



Research Article

A SCITECHNOL JOURNAL

Cancer Diagnosis: Who has the Right to Know?

Samia Mohammed Al-Amoudi^{1*}

Abstract

Objectives: To explore the current attitudes towards informing patients of cancer diagnosis. This specifically pertains to the attitude towards sharing the news with family members and others who have the right to know.

Methods: A cross-sectional study was conducted at Al-Amoudi Breast Cancer Center at King Abdulaziz University from September through November 2012. This study was performed by distributing questionnaires to 191 subjects (46 female, 45 male second-year medical students and 100 to the non-medical staff). The questionnaire consisted of five main questions.

Results: 191 subjects participated. Of these, 38 or 81% of female students, 31 or 70% of male students and 60 or 60% of the non-medical staff were in favor of providing full information to the newly diagnosed cancer patient.

45 or 98% of female and 43 or 96% of male students preferred to be provided with full information, compared to 89 or 89% among the public.

When asked if being informed is a health right, 42 or 90% of female students, 43 or 96% of male students and 88 or 88% believe it is a health right.

9 or 20% of female students and 21 or 21% of the public, compared to 30 or 67% of male students believe that the patient has no right to hide information.

Finally, 33 or 73% of female students, 25 or 56% of male students and 70 or 70% of the public believe that both the patient and the relatives have the right to be informed.

Conclusion: This study indicates that the majority preferred disclosure of full information, and to share information with their families. The majority believe that both the patient and relatives have the right to be informed. As a result, this study calls for further studies to be conducted towards the empowerment of patients' rights regarding cancer diagnosis disclosure.

Keywords

Cancer; Truth; Information; Patients' rights; Disclosure; Medical students; Saudi

*Corresponding author: Samia Mohammed Al-Amoudi, Arab Board OB/GYN, Associate Professor and Consultant, Faculty of Medicine, Department of Obstetrics & Gynecology, King Abdulaziz University, Sheikh Mohammed Hussein Al-Amoudi Center of Excellence in Breast Cancer, King Abdulaziz University, P.O. Box 140295 Jeddah 21333, Kingdom of Saudi Arabia, Tel: +966(2)6408416; Fax: +966(2)6408397; E-mail: dr.samia_amoudi@hotmail.com

Received: January 15, 2013 Accepted: March 20, 2013 Published: March 24, 2013

Introduction

Saudi Arabia is expected to face an increase in cancer incidence estimated at nearly 350% by the year 2025, presenting a major health burden to the country [1]. This health burden means that many challenges and aspects have to be faced. One of these factors is the critical, but sensitive issue of informing patients that they have been diagnosed with cancer. This is because the subject of cancer in our society is surrounded by myths and misconceptions, meaning that telling a patient they have cancer translates to them and their families as a death sentence. For this reason, disclosure of diagnosis is still a dilemma with health care providers facing many ethical issues, particularly when the family requests and insists on hiding information from the patient. It is important for those dealing with cancer patients to appreciate that the ethical commitment of telling the truth should be considered of the utmost importance, equal to the obligation not to do harm [2,3].

In Saudi Arabia, religious traditions and social factors have great influence on patients' and their families' decision. Lying is widely known to be ethically unacceptable, but on the other hand, some families at times are continuing to insist on not telling the patient about their diagnosis or treatment. Therefore, in a conservative culture within closed communities, where there are many socio cultural changes occurring such as Saudi Arabia, it is important to study these changes and the attitude towards disclosure of the diagnosis of cancer. Therefore, the objective of this study is to explore the current attitude towards informing the patient of a cancer diagnosis, the attitude towards sharing this news with family members and the question of who specifically has the right to know.

Methods

A cross-sectional study was conducted at Sheikh Mohammed Hussein Al-Amoudi Center of Excellence in Breast Cancer at King Abdulaziz University, Jeddah from the period of September through November 2012. The questionnaire was distributed to 191 subjects (46 female second year medical students, 45 male students who attended a workshop on breast cancer diagnosis) and 100 other respondents from the non-medical staff in the Faculty of Medicine i.e., Administrative Departments. Approval was obtained from the Unit of Biomedical Ethics, Research Ethical Committee (REC) at the Faculty of Medicine, King Abdulaziz University, Jeddah, Saudi Arabia.

The questionnaire consisted of five main questions with three optional answers for each question. The questions were as follows:

1. What is your opinion concerning providing full information to newly diagnosed cancer patients about his/her disease?
2. If you were diagnosed with cancer, would you want to be fully informed about the diagnosis and prognosis?
3. Is disclosure of full information one of the patient's health rights?
4. Does the patient have the right to hide information from his/her family?

5. In your opinion, who has the right to full information?
Patients only, close family or both?

The objectives of the study were explained in detail to the students and to the staff, who agreed to participate. The subjects responded to the questions, which were given in English to the students and were translated into Arabic for the staff. Respondents replied with a “Yes” or “No” answer to the questions, as they felt appropriate. The answers were collected and properly analyzed.

Statistical Analysis

Statistical analysis was conducted by using Version 16 of Statistical Package for Social Sciences (SPSS). The qualitative data was presented in the form of figures and statistics, with Chi-square being used as a test of significance for comparison of qualitative data of the studied group. Significance was considered when P value was less than 0.05.

Results

One hundred and ninety-one (191) subjects participated in this study, 46 female medical students, 45 male medical students and 100 from the non-medical staff. Each group was analyzed separately. Among the female medical student group, 38 or 81% were in favor of informing and providing full information to the newly diagnosed cancer patient about his/her diagnosis. In addition, 31 or 70% among male medical students and 60 or 60% in the non-medical group, stated they were also in favor, with 2 or 5% of female students, 10 or 23% of male students and 15 or 15% non-medical staff stating they were against disclosure, respectively (Table 1).

On the second question, as to whether they would want to be given full information upon being diagnosed with cancer, 45 or 98% of female medical students, 43 or 96% of male students and 89 or 89% among the non-medical staff responded in the affirmative. This was not statistically different (Table 2).

To the question regarding the perspective of whether this is a patient’s health right, 42 or 90% of female students, 43 or 96% of male students and 88 or 88% of the non-medical staff, believe it is the patient’s right. This was not of any statistically significant difference. Only 1 or 2% among female, none among male and 1 or 1% among the public, responded that they did not know (Table 3).

When respondents were asked whether the patient has the right to

Table 1: What is your opinion of providing full information to a newly diagnosed cancer patient about his/her disease?

	Yes	
	No#	%
Male Medical Students	31	70%
N=45		
Female Medical Students	38	81%
N=46		
Public	60	60%
N=100		
Test significance Chi-Square:		
	$\chi^2=7.39$	P=0.024
Male Medical Students vs. Female Medical Students	$\chi^2=2.34$	P=0.126
Male Medical Students vs. Public	$\chi^2=1.05$	P=0.30
Female Medical Students vs. Public	$\chi^2=7.30$	P=0.006

Table 2: If you were diagnosed with cancer (God forbid), would you want to be fully informed about the diagnosis and prognosis?

	Yes	
	No#	%
Male Medical Students	43	96%
N=45		
Female Medical Students	45	98%
N=46		
Public	89	89%
N=100		
Test significance:		
	$\chi^2=4.33$	P=0.114
Male Medical Students vs. Female Medical Students	NS	NS
Male Medical Students vs. Public	NS	NS
Female Medical Students vs. Public	NS	NS

Table 3: Is disclosure of full information one of the patient’s health rights?

	Yes	
	No#	%
Male Medical Students	43	96%
N=45		
Female Medical Students	42	90%
N=46		
Public	88	88%
N=100		
Test significance:		
	$\chi^2=2.11$	P=0.34
Male Medical Students vs. Female Medical Students	NS	NS
Male Medical Students vs. Public	NS	NS
Female Medical Students vs. Public	NS	NS

Table 4: Does the patient have the right to hide information from his/her family?

	Yes	
	No#	%
Male Medical Students	30	67%
N=45		
Female Medical Students	9	20%
N=46		
Public	21	21%
N=100		
Test significance:		
	$\chi^2=33.99$	P<0.001
Male Medical Students vs. Female Medical Students	$\chi^2=20$	P<0.001
Male Medical Students vs. Public	$\chi^2=28.2$	P<0.001
female Medical Students vs. Public	$\chi^2=.04$	P=0.84

hide this information from his/her family, 9 or 20% of female students, 30 or 67% of the male students and 21 or 21% of the non-medical staff said that the patient has no right to hide such information. This was significantly different and shows P<.001 (Table 4).

On the fifth question, 33 or 73% of female students, 25 or 56% of the male students and 70 or 70% of the non-medical staff said they believe both the patient and the relatives have the right to be informed about the diagnosis and prognosis. In contrast, 11 or 22% of female students, 13 or 29% of male students and 14 or 14% of the public

Table 5: In your opinion who has the right to full information?

	Patients Only		Family Only		Both		TOTAL	
	# / No	%	# / No	%	# / No	%	# / No	%
Male Medical Students	13	29%	7	16%	25	56%	45	100%
Female Medical Students	11	22%	2	5%	33	73%	46	100%
Results from the Public	14	14%	16	16%	70	70%	100	100%

stated that only the patient has the right to be informed. Still, 2 or 5% among female students, 7 or 16% of male students and 16 or 16% of the non-medical staff think that only the family has the right to full information (Table 5).

Discussion

Disclosing to a patient that they have cancer is a critical, but sensitive issue. Although there has been great progress in cancer diagnosis and treatment, some still envision the diagnosis of cancer as a sentence of death [4,5]. Nonetheless, telling the patient truth is not only an ethical issue and a way of building confidence within the doctor -patient relationship, but also a patient’s right.

It is important of course, to understand that disclosing such negative news might result in a loss of hope, but still worse is hiding this information, which could have a far more negative impact on the management and adherence of a treatment plan in addition to denying the patient the right of choice, which is considered among the most basic health and human rights.

Among the most difficult problems health care providers are facing when dealing with cancer patients, is what to tell the patient in addition to, when, how and to whom disclosure is necessary. Still worse than this, is the instance that family members insist on hiding the diagnosis, which at times we face in our daily practice. This is why non-medical staff was included as they are from the community and could impact patient decision making if they have a member affected in the family.

In a medical school setting, this issue is left until the post-graduate years of training, but medical students as part of the community have the power to influence their families and more importantly are the doctors of the future. They should be involved and prepared for these medical and ethical issues from the beginning of their academic years. Unfortunately, their opinions and attitudes have only been assessed in a few studies in Saudi Arabia, with results indicating that almost all medical students believe full information should be given [6]. This is not different from the results in our study where a majority or 81% of female and 70% of male medical students exhibit the same opinion.

Concerning the topic of disclosure of diagnosis, as assessed in other studies, the conclusion was that the majority of patients also wanted to be fully informed of the diagnosis [7]. Saudi patients are not different in this respect, since the results of one study found that 98% of cancer patients wanted to know the diagnosis [8]. In our study, 60% of the public are in favor of disclosure, as well.

While the issue of telling the truth varies from one country to another, socio-cultural factors play a major role in shaping this attitude. In Japan, family members, not the patient play a major role in decision-making [9]. Similarly, these practices are observed in some Arab and Islamic cultures. Studies have shown in Turkey that

patients might not know their own diagnosis in 44% of cases [10]. Likewise, in Kuwait, 79% of physicians may respond to a family’s request and withhold information from patients [11].

In our survey, we explored the right of the patient to hide the information from his/her family. The results showed that 20% of the female medical students and 21% of the public believe that the patient has no right to hide the information, compared to 67% among the male medical students. This result is alarming as these are future doctors, whose views could influence patients’ decisions and their rights for not telling their families about their diagnosis. It also provides evidence of the weight applied to some principles, such as the wishes of the family, overprotection and control. It also shows the understanding of ethical issues and patients’ rights. For these reasons, the “health right” issue needs further studies to be conducted, due to the rights of health being a basic human right and a concept that has not been studied well in our community.

The role of the family is also apparent in our survey, where 73% of female medical students were in favor of informing the family, 70% of the non-medical staff and only 56% of male students said that, both the patient and the family have the right to the full information. This is in agreement with other studies in Saudi Arabia [6] where patients preferred a family-centered model of care [12].

While this is a limited study, it could still provide an excellent starting point for further, more comprehensive studies since there is a lack of sufficient data on these critical and sensitive issues, impacting treatment and its outcome. Not only have this but studies showed change in physician’s attitudes toward telling the cancer patient. e.g., in one study this was obvious as in 1961, clinical experience was the major policy determinant but the 1977 population emphasized the influence of medical school and hospital training [13].

We have to keep in mind as well that our what is applicable in western countries might not be the same in Arab countries as in a survey of 1251 patients in the USA showed that 96% of them wished to be told if they are suffering from cancer and 85% wished to know how long they were going to survive [14].

In Islam and medical ethics, the law is clear about privacy in general for medical issues but more studies are vitally needed to formulate guidelines for the issue of disclosure of cancer diagnosis and treatment in cancer and to emphasize that these human rights are becoming basic issues and should be integrated and intermingled with the rights of health.

Conclusion

This study shows that it is essential to empower all medical and non-medical subjects in the issues of patients’ rights, regarding cancer diagnosis and information disclosure.

In addition, the study has highlighted that human rights are basic

issues that are integrated and intermingled socially, therefore further studies are recommended concerning especially, women's health rights in the Arab and Muslim world.

Disclosure

Sheikh Mohammed Hussein Al-Amoudi Scientific Chair sponsored this study for Women's Health Empowerment (Women's Health Rights) Research.

Acknowledgment

I would like to especially thank Professor Basem El-Deek at the Medical Education Department, as well as participating students and Nurse Sara Bugshan for their kind assistance during the preparation of this study.

References


1. Ibrahim EM, Zeeneldin AA, Sadiq BB, Ezzat AA (2008) The Present and Future of Breast Cancer: Burden in the Kingdom of Saudi Arabia. *Med Oncol* 25: 387-393.
2. Hagerty RG, Butow PN, Ellis PM, Dimitry S, Tattersall MH (2005) Communicating Prognosis in Cancer Care: A Systematic Review of the Literature. *Ann Oncol* 16: 1005-1053.
3. Ptacek JT, Ptacek JJ (2001) Patients' Perceptions of Receiving Bad News about Cancer. *J Clin Oncol* 19: 4160-4164.
4. Georgaki S, Kalaidopoulou O, Liarmakopoulos I, Mystakidou K (2002) Nurses' Attitudes toward Truthful Communication with Patients with Cancer. A Greek study. *Cancer Nurs* 25: 436-441.
5. Costello J (2004) Is it Always Ethical for Health Professionals to Tell the Truth about Cancer? *Cancer Nursing Practice* 3.
6. Al-Amri AM (2011) Attitudes of Saudi medical students toward the disclosure of information on cancer in eastern Saudi Arabia. *J. Family Community Med* 18: 54-58.
7. Al-Mana W, Ahmed E, Al-Emadi K, Ahmed N, Al-Jalahma M, et al. (2003) Serious Illness Disclosure-Preference of Bahraini Patients. *Bahrain Medical Bulletin* 25.
8. Al-Amri AM (2010) Saudi Cancer Patient's Attitudes towards Disclosure of Cancer Information. *Middle East J Cancer* 1: 175-180.
9. Mizuno M, Onishi C, Ouishi F (2002) Truth Disclosure of Cancer Diagnosis and its Influence on Bereaved Japanese Families. *Cancer Nurs* 25: 396-403.
10. Bozcuk H, Erdoğan V, Eken C, Ciplak E, Samur M et al. (2002) Does Awareness of Diagnosis make any Difference to Quality of Life? Determinants of Emotional Functioning in a Group of Cancer Patients in Turkey. *Support Care Cancer* 10: 51-57.
11. Qasem AA, Ashour TH, Al-Abdulrazzaq HK, Ismail ZA, et al. (2002) Disclosure of Cancer Diagnosis and Prognosis by Physicians in Kuwait. *Int J Clin Pract* 56: 215-218.
12. Mobeireek AF, Al-Kassimi F, Al-Zahrani K, Al-Shimemeri A, al-Damegh S, et al. (2008) Information Disclosure and Decision-Making: The Middle East versus the Far East and the West. *J Med Ethics* 34: 225-229.
13. Novack DH, Plumer R, Smith RL, Ochitill H, Morrow GR, et al. (1979) Changes in physicians' attitudes toward telling the cancer patient. *JAMA* 241: 897-900.
14. Morris B, Abram C (1982) Making health care decisions. The ethical and legal implications of the informed consent in the practitioner-patient relationship. *United States Superintendent of Documents*. Washington 119.

Author Affiliation

Top

¹Sheikh Mohammed Hussein Al-Amoudi Scientific Chair for Women's Health Empowerment, King Abdulaziz University, Jeddah, Kingdom of Saudi Arabia

Submit your next manuscript and get advantages of SciTechnol submissions

- ❖ 50 Journals
- ❖ 21 Day rapid review process
- ❖ 1000 Editorial team
- ❖ 2 Million readers
- ❖ More than 5000 
- ❖ Publication immediately after acceptance
- ❖ Quality and quick editorial, review processing

Submit your next manuscript at • www.scitechnol.com/submission