

Disclosure of Cancer Information in Iran: a Perspective of Patients, Family Members, and Health Professionals

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Abstract

Background: In the last decades cancer has become one of the important causes of death in Iran. This study examined perspective of a group of Iranian health professionals, patients and patients' family members regarding their view on disclosure of cancer information at a university hospital in Tehran, Iran.

Methods: The method of study was qualitative semi-structured focused group content analysis. Two group leaders (psychologist and psychiatrist) run the focus groups. Oncologists, nurses, patients and family members participated in separate focus groups. Five group sessions were held to sum up the participants views in four major topics related to disclosure of cancer information to patients and families.

Results: Most of physicians and nurses believed that disclosure of cancer diagnosis is a mistake. Family members think that it should be delivered gradually during stages of therapy based on patient's psychological state, but most of the patients consider truth telling as a patient right. All physicians, most of nurses and all the patients see the physician as a person responsible to break the diagnostic disclosure. All patients wanted the physicians to take the total control of decision-making process for their treatment.

Conclusion: Iranian physicians and nurses hesitate to disclose cancer diagnosis compared to patients, who want to know the truth. Patients, nurses and physicians consider the physician to be the person responsible for delivering the information of cancer diagnosis. Development and implementation of a protocol based on Iranian culture is a necessity.

Key words: Neoplasm; Physician-Patient Relations; Professional-Family Relations; Truth Disclosure; Culture

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Introduction

In the last decades cancer has become one of the important causes of death in Iran[1], therefore encountering a newly diagnosed cancer test is not a rare situation and despite the significant improvements in cancer treatment it is still often perceived the same as a death sentence[2]. This makes the cancer information disclosure a challenging situation[3], a crisis that involves the whole psycho-socio-biological system of patient. This demands a new coping style, not only for the patient but for family and health professional too[4].

Telling the truth about cancer diagnosis is a difficult task mostly due to growing sensitivity of ethical and legal issues about patient's rights as well as fear of health professionals to destroy the patient's hope and lack of appropriate skills and

education among health professionals for breaking bad news. Another factor with profound effect is cultural context [5-6].

In spite of evidence suggesting that truth telling of cancer diagnosis lead to better outcomes in areas such as the trust between patient and medical staff [7], patient and family[8], treatment compliance [9], level of hope [10] and quality of life [11], there is different data from studies in Iran indicating newly informed patients had higher psychological distress [12] or lower quality of life [13] compared to non-informed patients. These data suggest the need for a domestic protocol appropriate for our population based on their unique complexities.

One of the most influential cultural variables is family members and relatives [5]. It affects attitude toward patient autonomy and reveals itself by

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family-centered model of medical decision making [14]. The family is the strongest support system for patients usually eager to protect the patient from any harm. This represents the extra pressure on the health professional on how the information should be delivered even if they are not opposed to complete information disclosure to patient.

A similar attitude has been found in many countries like Spain [15], Saudi Arabia [16] and Italy toward concealing the prognosis from the patients but not the family [17].

Physician attitude of non-disclosure are reported from studies in Greece [18], China [19], Singapore [20], Japan [21], Iran [22]. In a multinational survey conducted in 1987 in South Africa, France, Hungary, Iran, Panama, Portugal, Spain showed that only 40% of the oncologists disclosed the diagnosis of cancer to the patient, while almost all physicians revealed the truth to at least one member of the patient's family [23-24]. Moreover in Iran beside the close family, in most cases extended family members are also involved in the process of truth telling [25].

More recently a considerable amount of studies in western countries showed that most of people (whether they have cancer or not) prefer being informed about their diagnosis [26-27]. Although in other countries e.g. Saudi Arabia [28], Japan [21, 29-30], Southern Europe [31], Greece [32], Italy [33], and Poland [34], the patient do not ask about their diagnosis or simply are not informed. This attitude seems to be grounded in some western countries based on respect to individual autonomy in contrast to other cultures principle of family beneficence for patient [35].

In the last decades there is more emphasis on patients' right to have autonomy of knowing the information related to their disease and engaging in the process of decision making [36]. A similar attitude has been recently observed in Iranian patients [37]. The objective of this study was to examine perspective of a group of Iranian health professionals, patients and patients' family members regarding their view on disclosure of cancer information at a university hospital in Tehran, Iran.

Materials and Methods

The method of this qualitative study was semi-structured focus group content analysis. Subjects of study were hematology/oncology physicians, nurses and medical staff of hematology/oncology ward, family members of cancer inpatients and patients of Taleghani university hospital in Tehran, Iran. The inclusion criteria were cancer patients, from department of oncology, who knew their diagnosis

and had the physical ability to participate in the focus groups.

Five focus groups were formed including: five hematologist/oncologist physicians, two hematology/oncology fellowships, six hematology/oncology nurses, five family member, eight cancer patients (four women, three with breast cancer, and one ovarian cancer and four men, two with testis cancer, one with intestinal and one with acute leukemia). Each session was managed by one psychiatrist and a psychologist. Sessions lasted about one and half hour and was tape-recorded with participants' consent. Family members and patients completed a questionnaire including demographic information and information on cancer disclosure, patient's emotional reaction when the news delivered and expectations of the patient and family in regard to physician-patient effective communication. It should be mentioned that all patients and family members who participated in the study knew the diagnosis of cancer. Four main topics were covered during focus groups session: 1) whether cancer diagnosis should be disclosed to the patients? 2) What is the best manner for disclosing cancer diagnosis? 3) Who should disclose the diagnosis? 4) Is it necessary for patients to be involved in the process of clinical decision making?

Results

The results are organized by four main topics:

1) Whether cancer diagnosis should be disclosed to the patients?

Four from five physicians oppose the use of term "Cancer", and believed this term should not be used directly and should be replaced with a word with much less negative impression like tumor, in an attempt to not be specific. Physicians also believed that diagnosis should be delivered with vague wording considering the emotional and social status of patient. For example the patient should be informed that she/he have a serious intestinal disease not using the word cancer.

Five from six nurses disagree with truth telling of diagnosis in any direct form and believe it is better to be revealed spontaneously during the treatment. Four family members agree with disclosure but believe the way of delivering should be in a gradual manner and modified by patient's emotional status at the time. All of patients see it as their right that can help them participate more actively in treatment process.

2) What is the best manner for truth disclosing cancer diagnosis?

Most physicians believed that family is better to be involved from the beginning and patients should be informed gradually during different steps of treatment.

Most of the nurses think that it would be least harmful for the patient to find the diagnosis himself and indirectly by the behaviors and conversations in the ward. Family members preferred piece by piece truth telling based on psychological and emotional status of patient but patients believed they had the right to know the truth from the very beginning to become more effectively engage in treatment.

3) Who should disclose the diagnosis?

All of physicians and patient and almost all the nurses and family members see the physician as the only competent person for giving information regarding diagnosis. One of family members believed that family should disclose the diagnosis to the patient.

4) Is it necessary for patients to involve in clinical decision making?

All of nurses and five of physician believed in patient's involvement. Family members believed the same but family believe that ultimately the person who should decide about the treatment process is the physician. Patients believed they should be first ones to know the decisions but physician and family members prefer the family to be informed as the first step.

All of patients said that they have total trust and faith in their physicians and ready to follow all the treatment steps without any doubt.

Patient and the family members complain that they were not informed enough about the prognosis and treatment process. They also want physicians to work on their communication skills considering their day to day encounter with patients because it will have a very good impact on patient and family members.

Discussion

This is the first study that examined attitudes toward cancer diagnosis disclosure in Iran that includes health professionals, family members and patients at same time. In this study we found that most of physicians had an attitude toward concealing the diagnosis from the patients similar to studies during 1960s in USA, Southern and Eastern Europe [5], a multinational survey (Africa, France, Hungary, Iran, Panama, Portugal, Spain) conducted in 1987

[23], Spain[15], Saudi Arabia[39], Italy[40-41], Greece[18], China [19], Singapore [42], Japan[43], and previous studies in Iran [12, 22, 44, 45] which were in contrast with studies from western countries[46].

In recent studies in western countries truth telling centered strategies are supported by evidence of benefits in many aspects like quality of life [11]. This mostly contributed to doctrine of informed consent in medical ethics and law in these countries.

In contrast Iranian physicians worry about patients losing hope for a successful treatment. This is evident by other studies in Iran which demonstrates significant increase in psychological distress if the patients are informed [12] consistent with similar result in Japan [47] causing decreased quality of life [13]. There could be a number of explanations for these results. The better function of non-informed patient may be due to low skills of Iranian physicians in breaking bad news, inappropriate emotional management of informed patient or patients with more deteriorated condition are more likely to be informed because of the prominent symptoms which cannot be concealed from the patient.

It is worth to mention that in one study there was a strong relationship between illiteracy and not knowing the diagnosis [12].

Family members believed that the diagnosis should be delivered to patients. This is different from many societies with high level of family involvement who oppose to diagnosis disclosure such as Spain, Greece, China, Singapore, Japan, Saudi Arabia and Korean-Americans and even Mexican-Americans in USA [5]. Although Iranian families think diagnosis should be delivered gradually during different stages of treatment and based on psychological state of the patient and are concerned that disclosure could be a great emotional burden for patient. This is in line with other studies [10, 20, 48-49].

Most of Iranian patients want to be informed like the patients in many western countries[51] but there were different attitude in other Asian countries for example in Japan[29], Southern Europe[31], Greece, Italy, and Spain.[51]

Patient felt distressed about ineffective physicians' communication and demanded improvements in this area. A similar result was reported in a previous study in Iran indicating most of the cancer patients (69%) not satisfied with level of information [44-52]. Because patient distress could reduce compliance it seems that physicians' skills need to be further enhanced. In some degree physician worry about consequences of revealing the diagnosis (mostly

decrease of patients' hope) make physician to remain distant from the patient.

In topic of involvement in decision making, patients neither want family centered decision making nor patient autonomy like in U.S.A [30, 46]. Physician paternalistic view in breaking bad news (question 1) and individualistic view in decision making (question 4) is also showed in this study. Our patients completely trust their physicians when it comes to decision-making that was in contrast of a previous study in Iran [37].

Conclusion

It seems that the attitude toward truth telling of cancer in our country has a mixed pattern and is not similar to other cultures. Limitation of our study is small number of subject due to qualitative method. This indicates the need for further studies covering more cases and with better design to investigate it.

The need for development and implantation of a protocol in this area for breaking bad news based on our culture is a necessity.

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Conflict of Interest

The authors have no conflict of interest in this article.

Authors' Contribution

BN and MY designed the study, managed the focus groups, helped with analysis and revised the manuscript. MA wrote the manuscript, EE managed the focus groups, helped with data gathering an analysis while EF coordinated the participation for subjects.

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