

Breaking bad news of cancer diagnosis – Perception of the cancer patients in a rural community in Malaysia

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Abstract

Context: Breaking of bad news is an important component in the management of cancer patients. **Aims:** This study aimed to assess the perceptions of breaking bad news of cancer diagnosis. **Settings and Design:** It was a cross-sectional study using Breaking Bad News Assessment Schedule (BAS) questionnaire on cancer patients in Serian district. **Materials and Methods:** Using snowballing sampling method, a total of 134 patients were interviewed face-to-face after the consent was obtained from each of the respondents. **Statistical Analysis Used:** Data was entered and analyzed using SPSS version 19.0. **Results:** Majority were comfortable with the current method of breaking bad news. The main aspects found to be the areas of concern were the importance of the usage of body language, management of time and identifying patients' key area of concerns. There were significant difference between sex and "information giving" ($P = 0.028$) and "general consideration" ($P = 0.016$) and also between "the age and setting the scene" ($P = 0.042$). Significant difference was also found between the types of cancer and "the setting of scene" ($P = 0.018$), "breaking bad news technique" ($P = 0.010$), "eliciting concerns" ($P = 0.003$) and "information giving" ($P = 0.004$). **Conclusion:** Good and effective communication skill of breaking bad news is vital in the management of cancer patients. As the incidence of new cases of cancer increase every year, breaking of bad news has become a pertinent to the medical professionals' role. Specific aspects of communication skills based on local characteristics should be more emphasized in the formulation of training for doctors.

Key words: Breaking bad news, cancer, patients' perception

Introduction

Breaking bad news has always been an extra burden for medical officers and specialists, especially when dealing with diagnosis of cancer or imminent death. Bad news as defined by Buckman^[1] is any news that drastically and negatively alters the patient's view of her or his future. During the delivery of bad news, patients often feel hopeless as they are often being forced to make limited choices that involved their mental and physical well being.^[2] This complexity can create serious miscommunications, such as the patient misunderstanding the prognosis of the illness or purpose of care.^[3] According to Fallowfield and Jenkins^[4], if bad news is communicated badly it can cause confusion, long-lasting distress, and resentment; if done well, it can assist understanding, acceptance, and adjustment. It is an important communication skill in the medical profession, in which formal training is rarely available. Even though such training has been shown to be helpful and effective,^[5]

it requires a complex communication task that requires expert verbal and non-verbal skills.

Cancer is a leading cause of death worldwide and the total number of cases globally keeps increasing. In Malaysia, a total of 18,219 new cancer cases were diagnosed in 2007 and registered in the National Cancer Registry, with the ten leading cancers: Breast, colorectal, lung, nasopharynx, cervix, lymphoma, leukaemia, ovary, stomach and liver. According to the Ministry of Health Malaysia^[6], cancer is the fourth leading common cause of death in public hospital in Malaysia (11.12%), after the diseases of circulation system, diseases of respiratory system and infectious and parasitic diseases. In Sarawak itself, there were 1,580 (8.7% of the national figure) new cases of cancer in 2007, registered in National Cancer Registry with the top five most common cancers among males being nasopharynx, colorectal, (trachea, bronchus, lung), liver, stomach, meanwhile among females were breast, cervix, colorectal, ovary and nasopharynx. In contrast with the national cancer ethnicity distribution, Bidayuh, one of the indigenous communities of Sarawak has the highest age-standardized incidence rates (ASR).

As the incidence and mortality rate associated with cancer cases increases each year, delivering the bad news has become more pertinent and essential role for medical professionals. In order to perform this role efficiently, it is necessary to understand how competent doctors are from patients' perspective and the factors that may affect patient's perception of breaking of bad news. Previous studies had showed that delivering of bad news is affected by socio-demographic factors such as education level, socio-economic status, gender, cultural background.^[7-9]

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Many studies had investigated breaking of bad news for all types of cancer in clinical setting, but study conducted at the community level is limited, particularly among those patients who were diagnosed at the hospital, but might have resorted to other treatment methods such as traditional therapy. As cultural differences and the type of cancer may affect patients' perception, this study aimed to assess the perceptions of cancer patients in a rural community in Sarawak, Malaysia.

Materials and Methods

This cross-sectional study was conducted in Serian district, located about 60 km from Kuching city. It has an area of 2,106 sq km, 203 villages and a population of 80,200 people. Its ethnic groups are predominantly Bidayuh (59%), followed by Iban (17%), Chinese (14%), Malays (8%) and others (2%).^[10] As there is no detailed information pertaining to the number of cancer patients in Serian district, sample size calculation was based on a pilot study carried out. Using PS software, a minimum sample size of 170 was needed for this study.

Snowball sampling method was used in this study based on two reasons (a) to include cancer patients who had defaulted treatment or did not seek treatment at the hospital or had resorted to traditional therapy after they had received the bad news of cancer diagnosis; (b) to ensure better recruitment of respondents as fewer cancer patients had their follow-up visit at Serian Hospital and the effort to reach others was difficult due to insufficient availability of information in the cancer registry. For those cancer patients who seek treatment at Serian hospital, were asked if they knew any other cancer patients in their villages who might be interested to participate in this research. These patients were then either contacted by the first researcher or they contacted the researcher, so as a suitable venue and time could be set for data collection. This process was repeated until the researcher reached the targeted sample size within the stipulated data collection period.

Breaking Bad News Assessment Schedule (BAS)^[11] was used to collect data. BAS uses a five point Lickert-type scale (1, poorly or not at all while 5, fully, or definitely) for the patients to rate their doctor's skill in breaking bad news. The total scores of BAS would be divided into four quartiles for classification; outstanding, pass, borderline and fail. The BAS has 23 questions grouped under five sections: (a) setting the scene; (b) breaking the news; (c) eliciting concerns; (d) information giving and (e) general consideration. For each question, there are few desirable behaviors, stated to guide patients in grading their doctors' competency in breaking the bad news. BAS was reported to have high internal consistency (Cronbach's alpha = 0.93).^[11] In order to facilitate the process of interview, the questionnaire was translated to Malay language using back-to-back translation technique. To ensure confidentiality of the data collected, all forms were anonymized. One-to-one interview was carried out in a separate room or area without any disturbance.

Although self-report bias issue could not be ruled out, interview was necessary for data collection, as majority of the respondents had no formal education or with low literacy level. It is taken that the bias issue could be reduced, as the researcher had no contact with these respondents before data collection and they were assured that whatever responses they gave would not affect their subsequent treatment.

Ethical approval was obtained from Ministry of Health Malaysia (NMRR-10-1183-7440) and permission to conduct this study was obtained in Serian Hospital. All respondents were given patients information sheets and informed consent was sought. For respondents below 18 years old, informed consent was obtained from their parents or guardians.

The statistical analysis was performed using the Statistical Package for Social Science Software (SPSS) version 19.0. Descriptive statistics (frequency, percentages and means) were used to analyze the distribution of the socio-demographic factors, health profiles and BAS score. Independent *t*-test and one-way ANOVA were utilized to test the relationship of socio-demographic factors and health profiles with the score of each section of the BAS. The level of significance was set at $P < 0.05$ (2-sided).

Results

A total of 134 respondents were recruited for this study (response rate of 78.8%). The mean age of the respondents was 55.99 years (SD = 13.671) and ranged from 17 years to 87 years, with 50.7% ($n = 68$) of them female. Majority of the respondents were Bidayuh (67.9%) followed by Chinese (18.7%), Iban (8.2%) and Malays (5.2%). A total of 12.7% of the respondents were employed with a mean reported monthly income of RM354.85. Table 1 shows the socio-demographic characteristics of the respondents.

Most of the respondents suffered cancer originating from the nasopharynx (38.1%). Approximately 34.3% of the respondents were in stage 4 of their disease and 82.1% of them did not have any previous medical history. The mean duration of suffering from cancer was 37.1 months (SD = 13.761). Majority of the respondents had a combination of chemotherapy and radiotherapy ($n = 84$, 62.7%). Table 1 shows the health profiles of the respondents.

The mean score for BAS questionnaire was 69.0 (SD = 15.71) with 64.2% of the respondents graded their doctors' skill on breaking bad news as "pass" and none of the doctor was graded "fail". The results of the questionnaire are as presented in Table 2.

In terms of individual questions in BAS, the top three areas that the respondents perceived as lacking in their doctors in the breaking of bad news were the "need of using appropriate body language" (mean = 2.4, SD = 1.19), "management of time" (mean = 2.7, SD = 1.13) and "identifying patients' key area of concerns" (mean = 2.8, SD = 0.92). In regards to the sections, the respondents graded the "General

Table 1: Socio-demographic characteristics and health profile of the respondents (n=134)

Socio-demographic variables	n (%)	Mean (SD)
Age		56 (13.67)
Sex		
Male	66 (49.3)	
Female	68 (50.7)	
Race		
Bidayuh	91 (67.9)	
Malay	7 (5.2)	
Iban	11 (8.2)	
Chinese	25 (18.7)	
Occupation		
Employed	17 (12.7)	
Non employed	117 (87.3)	
Income in RM (mean, range)		354.9 (49.92)
Past medical history		
HPT and DM	14 (10.4)	
HPT only	8 (6.0)	
HPT and Asthma	1 (0.75)	
HPT and DM and IHD	1 (0.75)	
None	110 (82.1)	
Type of cancer		
Breast	5 (3.7)	
Nasopharynx	51 (38.1)	
Gastro-intestinal tract	23 (17.2)	
Lung	22 (16.4)	
Reproductive system	14 (10.5)	
Others	19 (14.2)	
Duration of cancer (months)		37.1 (13.67)
Stage of cancer		
1	18 (13.4)	
2	34 (25.4)	
3	36 (26.9)	
4	46 (34.3)	
Treatment of cancer		
Radiotherapy only	16 (11.9)	
Chemotherapy only	28 (20.9)	
Radiotherapy and Chemotherapy	84 (62.7)	
Radiotherapy, Chemotherapy and surgery	1 (0.75)	
Chemotherapy and surgery	1 (0.75)	
Hormone therapy	1 (0.75)	
Palliative care	1 (0.75)	
Refuse treatment	1 (0.75)	
Follow-up only	1 (0.75)	

RM=Ringgit Malaysia, DM=Diabetes mellitus, HPT=Hypertension
IHD=Ischemic heart disease

Consideration” as less unfavorable with mean score of 2.9, (SD = 0.68). The analysis is shown in Table 2.

As indicated in Table 3, there was significant association between sex and “information giving” ($P = 0.028$) and “general consideration” ($P = 0.016$) and also between age and “setting the scene” ($P = 0.042$). It also showed that there was significant relationship between the types of cancer and the “setting of scene” ($P = 0.018$), “breaking bad news” ($P = 0.010$), “eliciting concerns” ($P = 0.003$) and “information giving” ($P = 0.004$).

Table 2: Respondents' score on BAS questionnaire (n=134)

	n (%)	Mean (SD)
Score		69.0 (15.71)
Ranking		
Fail	0 (0)	
Borderline	32 (23.9)	
Pass	86 (64.2)	
Outstanding	16 (11.9)	
Questions		
Setting the scene		3.0 (0.92)
Did the doctor arrange the environment?		3.0 (1.05)
Did the doctor use an appropriate greeting and introduction?		3.0 (1.02)
Did the doctor show interest in the patient's current state of well-being and personal circumstances at the beginning of the interview?		3.0 (0.97)
Breaking the bad news		3.1 (0.77)
Before breaking the news, did the doctor check what does this patient know already?		3.3 (0.93)
Before breaking the news, did the doctor introduce it with sensitivity?		3.1 (0.94)
When delivering the news did the doctor allow the patient to decide the detail and language used?		3.0 (1.02)
Did the doctor allow patient to set the pace for the delivery of the news?		3.2 (0.86)
Did the doctor use an appropriate pause after giving the news?		3.1 (0.92)
Eliciting concerns		3.0 (0.88)
Did the doctor specifically invite questions?		2.9 (0.98)
Did the doctor explicitly attempt to obtain a complete list of patients' concern?		2.9 (0.97)
Did the doctor explicitly check which area was most important to the patient?		3.0 (1.04)
Information giving		3.1 (0.76)
Did the doctor give information tailored to the patients' expressed concerns?		3.1 (0.87)
Did the doctor clearly explain any information given so that the patient understood?		3.0 (0.94)
Did the doctor manage to focus on any positive aspects?		3.2 (0.95)
Was the content of the interview factually inaccurate?		3.2 (0.92)
General consideration		2.9 (0.68)
How many of the patients concern from the attached list were aired?		3.0 (0.97)
How many of the key areas of the patients' concern were touched upon?		2.8 (0.92)
Were the psychosocial issues, which the patient flagged-up during the interview, explored?		3.2 (0.86)
Did the doctor manage to appear supportive during the interview?		3.0 (0.86)
Did the doctor use appropriate body language during the interview?		2.4 (1.19)
Did the doctor avoid appearing clumsy during the interview?		3.1 (0.88)
Did the doctor tailor the pace of the interview to suit the patient?		3.0 (0.81)
Did the doctor manage the time available?		2.7 (1.13)

BAS=Breaking bad news assessment schedule

Discussion

The main objective of this study was to assess the perception of cancer patients in a rural community on their doctors' competency in breaking of bad news. This was a preliminary attempt of using BAS to assess cancer patients' perception. One previous study used BAS to examine doctors' perception on their ability in breaking the bad news.^[12] The family physician group rated themselves a higher mean score of 78 (SD = 10.80) whereas the other specialties physicians, rated a mean score of 61 (SD = 12.40). This present study reported a mean score of 69 (SD = 15.71), which indicated that the respondents perceived their doctors' ability of breaking of bad

news slightly better than the specialties physician perceiving their own ability in Moawe *et al.*'s study.^[12] This finding was reassuring since in our setting of medical care of cancer patient, the breaking of bad news could happen at any stage from primary medical center to secondary and tertiary center of care and given by any doctor ranging from house officers, medical officer to specialist. As far as our knowledge, there was no formal education or trainings for undergraduate doctors and other healthcare workers or any standard guideline available on breaking bad news in Sarawak during the data collection period.

The respondents indicated that "body language" (mean = 2.4, SD = 1.19), "management of

Table 3: Relationship of sub sections of BAS questionnaire with socio-demographic factors and health profiles of the respondents

	Mean (SD)				
	Setting the scene	Breaking the bad news	Eliciting concerns	Information giving	General consideration
Age²					
0-39 (n=17)	2.9 (0.97)	3.2 (0.95)	3.0 (0.95)	3.3 (0.89)	2.9 (0.84)
40-59 (n=55)	3.2 (0.96)	3.3 (0.81)	3.1 (0.89)	3.2 (0.80)	3.0 (0.73)
>60 (n=62)	2.8 (0.82)	3.0 (0.70)	2.9 (0.86)	2.9 (0.67)	2.8 (0.58)
Sig. (2-tailed)	0.042*	0.113	0.508	0.066	0.356
Sex¹					
Male (n=66)	2.9 (0.81)	3.0 (0.70)	2.9 (0.81)	3.1 (0.64)	2.8 (0.54)
Female (n=68)	3.1 (1.00)	3.3 (0.82)	3.1 (0.95)	3.1 (0.87)	2.9 (0.80)
Sig. (P value)	0.144	0.253	0.558	0.028*	0.016*
Race²					
Bidayuh (n=91)	3.0 (0.90)	3.2 (0.75)	3.0 (0.86)	3.1 (0.75)	2.9 (0.64)
Chinese (n=25)	2.9 (1.09)	2.7 (0.82)	2.9 (0.95)	3.1 (0.73)	2.9 (0.77)
Iban (n=11)	2.9 (0.83)	3.1 (0.68)	3.0 (0.92)	2.9 (0.77)	2.8 (0.54)
Malays (n=7)	3.1 (0.92)	3.4 (1.081)	3.1 (1.03)	3.5 (1.04)	3.3 (1.08)
Sig. (P value)	0.878	0.596	0.960	0.556	0.539
Occupation²					
Employed (n=17)	3.2 (0.92)	3.2 (0.87)	3.0 (0.88)	3.3 (0.78)	2.92 (0.76)
Non-employed (n=117)	3.0 (0.92)	3.1 (0.76)	3.0 (0.89)	3.1 (0.76)	2.9 (0.67)
Sig. (P value)	0.617	0.347	0.445	0.992	0.683
Income²					
<RM 500 (n=82)	2.9 (0.92)	3.1 (0.71)	3.0 (0.82)	3.0 (0.70)	2.8 (0.60)
RM500-RM 999 (n=37)	3.1 (0.93)	3.1 (0.91)	3.0 (0.98)	3.2 (0.89)	3.0 (0.83)
>RM 1,000 (n=15)	3.2 (0.86)	3.4 (0.74)	3.1 (1.03)	3.3 (0.75)	3.1 (0.70)
Sig. (2 tailed)	0.562	0.304	0.826	0.430	0.266
Type of cancer²					
Breast (n=5)	3.1 (1.21)	3.6 (0.96)	3.4 (1.44)	3.6 (1.01)	3.4 (1.12)
Nasopharynx (n=51)	2.9 (0.90)	3.1 (0.74)	3.0 (0.82)	3.2 (0.71)	2.84 (0.56)
GIT (n=23)	2.6 (0.89)	2.7 (0.71)	2.4 (0.86)	2.6 (0.71)	2.6 (0.59)
Lung (n=22)	3.3 (0.82)	3.5 (0.75)	3.4 (0.73)	3.4 (0.75)	3.1 (0.77)
Reproductive system (n=14)	3.6 (1.12)	3.3 (0.96)	3.3 (0.77)	3.4 (0.81)	3.2 (0.84)
Others (n=19)	2.8 (0.60)	3.0 (0.54)	2.7 (0.85)	2.9 (0.63)	2.7 (0.68)
Sig. (P value)	0.018*	0.010*	0.003*	0.004*	0.10
Stage²					
1 (n=18)	3.2 (0.84)	3.1 (0.74)	2.9 (0.90)	3.19 (0.77)	2.8 (0.73)
2 (n=34)	3.2 (1.02)	3.2 (0.83)	3.3 (0.86)	3.3 (0.69)	3.0 (0.74)
3(n=36)	3.1 (0.77)	3.3 (0.77)	2.9 (0.92)	3.2 (0.79)	3.0 (0.65)
4 (n=46)	2.8 (0.94)	3.0 (0.74)	2.8 (0.85)	2.9 (0.76)	2.7 (0.62)
Sig. (P value)	0.121	0.240	0.197	0.052	0.132

¹Independent t test, ²One-way ANOVA, *Significant level at $P < 0.05$. RM=Ringgit malaysia, BAS=Breaking bad news assessment schedule, SD=Standard deviation

time” (mean = 2.7, SD = 1.13) and “identifying patients’ key area of concerns” such as treatment, prognosis, feelings and emotions, family and relationship issues, effect on social circumstances (mean = 2.8, SD = 0.92) were the areas that their doctors did not performed as well. In the “body language” section, the desirable behaviors stated as guiding points that included (a) maintained an appropriate level of eye contact; (b) looked interested and alert to patients’ needs and (c) show a competent and caring professional manner. The lower mean score on this section suggested that the respondents perceived their doctors lacking these skills. Narayan *et al.*^[13] suggested that doctors should relay the information face-to-face and maintain eye-to-eye contact. Bruera *et al.*^[14] found that patients preferred doctor to be seated with them while breaking the news rather than standing up. Beside, good communication skills and showing other respectful gestures by the doctors were also perceived as important.^[14] However, use of body language should be tailored to the local culture and custom. As an example, Japanese patients did not rate having their doctors hold their hand or touch their arm while breaking the bad news as being important.^[15] Patients in this study also perceived their doctors less able to address “patients’ key area of concerns”. After breaking the bad news, patients should be given adequate time to express their emotions and discuss their illness, their chances of cure, the side effects of therapy and a realistic estimate of how long they would live. Doctors also should not forget to touch on issues regarding the family and relationship that the disease may have on social circumstances.^[13,16-21]

The current study found the respondents’ perception of breaking bad news was lowest for “general consideration” (mean = 2.9, SD = 0.68) followed by “eliciting concern” (mean = 3.0, SD = 0.88), “setting the scene” (mean = 3.0, SD = 0.92), “information giving” (mean = 3.1, SD = 0.76), and “breaking bad news” (mean = 3.1, SD = 0.77). This finding differed with those of Moawed *et al.*’s study^[12], where the respondents from the family physicians group rated themselves low on “eliciting concern”, while those in the specialties group rated themselves low on “setting the stage”, followed by “giving bad news” and then “eliciting concern”.

This research also revealed that there were significant difference between sex and “information giving” ($P = 0.028$) and “general consideration” ($P = 0.016$) [Table 3], whereby the female patients perceived more favorably on these two aspects. This outcome was different compared to a study done by Parker *et al.*,^[19] where women emphasized highly on “content” sub-scale, which was related to what and how much information was being told, and support given. Age was also found to have significant association with “setting the scene” ($P = 0.042$). Those respondents in the age bracket between 40-59 years did not perceive “setting the scene” as important compared to younger or older respondents. Other studies found respondents in younger age group emphasizing more on message delivery.^[18,19] Ptacek and Ptacek^[18] also

found that the younger patients and women found the breaking bad news process to be more stressful as compared to older patients.

Patients with different types of cancer were found to have significant difference in the score for four sections of BAS namely: “Setting the scene” ($P = 0.018$), “breaking bad news” ($P = 0.010$), “eliciting concerns” ($P = 0.003$) and “information giving” ($P = 0.004$); whereby patients with gastrointestinal cancer gave the lowest score. There was no study on the association of types of cancer and breaking of bad news, an area that may require future study.

In contrast to the findings of other studies^[19], this study indicated that there is no significant difference in the BAS with stages of illness. According to the literature, patients with early stage disease preferred delivering of bad news that includes prognosis, if the prognosis was hopeful.^[22] Unlike early stages of illness, patients who were in the advanced cancer were more sensitive towards the bad news delivered by the clinicians as it involves issue of survival.^[23] The findings of this study might be indicating that the stages of illness are not important in delivering of bad news in this rural community. Once they were diagnosed with cancer, the stages of illness are not an issue to be concerned.

Conclusion

This study indicated that majority of the respondents perceived favorably their doctors’ ability in breaking bad news. However, issue such as usage of “body language”, “management of time” and “identifying patients’ key area of concerns” need to be improved and enhanced as perceived by the respondents. Age, sex, and types of cancer of patients were significantly associated with doctors’ skills, which need to be taken into consideration when breaking the bad news.

This study used snowballing sampling method, which would preclude the generalization of the findings to all cancer patients in Malaysia. Nevertheless, the findings provided by this preliminary study indicated areas of concerns about doctors’ ability in breaking of bad news. Breaking of bad news is an important component in the management of cancer patients. As the incidence of new cases of cancer increases every year, breaking of bad news has become a pertinent medical professionals’ role. As doctors are responsible to break bad news in Malaysia, it is recommended that they should be trained in order to perform the task effectively. In addition, hospitals should have a standard protocol to ensure breaking of bad news is done professionally. It is also recommended that further in-depth studies to be conducted in Malaysia in order to identify issues related to the breaking of bad news that are perceived as important by the patients.

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News

Congratulations **First rank at ESMO Examination:**

Dr. Manish K Singhal, MD, DM: A leading medical oncologist working at Noida (NCR), he is a graduate of AIIMS (All India Institute of Medical Sciences), New Delhi where he did post-doctoral training in Medical Oncology. He learned bone marrow transplant at Barabara Ann Karmanos Cancer Institute, Michigan University, Detroit, USA. He visited Oxford University regarding randomized controlled clinical trials. He is presently in charge of the department of Medical Oncology at, Fortis hospital, Noida under the aegis of International Oncology Group. He has made us proud by scoring the highest marks in the prestigious ESMO (European Society of Medical Oncology) Examination 2013, the first Indian to do so. He will be presented with the Best exam Award at the forthcoming ESMO meeting in Sept 2014 at Spain, Madrid.

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