

Mothers' preferences toward breaking bad news about their children cancer

Zahra Mostafavian¹, Zahra Abbasi Shaye², Arezou Farajpour^{3,4}

¹Department of Community Medicine, Mashhad Branch, Islamic Azad University, ²Clinical Research and Development Unit, Akbar Hospital, Mashhad University of Medical Sciences, ⁴Educational Development Center, Mashhad Branch, Islamic Azad University, Mashhad, ³School of Medical Education, Shahid Beheshti University of Medical Sciences, Tehran, Iran

ABSTRACT

Background: The responsibility of breaking bad news (BBN) to patients is one of the most difficult tasks of a medical profession. **Aim:** The current study aimed to investigate the preferences of mothers of children with cancer about BBN. **Materials and Methods:** In this cross-sectional study was conducted in Mashhad during years of 2016, 62 mothers of children with cancer at Dr-Sheikh hospital were recruited by convenience sampling and completed a questionnaire including demographic data and 20 questions about the mothers' preferences to BBN. Data displayed as percent by SPSS V20 software. **Results:** Mothers preferred that BBN conducted by their child's doctor (93.5%), with an emotional and compassionate way (83.9%), and in a private setting (90.3%). Be told completely about the process of diagnosis (98.4%), meet people with similar conditions (83.9%), receive psychological (85.5%), and religious (79%) support after getting bad news, being in touch with a close relative (82.3%) and applying another term-like malignancy instead of cancer (95.5%). **Conclusion:** We tried providing helpful information for developing national guidelines about how to breaking news in Iran, by doing this study.

Keywords: Breaking bad news, cancer, children, mothers' preferences

Introduction

One of the most difficult duties of the physician is breaking bad news (BBN)^[1] and nearly all physicians have to deliver bad news to patients in their career life. Bad news about cancer or incurable disease can be very uncomfortable for patients and also might have a serious adverse effect on them.^[2]

Bad news has different definitions such as news which leads to losing hope; put the physical or mental condition of persons in danger, destroying the foundation of life, or any news that brings little or no hope for the future.^[3] How to deliver bad news is one of the challenging issues in today's Medical Ethics. It is very crucial for all health provider teams to be aware of

the appropriate technique of delivering bad news.^[4] One of the most important protocols for delivering bad news is SPIKES – a six-step protocol which can achieve four essential goals. The first is gathering information from the patient. This allows the physician to determine the patient's knowledge and expectations and readiness to hear the bad news. The second goal is providing intelligible information in accordance with the patient's needs and desires. The third goal is to support the patient by employing skills to reduce the emotional impact and isolation that experienced by the recipient of bad news. The final goal is to develop a strategy in the form of a treatment plan with the presence and cooperation of the patient.^[5]

Another method for BBN was named as ABCDE. This method includes preparation, proper physician-patient relationship, good communication skills, and sensitive to the reaction of patients and their families.^[6]

Address for correspondence: Dr. Zahra Abbasi Shaye, Clinical Research and Development Unit, Akbar Hospital, Mashhad University of Medical Sciences, Mashhad, Iran.
E-mail: drabbasi_94@yahoo.com

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Knowing about health conditions is one of the patients' rights,^[4] although it is always important to consider the capacity and willingness of patients about how much information they would like to receive.^[7] Patients exhibit different responses when they receive the bad news. These responses vary from the range of physical to emotional and psychological.^[8] Knowing patients' personalities and their preferences are important in delivering bad news.^[9] People with different cultural backgrounds have different tendencies toward receiving bad news^[10-15] Most guidelines about BBN are based on physician' view and developed in Western cultures.^[4] In Iran, some studies have been conducted to examine the patient's tendencies toward receiving bad news.^[16,17]

In cases of childhood cancer, how to transmit bad news can have an important effect on the attitude of mothers toward the disease, their long-term relationships with doctors and parent and provider satisfaction.^[18] The time immediately after diagnosis is considered as the most stressful period, leading to the highest drop in the quality of life of mothers and in many cases, several years after they encounter bad news, these people remember the smallest details, and even after, a significant period, they are experiencing intense emotional responses.^[19] Evidence suggests that, based on different cultures in different regions, there are various attitudes toward the disclosure of bad news.

In some regions, such as North America and Europe, the doctor mostly declares the disease of patient clearly, but in South and East Europe and China, because of the current paternal viewpoint, some patients are denied access to information about their illness.^[20,21]

From parents view, in Saudi Arabia, 80% of parents wanted to know all the details about their children's cancer.^[22] In Canada, 79% of parents who received full details of news expressed their full satisfaction.^[23]

The preferences of mothers for how to be told about their child's cancer is not well-investigated in Iran. Therefore, the present study aims to investigate Iranian Mothers' preferences for how to receive bad news about their child's cancer.

Materials and Methods

This is a cross-sectional study which was done at Sheikh Children's Hospital in Mashhad, Iran in the year 2016. Participants were mothers of children with cancer admitted to the pediatric ward of Sheikh Hospital that enrolled by convenience sampling. Inclusion criteria were being from Iran, aged over 18, no previous experience with BBN, not being a health-care provider as a profession and have consent to participate.

Data were collected by a trained medical student using researcher made questionnaire including demographic data (age, education, and occupation of mothers, age, sex, type of cancer and treatment, and frequency of hospital admissions of children) and 20 questions were about the mothers' preferences to BBN.

To develop this questionnaire, we used BBN questionnaires which were already used in similar studies.^[22,24] Each preference question was measured on a 5-point Likert scale ranging from strongly agree, agree, no idea, disagree, and strongly disagree. Face and content validity of questionnaire confirmed by a panel of experts including community medicine specialist, pediatrician, and oncologist. We used Cronbach's alpha coefficient to assess the reliability of the questionnaire which showed 72%.

Sample size was calculated according to Abdelmuktader's study^[24] using the estimation of a proportion formula with regarding 78% rate of mothers want to be alone when they received bad news ($P = 78\%$), $\alpha = 0.05$ and $d = 0.1$; finally, 62 mothers were entered to our study.

The study was approved by the Ethics Committee of Islamic Azad University of Medical Sciences, Mashhad branch. Participants were obtained an informed consent before entering the study. Data analysis was done by specialist of community medicine using IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp with descriptive statistics.

Results

Sixty-two mothers of children with cancer participated in this study. Demographic information of mothers and their children is shown in Table 1.

A number of 20 mothers' preferences about how to break bad news were detected. These preferences were in various fields including the person who informed the illness to mothers and their children, the time and place of notifying the disease, and how to notify. Mothers' preferences toward BBN about their children cancer are summarized in Table 2. The frequencies of the two options "strongly agree" and "agree" for each question were combined and considered as percent who agree in Table 2. As shown in Table 2, almost all mothers wanted to be aware of the stages of diagnosis completely (98.4%) followed by applying another term such as malignancy instead of cancer (95.2%).

Discussion

The most difficult step for the patient and the doctor in the process of treatment in debilitating and incurable disease is delivering bad news. How to deliver bad news has a significant impact on the mothers' views, ongoing relationship with the physician during treatment, and patient and physician satisfaction. This study is one of the first studies to assess the preferences of Iranian mothers that how would like physicians break bad news about their child's disease.

Complete awareness of the stages of diagnosis

Our findings showed that almost all mothers (98.4%) would prefer be fully informed about the process of diagnosing their children's disease. Nearly 83.9% of them would prefer to hear the news immediately after the diagnosis was confirmed. The

Table 1: Demographic characteristic of mothers and children

Variable of mothers	Group	n (%)
Education	>12 years	38 (61.3)
	≤12 years	24 (38.7)
Occupation	Housekeeper	53 (85.5)
	Employed	2 (3.2)
	Jobless due to their child disease	7 (11.3)
Age (years)	Mean	34.02
	SD	5.76
	Minimum	21
	Maximum	56
Variable of children	Group	n (%)
Sex	Boy	34 (54.8)
	Girl	28 (45.2)
Type of cancer	Hematologic	43 (69.4)
	Nonhematologic	19 (38.6)
Type of therapy	Chemotherapy	51 (82.3)
	Surgery and chemotherapy	7 (11.3)
	Surgery and chemotherapy and radiotherapy	4 (6.5)
Age (years)	Mean	6.8
	SD	4.09
	Minimum	1
	Maximum	16
Frequency of hospital admissions in children	Mean	7.52
	SD	8.98
	Minimum	1
	Maximum	40

SD: Standard deviation

majority of them (74.2%) would not like their children be informed about their cancer. Similar to this, in Egypt, only 15% of mothers would like to hear news about their children disability in front of them.

Physicians usually underestimate the amount of information which patients need to know and they assume that patients usually do not want to know all the details about their diseases, while in our study, 98.4% of mothers would like to know all the details about their children and in a study in 2001 which was done in New York, 72% of patients stated that they would like to know all the details of their illness. Though, in Sullivan's study, Only 42% of physicians and 42% of nurses said patients want to be told all details about a serious illness.^[25]

In a study in 2004, Canadian and Spanish patients were compared about receiving details of bad news. The results revealed that Canadian patients preferred to know more details compared to Spanish patients. In that study, Canadian families preferred their patients to receive as much detail as possible about their illness; however, 89% of Spanish families mentioned that it is not necessary for their patients to know any details.^[26]

In a study, which was conducted in Canada between June and August 2016 among 116 parents, 77% of parents received the news of their children's cancer with all the details. Twenty

percent received the bad news without more details, and a small number found the news vaguely. About 1% did not know anything about their children's cancer. The parents who received the details of bad news were more satisfied than others and they mentioned it as a positive experience. Nearly 21% remembered it as a negative experience. The results of this study showed that most parents would like to know all the details about their children's diseases.^[23]

Hearing news from relatives or friends, being in touch with a close relative when hearing bad news

Culture of societies is effective in providing information to cancer patients. In the countries of North Europe and the United States, the usual practice of most doctors is telling disease diagnose to the patients, but in Iranian society, the dominant culture is serious support for the untreatable and highly ill patients, and doctors prefer to tell the disease to the family of patients instead of patients itself.^[26,27]

Being alone when hearing bad news

Our results showed that only 8.1% of mothers preferred to be alone and 82.3% would like to be in touch with a close relative when hearing bad news. In another study, which was conducted in Saudi Arabia between 2009 and 2011 among mothers of infants with trisomy 21, a 12-item questionnaire was used. The results of this study showed that only 16% of mothers were satisfied with being the first person who was received the bad news, 56% preferred to have a company at the time of receiving bad news, and 64% of mothers would prefer to be alone at that time.^[22]

Being aware of the possibility of cancer before the final diagnosis

Our study showed that 46.8% of mothers liked to be aware of the possibility of cancer before the final diagnosis. In another study, which was done in Egypt, 94% of mothers preferred to receive the bad news as early as possible with more details.^[24]

Meet people with similar conditions after diagnosis

The preference "meeting people with similar conditions after diagnosis" was important by 83.9% of mothers, possibly indicating a mother's desire not to be the only one who has a child with this problem.

Get informed with an emotional and compassionate way

Parent-to-parent contacts often serve as a network for transmitting information and emotional support.^[28] Establishing good communication between the doctor and the patient will increase the accuracy of diagnosis, make better treatment decisions, reduce inappropriate treatments, increase doctor's satisfaction and reduce patient anxiety, as well as their confidence and satisfaction.^[18] Nearly 93.5% of mothers in our study would like hearing bad news from their child's doctor and 83.9% of them said that getting informed with an emotional and

Table 2: Ranking of mothers' preferences toward breaking bad news about their children cancer

Item no	Preference	Percentage who agree (n)	Item no	Preference	Percentage who agree (n)
13	Complete awareness of the stages of diagnosis	98.4 (61)	16	To prefer the child not be informed of his disease	74.2 (46)
20	Applying another term like malignancy instead of cancer	95.2 (59)	2	Being aware of the possibility of cancer before the final diagnosis	46.8 (29)
3	Hearing the news from their child's doctor	93.5 (58)	14	Get notified explicitly and without emotional method	29 (18)
6	A private room is a good place to give bad news	90.3 (56)	4	Informing the child about his/her disease at the level of his own perception by his/her mother	21 (13)
15	When it comes to bad news or afterward, there is a need for a psychological counselor	85.5 (53)	1	Being alone when hearing bad news	8.1 (5)
7	Meet people with similar conditions after diagnosis	83.9 (52)	5	Bring the news to the mother by the nurse or other medical staff	4.8 (3)
9	Being aware of cancer after the final diagnosis	83.9 (52)	18	Breaking bad news by medical students	4.8 (3)
10	Get informed with an emotional and compassionate way	83.9 (52)	11	Busy places such as the hospital corridor are a good place to give bad news	3.2 (2)
8	Being in touch with a close relative when hearing bad news	82.3 (51)	17	Hearing news from relatives or friends	3.2 (2)
12	Talk to a religious adviser after hearing bad news	79 (49)	19	Get informed the child about the disease by a health worker	3.2 (2)

compassionate way was important. In one study titled "Egyptian mothers' preferences regarding how physicians break bad news about their child's disability" is expressed this emotional way of the informer is publicly linked to the long-term understanding of parent about their child.^[24]

When it comes to bad news or afterward, there is a need for a psychological counselor

Arbabi *et al.* study that was conducted on adult cancer patients proposed that the disclosure of cancer diagnosis be done by a physician and in the presence of a family member and the patients be consulted by their physicians about treatment options.^[16]

Hearing the news from their child's doctor, a private room is a good place to give bad news

In Aminiahidashti study which was done on adult patients with malignancy or chronic diseases, the majority of patients believed that they should be fully informed of their health by experienced and skillful physicians and expressed that, it is best to hear bad news in a private calm and suitable place and time.^[17]

One of the strengths of this study is the identification of important items for designing specific protocols in giving news by physicians to mothers of cancer patients and also this project is one of the few studies that have been conducted in this regard in Iran.

There are some limitations in our study such as convenience sampling from one hospital that limit the generalizability of our result to some extent, but we try solve this problem by selecting the largest referral hospital in oncology of pediatrics in Mashhad city. Despite the challenges involved in delivering bad news, the evidence shows that Physicians' skills in delivering bad news and establishment of good communication with the patient and his relatives

are very important in compliance and conformity with the event.^[29] According to cultural differences in Iran with Western countries; further research is needed to provide empirical support for developing national guidelines in Iran. In addition, it seems there is a need regarding teaching and studying of ethical issues, especially how to discuss bad news.

Conclusion

The findings of the present study show that most mothers want to be fully aware of the process of their children's disease diagnosis and after that, hearing bad news from their children's doctor with an emotional and compassionate way, using another term like malignancy instead of cancer in a private place. They expressed their needs to psychological support.

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Conflicts of interest

There are no conflicts of interest.

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