Original Article

Perceptions of Receiving Bad News about Cancer among Bone Cancer Patients in Sarawak General Hospital - A Descriptive Study

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Abstract

Background: **This study aimed to determine the perceptions and expectations of bone cancer patients with respect to their doctors and the breaking of bad news as well as the environment in which the news was delivered.**

Methods: **A cross-sectional study using a pretested 41-item questionnaire was conducted using convenience sampling among bone cancer patients in Sarawak General Hospital. Face-to-face interviews were conducted after consent was obtained. Data were analysed using SPSS version 16 (SPSS Inc., IL, US).**

Results: **A total of 30 patients were interviewed. The majority of the respondents were younger than 40-years-old, Malays, and female. All of the respondents perceived that they received news in a comfortable place, agreed that the doctor used simple language and appropriate words during the interaction, and believed that the way the doctor delivered the news might influence their life. The majority of the respondents reported that their news was received without interruption, that the doctor was sitting close but without making physical contact, and time was given for patient to ask questions and they were informed accordingly.**

Conclusion: **Delivering bad news regarding cancer is an important communication skill and a complex task that can be learned and acquired. Specially tailored training is proposed to improve medical practice in this area.**

Keywords: *bone neoplasms, communication barrier, health care, truth disclosure*

Introduction

Cancer is one of the leading causes of death in the world today. The estimated cancer incidence in Malaysia is 30 000 cases annually with a prevalence of 90 000 (1). Bone cancer is relatively uncommon and involves tumour growth in the bone resulting in pain, hypercalcemia, anemia, skeletal fractures, and spinal related injuries that can affect mobility and subsequently the patient's functional status, quality of life, and survival (2). The most common type of bone cancer is osteosarcoma; mainly affects children and young adults, chondrosarcoma; usually afflicts adults over 40 years of age, and Ewing's sarcoma; which is commonly found in children and teenagers (3).

As cancer is a complicated illness that often leads to a poor prognosis, it is a major challenge to healthcare providers, particularly at the point when they have to break bad news to the patient. Bad news can be regarded as unfavourable news that in the context of medicine has been defined as "any news that drastically and negatively alters the patient's view of her or his future" (4). It is often a dilemma for the physician in charge to be able to break the bad news to patient and family members without giving a sense of false hope. Effective breaking of bad news must consist of the ability to break the news compassionately, clearly, and at the same time provide emotional support, respond to questions, and maintain a sense of hope. A good breaking of bad news should avoid

misunderstandings with regard to the disease, treatment, management, and prognosis, which would contribute to better treatment compliance and emotional adjustment (5).

Communication barriers such as educational level, socio-economic status, language, and gender may hinder the effectiveness of delivering bad news (3). Additionally, the patient's emotional state, the doctor's sensitivity, and perception can all be crucial factors to consider when delivering bad news (5). Moreover, cultural influences observed in countries like Japan, Pakistan, Turkey, and Saudi Arabia, often discourage the patient from knowing the truth to prevent emotional breakdowns (6–9). Thus, the breaking of bad news may pose different challenges.

Previous studies have described the challenges in the patients' perceptions of the breaking of bad news (7,8,10). However, most of these studies have focused on breaking bad news for more common types of cancer in developed countries. As cultural differences and the type of cancer may affect the patients' perception on doctor's effectiveness in breaking bad news, currently available findings may not be applicable in Malaysia. This study aimed to determine the perceptions and expectations of bone cancer patients with respect to their doctors and the breaking of bad news, as well as the environment in which the news were delivered.

Materials and Methods

A cross-sectional study using a pretested 41 item questionnaire adopted from Ptacek and Ptacek (10) was performed. The questionnaire consists of 5 subscales that measured the perception of bone cancer patients on the breaking of bad news: (a) Environment (7 questions), (b) Physician behaviours (7 questions), (c) Physician speech (9 questions), (d) Patient-centred (9 questions), and (e) Miscellaneous (3 questions). A yes-no response was obtained for each item. Using a back-to-back method, the questionnaire was translated into the Malay language to facilitate the interview process. A pilot study was not conducted due to the limited number of bone cancer patients at the time of the study. The questionnaire was reported to be reliable with a Cronbach's alpha of 0.89 and an average inter-item correlation score of 0.36 (11). The content validity of the questionnaire was achieved from the extensive literature as previously reported by Ptacek and Ellison (11) and Ptacek and Eberhardt (12).

This study was conducted in the orthopedic ward of the Sarawak General Hospital, the regional hospital that offers specialist treatment for osteosarcoma and soft tissue sarcoma patients in Sabah and Sarawak. The ward consists of 72 beds that accommodate both male and female patients. The patients were normally diagnosed in the outpatient clinic, followed by the breaking of news regarding the diagnosis and treatment. Only the patients admitted for treatment were recruited for this study.

Ethical approval for this study was obtained from the Ministry of Health Malaysia (NMRR-10-931-7508). All sarcoma patients admitted to the ward who gave consent were recruited for this study. Patients who were ill, mentally challenged, or refused to participate were excluded from the study. After obtaining informed consent, a face-to-face interview was conducted. The second researcher performed all face-to-face interviews using the questionnaire. A total of 30 patients were interviewed during the 2 months data collection period. Data were entered and descriptive analyses were performed using SPSS version 16.

Results

All respondents were interviewed between January and February 2010. The socio-demographic data of the respondents are presented in Table 1. More than 75% of the respondents were younger than 40-years-old, and the majority of the respondents were Malay, followed by other Sarawak natives (23.3%). A total of 63.3% of the respondents were women, the majority of whom were either single or married. Approximately 40% of the respondents were working and 60% had a secondary level of education.

Table 2 presents the health profile of the respondents. An equal number of patients were diagnosed with osteosarcoma and soft tissue sarcoma (36.7%, respectively) while the rest were diagnosed with Ewing's sarcoma and synovial sarcoma. The majority of the respondents were informed of their diagnosis more than 4 months previously (43.3%). All respondents at the time of the study were receiving intravenous chemotherapy as their treatment.

Table 3 presents the findings of patients' perceptions and expectations of the doctor when breaking bad news and the environment in which the news was delivered. All of the respondents perceived that they received the news in a comfortable place, agreed that the

Table 1: Socio-demographic characteristics of the respondents (n=30)

Socio-demographic characteristics	Number of respondent (n)	Percentage of respondent (%)
Age (years)		
≤ 20	8	26.7
21–30	6	20.0
31–40	9	30.0
> 40	7	23.3
Races		
Malay	11	36.7
Pribumi Sarawak (Iban & Bidayuh)	7	23.3
Chinese	5	16.7
Others	7	23.3
Gender		
Male	11	36.7
Female	19	63.3
Marital status		
Single	14	46.7
Married	14	46.7
Divorced	2	6.6
Occupation		
Currently employed	12	40.0
Unemployed	8	26.7
Studying	10	33.3
Educational level		
Primary school	3	10.0
Secondary	18	60.0
Diploma and above	9	30.0

Table 2: Health status of the respondents (n=30)

Health profile	Number of respondent (n)	Percentage of respondent (%)
Cancer type		
Osteosarcoma	11	36.7
Soft tissue sarcoma	11	36.7
Synovial sarcoma	6	20.0
Ewing's sarcoma	2	6.6
Duration of diagnosis (months)[a]		
< 1	7	23.3
1–4	10	33.3
> 4	13	43.3

[a] The duration of diagnosis is the duration of time since the patient was informed of his/her diagnosis.

Table 3: Perceptions of the patients (n=30)

Characteristic	Percentage of "Yes" answer (%)
Environment	
Did you receive the news in the ward?	96.7
Did you receive the news in a comfortable place?	100
Did you receive the news in a private location?	10.0
Did the doctor deliver the news by himself?	96.7
Did the doctor make certain there were no interruptions while breaking the news?	93.3
Did the doctor deliver the news at the location he selected?	13.3
Did anyone accompany you when the doctor delivered the news?	86.7
Did any nurse accompany the doctor when breaking the news?	6.7
Physician behaviours	
Did the doctor decide where he/she wanted to deliver the news?	10.0
Were you given written material about the condition or services?	70.0
Did the doctor sit close to you while breaking the bad news?	96.7
Did the doctor check if you had any questions?	20.0
Did you feel that the doctor hid his real feelings about the disease during the interaction?	16.7
Did the doctor use non-verbal cues or body language indicating that bad news was forthcoming?	6.7
Did the doctor have any physical contact while breaking the news, such as holding your hand?	10.0
Physician speech	
Did the doctor use simple language during the interaction?	100
Did you understand the news and implications when the doctor broke the news?	86.7
Did the doctor deliver the news in a warm and caring manner?	96.7
Did the doctor convey some hope to you?	96.7
Did the doctor use appropriate words during the interaction?	100
When you asked a question, did you think the doctor had the ability or knowledge to answer?	96.7
Did you think the doctor took his time or rushed when delivering the news?	83.3
Did the doctor use humour/jokes to ease the situation during the interaction?	6.7
Based on your observation, did you think the doctor was struggling to find the right words when delivering the news?	16.7
Patient-centred	
Were you given a chance to ask questions?	86.7
Did the doctor show sensitivity to how you felt?	20.0
Were you given the opportunity to express your feelings?	30.0
Did the doctor show that he/she thought about your needs during the interaction?	33.3

Characteristic	Percentage of "Yes" answer (%)
Did the doctor take seriously your personality and emotions when delivering the news?	26.7
Did the doctor take into account that you already knew about the news?	13.3
Did the doctor give you the option of how the news should be delivered?	13.3
Did you think the manner in which the doctor delivered the news might influence your life?	100
Did you think the doctor only took care of his/her own needs during the interaction?	0
Miscellaneous	
Were you sad when the doctor delivered the news?	93.3
Was the doctor nervous when you received the news?	3.3
When you received the news, did you blame the doctor for the unexpected news?	0

[a] The duration of diagnosis is the duration of time since the patient was informed of his/her diagnosis.

doctor used simple language and appropriate words during the interaction, and believed that the manner in which the doctor delivered the news might influence their life. The majority of the respondents reported that they received the news in the ward, agreed that the doctor delivered the news by him/herself without interruption during the news breaking and that they were accompanied by someone (86.7%–96.7%). However, most of the bad news were not delivered in a private location, the location was not chosen by the doctor (10%–13.3%) and no nurse accompanied the doctor.

In terms of physician behaviours, the majority of the respondents reported that the doctor sat closely to them, but only 10% had physical contact such as holding hands during the breaking of bad news. Approximately 70% of the patients were given written materials about the illness and the health care services available. Less than 20% of the patients felt that the doctor hid his/her real feelings about the disease or used non-verbal cues during the delivery of bad news.

Based on the responses for each subscale, the physician's speech was perceived to be the most favourable. The majority of the patients (83.3%–100%) reported that the doctor used simple language, delivered the news in a warm and caring manner, conveyed hope to them, was able to answer questions, took his/her time in delivering the news, and explained the implications properly. Many patients did not think the doctor was struggling to find the words or use humour/jokes to ease the situation during the delivery of the bad news.

On the patient-centred subscale, only 2 items were rated above 85% by the respondents: patients were given a chance to ask questions and patients believed that the manner in which the doctor broke the news might influence their life. Less than 15% of the respondents reported that the doctor took into account what they knew or gave them the option on how the news would be delivered. Approximately 20% of the respondents felt that the doctor allowed them to express their feelings and none of the patients thought the doctor only took care of his/her own needs during the interaction. On the miscellaneous subscale, almost all of the respondents admitted they were sad when receiving the bad news, but none of them blamed the doctor for the unexpected news.

Discussion

This preliminary study provides an important local perspective on the perception of sarcoma patients regarding the breaking of bad news by their doctor. Although privacy was limited, more than 95% of the respondents reported that the environment (the ward) in which they received

bad news was comfortable, and particularly so when the doctor made certain that there were no interruptions during the process. The literature suggests that a comfortable environment is a significant independent predictor of satisfaction for the delivery of bad news (10). The ideal location for breaking news should be comfortable and without interruption to ensure patients are in the best condition to receive the news (10). Only 6.7% of the respondents received bad news in the presence of a nurse. This finding is of concern. Although breaking bad news is the doctor's responsibility, using a multi-professional team is also important (13). When cancer patients receive their diagnosis, they tend to lose part of the information due to their reactions to the news (13), and they will subsequently turn to nurses to obtain the missing information or to confirm the information that they have heard (14). In addition, studies have also shown that nurses can be the interpreters when patients do not understand what is explained to them due to the complexity of the medical terminology used in breaking the news (15).

Physicians were reported to break the bad news themselves, using simple and easy language and proper body language (sitting close, warm, and caring manner). These findings indicated that the doctors were perceived to be competent in the task of breaking bad news. However, only a small percentage of the respondents indicated that the doctors initiated physical contact such as holding their hands. This finding is not surprising, as using physical contact to offer comfort is not part of the Malaysian culture. Two-thirds of the respondents reported that their doctors did not show any sensitivity to their feelings or consider their needs or emotions during the interaction, which prevented them from expressing their feelings. One possible explanation could be that the doctors were trying to maintain professional distance to prevent any outburst of emotion that might be difficult to handle (10). Other physicians may feel that psychological assistance is beyond their job description (16).

The breaking of bad news to cancer patients is an important communication skill, but it is also a complex communication task. In addition to having the ability to break news verbally, the doctors also need to have effective non-verbal skills. These include responding to a patient's emotional reactions, involving the patient in decision making, helping patients to cope with many issues, and addressing the dilemma of not giving false hope to the patients. It is recognised that breaking bad news is one of a doctor's most difficult duties, yet most doctors are not formally trained for the task (17). Among those doctors who directly interact with cancer patients, specially tailored training has proven to be helpful and beneficial in their daily practice (18).

Approximately 13% of the doctors took into account that their patients already knew the news. Had the doctor inquired, the patient would have informed the doctor about knowing their diagnosis. This would foster a better doctor-patient relationship in cancer treatment and save the doctor time for other useful activities. Additionally, only approximately 13% of doctors gave the patient the option on how the news should be delivered. These findings indicated that some doctors might still practice paternalism in the doctor-patient relationship where they see themselves in a superior position to their patients (19).

Conclusion

Despite high levels of self-reported satisfaction by patients on some of the aspects of breaking of bad news, there are some areas of concern. The findings suggest that special attention should be given in creating a more conducive environment and specific training to help the physicians to be more confident and competent in delivering of bad news. Doctors need to take into consideration their patients' prior knowledge about their cancer in order to be more effective in breaking the bad news. In addition doctors need to allow their patients to express their feeling, which is very important after receiving a bad news.

This study has 2 limitations. First, the study was based on convenience sampling performed in a single locality, and therefore, generalisation of the findings is limited. Second, given the self-reporting methodology used, self-reporting bias might have occurred. Despite these limitations, to the best of our knowledge this is one of the first studies performed on this issue conducted in Sarawak. Additional research should include a larger scale, different cancer types and the use of mixed methods for data collection. Use of mixed-methods research would have been ideal to capture important data on patients that cannot be measured solely by quantitative research methods. Given the potential importance of this topic to the well-being of both patients and healthcare providers, more studies should be performed in the future.

Authors' Contribution

Conception and design, analysis and interpretation of the data, drafting of the article, critical revision of the article for important intellectual content, statistical expertise, and administrative, technical, or logistic support: CWL
Conception and design, analysis and interpretation of the data, drafting of the article, critical revision of the article for important intellectual content, final approval of the article, provision of study materials or patients, statistical expertise, administrative, technical, or logistic support, and collection and assembly of data: NBD
Conception and design, drafting of the article, critical revision of the article for important intellectual content, and final approval of the article: CCT

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