Around half of the patients believed that cancer affects life aspects (48.5%).

Table 1. General Characteristics of the Studied Patients (n = 200)

General characteristics	
Age (years)	50 ±13
Gender	
Males	84 (42.0)
Females	116 (58.0)
Education level	
Illiterate	105 (52.5)
1ry school	25 (12.5)
Secondary school	15 (7.5)
Diploma	47 (23.5)
University	8 (4.0)
Employment	56 (28.0)
Marital status	
Married	135 (67.5)
Divorced	23 11.5)
Widowed	31 (15.5)
Not married	11 (5.5)
Residence	
Rural	114 (57.0)
Urban	86 (43.0)
Cancer type	
Bone and soft tissue	19 (9.5)
GIT	56 (28.0)
Gynecological	44 (22.0)
Head and Neck	41 (20.5)
Blood	13 (6.5)
Lung	8 (4.0)
Urogenital	19 (9.5)
Metastasis	44 (22.0)
Time since diagnosis	5 y (7 d - 9 y)

Data were presented as mean SD, number (percentage), or median (min-max)

Patients experience during disclosure of cancer diagnosis

Physicians directly told more than three-quarters of the patients about their diagnoses (76%). More than one-third (42.2%) of the patients, who were directly told the diagnosis by the physician, had their spouses with them, and only 17.8% reported that privacy was achieved during disclosure.

About half of the patients (48%) reported that physicians invited them to ask questions. Only 9.9% received information about how cancer would affect life expectancy. Less than one-quarter of patients (19.7%) received information about treatment, and approximately one-third (33.6%) received information about prognosis. About two-thirds of patients (67.8%) stated that the physician provided psychological support and gave them hope for a cure.

Patients' preferences

Most patients (89.5%) preferred to be told the diagnosis. Of them, 94.4% wished to know the diagnosis from the physician. More than two-thirds of patients (70.8%) who preferred to know the diagnosis from the physician preferred to have their spouse with them during disclosure. Only 12.4% stated that privacy was an important issue. Most patients preferred to be invited by the physician to ask questions (98%), to receive information about how cancer would affect life expectancy (83%), and to know information about treatment (83%) or prognosis (89.3%).

Agreement between patients' preferences and experience during cancer disclosure

As shown in Table 2, most practices did not show agreement with patients' preferences, except for privacy, which showed a moderate significant agreement (Kappa = 0.589, P-value < 0.001).

Factors affecting patients' disclosure preferences

As shown in Figure 1, those who preferred to know the diagnosis had significantly higher male gender (44.7% vs. 19%, P = 0.024), education (50.8% vs. 19%, P = 0.006), and employment (31.3% vs. 0%, P = 0.003).

Predictors of patients' preference to know the diagnosis

As shown in Table 3, multivariate logistic regression analysis revealed that education was the only significant predictor of patients' preference to know the diagnosis (OR = 5.298, 95% CI = 1.258-22.301, P-value = 0.023).

Discussion

In contrast to western culture, Egypt's social structure is based on the importance of family bonds instead of individual autonomy. Furthermore, the word "cancer" invokes fear even in those diagnosed with it, mainly due to the deep-rooted stigma associated with this emotive

Table 2. Agreement between Patients' Preferences and Actual Experience

Items	Preference (%)	Actual (%)	Agreement (%)	Kappa	P-value
To be told the diagnosis	89.5	76	71.5	0.033	0.604
Privacy to be achieved*	14.1	15.6	89.6	0.589	< 0.001**
Treatment information*	94.1	22.2	28.1	0.035	0.119
Prognosis information*	87.4	35.6	37.8	-0.023	0.605
Life expectancy information*	81.5	11.1	26.6	0.015	0.583
Physician to invite questions*	97	51.1	51.4	0.062	0.038**

* Number of patients who were told the diagnosis by a physician and their preference was to be told by a physician (135) was used as a denominator for these percentages; **Significant
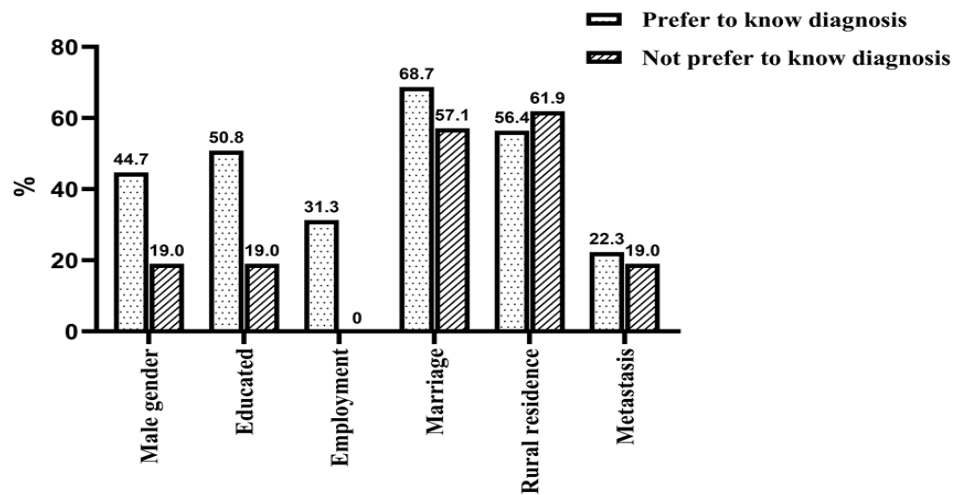
Figure 1. Factors Affecting Patients Disclosure Preferences

Table 3. Logistic Regression Analysis for the Prediction of Patients' Preference to Know the Diagnosis

	OR (95% CI)	P-value
Age (years)	1.018 (0.979 - 1.06)	0.372
Female gender (female vs. male)	0.389 (0.115 - 1.312)	0.128
Education (educated vs. not educated)	5.298 (1.258 - 22.301)	0.023*
Employmenet (employed vs. not employed)	4.485 (0.541 - 37.161)	0.164
Marriage (married vs. not married)	0.731 (0.257 - 2.078)	0.556
Urban residence (urban vs. rural)	0.486 (0.155 - 1.517)	0.214

* Significant; OR: Odds ratio; 95% CI, 95% Confidence interval

word. For many, cancer means an incurable and fatal disease (Bhatt and Klotz, 2016).

The current study explored cancer patients' attitudes and preferences regarding disclosing bad news. It could be a primary step for developing culture-based protocols for truth-telling to cancer patients. Despite the importance of this topic, few Egyptian studies have explored it (El Ghazali, 1997; Hammad et al., 2016; Alsirafy et al., 2017).

The results of the current study contradict the paternalist and family-centered decision-making approaches adopted in Egypt for many years (Alsirafy et al., 2017). Many recent studies in countries of similar cultures align with our results (Zekri et al., 2016; Al Qadire, 2018; Alzahrani, 2018; Mansour et al., 2017). A possible explanation for this high percentage of patients who needed to know more about their disease might be due to globalization, education, the development of social networking, and the increasingly Western lifestyle (Al Qadire, 2018).

In the current study, physicians' practice was far from patients' preferences. No agreement was found between patients' preferences and their experience during the disclosure session. The same no agreement also presents in a similar study, which reports that most patients (96.8%) prefer clarity about suffering and disease progression, but only 77.9% get it (Brown et al., 2011).

This gap between physicians' practice and patients' preferences might be due to the absence of protocols for disclosing cancer diagnosis that consider patients' needs and standardize practice among physicians.

The current study showed no age effect regarding factors that influence patients' disclosure preferences. Males preferred to know cancer diagnosis more than females. Education and being employed were associated with the preference to know the diagnosis. These findings align with Richter et al., who report no age effect but contradict Chen et al., who report no gender-based differences regarding disclosure preferences. Still, it agrees with Lashkarizadeh et al., who report that males are more interested in being informed of their disease than females. In addition, they agree with Tricou et al., who report that education and employment are associated with patients' preference for active or shared decision-making.

One of the important findings in our study was that less than one-quarter of the patients knew information about cancer disease (24.0%), and almost half of the patients believed that cancer affects life aspects (48.5%). This finding could be explained by the lack of disseminating accurate cancer-related information to the public through various means, such as media and social media awareness campaigns.

A possible limitation of this study is that all patients were selected from a single hospital of the National Cancer Institute. Although patients visit NCI from all over Egypt, it is still a single hospital. This may restrict the generalizability of the results.

Patients have a great desire to know the diagnosis and other information related to treatment and prognosis. We strongly recommend that the paternalistic and family-centered decision-making approaches should

be replaced by individualized decision-making approaches to respect patients' autonomy and the right to self-determination. Also, a culture-based protocol for disclosing bad news, tailored according to Egyptian patients' needs and beliefs, is urgently needed to standardize the practice of communicating bad news. Additionally, further multicenter studies exploring Egyptian patients' preferences are highly recommended to support our findings, in addition to studies on specific cancer types, as only few studies are available in the literature.

Author Contribution Statement

The authors confirm contribution to the paper as follows: Ghada M Sherif, Amal S Ibrahim, Mohsen A Gadallah were involved in the study conception and design and supervised the development of work. Mohamed M Bendary was involved in data collection and analysis and manuscript preparation. All authors reviewed the results and approved the final version of the manuscript.

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Conflict of interest
All authors declare no conflict of interest.

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