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Breaking bad news: patients' perspectives of the information process in a general surgery outpatient clinic survey

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Abstract

The aim of this study is to investigate the perspectives of the patients admitted to a general surgery outpatient clinic towards the processes of being informed and receiving bad news. A questionnaire developed by the authors was provided to 319 patients. The scoring of some statements was based on a 5-item Likert scale, while other statement scoring was based on an 11-item Likert scale. Of all, 74.1% of the participants stated that "the doctor's way of communicating information to them" is absolutely important, while 49.2% stated that "to whom the physician will communicate a bad news /malignant illness about oneself" is also of absolute importance. In case of a malignant illness, statements emphasizing that only the patient is to be notified have been adopted more commonly. Single participants stated it was more important to be personally notified first, rather than their relatives. The long-held idea that the patient may be affected by bad news and disrupt his/her treatment is no longer a consideration by patients. Even if their relatives are involved in the process in the later stages of the disease, the patients wish to hear the news first themselves.

Keywords: Breaking bad news, clinical ethics, communication, informing patient, patient's relatives

Introduction

All physicians face ethical conflicts in breaking bad news to their patients. The doctor-patient relationship is a multi-dimensional issue that has not only attracted the attention of medicine since Hippocrates, but also within philosophy, sociology and the current literature. The most important reason for this attention is that the doctor-patient relationship is a type of human-to-human relationship, and as this relationship emerges and progresses through a distressing process like illness, it contains stages that may be difficult to cope with and to overcome for patients. Although there are various areas of difficulty in doctor-patient relationships, one of the most important among these is breaking bad news to the patient. This process is a common and a difficult task for physicians

regardless of their specialty [1]. The process of breaking bad news is a stressful situation for doctors as much as it is for patients [2,3]. In this bi-directional process, which concerns both patients and doctors, the professional side is undoubtedly that of the doctors [4].

Nevertheless, some studies report that doctors do not feel that they are sufficiently skilled in breaking bad news [5,6]. Breaking news has not only medical but also ethical and sociological ramifications because, in such cases, the physician's addressee is not only the patient. In most societies, patient relatives also take part in patient-related clinical issues [7]. In the case of an illness with a poor prognosis, it is critical with whom, how, and how much of this information is shared has been an important issue since the early age of medicine [8]. Contrary to times when a paternalistic approach was dominant, in today's patient-centred approach, the quality of doctor-patient communication is highly crucial, and patients wish to participate more in clinical decision-making processes [9,10]. However, in such cases, physicians may encounter a dilemma concerning whether the patient can bear the burden of psychological stress and

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how much patient relatives should be involved in the process.

The issue of breaking bad news is mostly examined from the perspective of doctor-patient communication and doctor's professional skills [11]. As is true in different areas of life, receiving bad news in any subject or process is a stressful experience. The fact that the situation entails news/information directly related to one's health (and potentially) one's life makes this process even more complicated [12]. Good management of the process requires effective doctor-patient communication. If the process is successfully executed, the patient's compliance with the treatment could be significantly improved, the patient would be enabled to handle the news/information in a less traumatizing manner, the patient's satisfaction would increase, and the patient would experience less stress [11,13,14].

These processes also entail socio-cultural values that may make it difficult for patients to understand the clinical facts that they are likely not yet ready to hear. In a similar vein, these issues may cause patients to hesitate to comply with the doctor's recommendations and treatment decisions. In this study, how patients wish to hear about an illness or a condition which carries a poor prognosis was investigated.

Material and Methods

A data collection form was developed by the authors and was piloted among 15 participants from different professions and age groups; subsequently, this form was revised in line with the feedback received regarding the pilot form. The revised form was distributed to 352 patients who were referred to the general surgery outpatient clinic of Sereflikochisar State Hospital for routine examinations. The participants were informed about the study and those who expressed consent were included in the study. The first part of the data collection form, which consists of two parts, was designed to collect demographic data, and the second part was the questionnaire form. The questionnaire form consisted of seven main statements and different sub-versions of each statement. The scoring of the main statements was based on a 5-item Likert style scale and sub-expressions on an 11-item Likert style scale. Prior approval of the data collection form was obtained from hospital administration and the local ethics committee, and data were collected between May 2017 and August 2017.

For the purposes of evaluation, the first five statements were excluded from the evaluation, while the sixth and seventh statements were included in the evaluation consistent with the purpose of this study. Thirty three (33) incompletely filled data collection forms were excluded from the evaluation, thus, the final evaluation was carried out on 319 forms. All data were transferred to an Excel spreadsheet, basic statistical methods were applied and the differences among groups were analysed using a Mann-Whitney Test and the Kruskal-Wallis Test was used to analyse variance.

Results

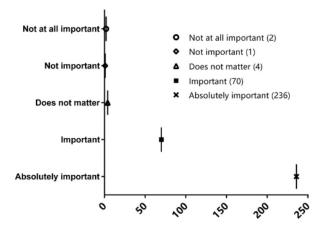
The mean age of the participants was 34.6 ± 10.3 years of age. Of all the study participants, 38.8% (124) of the participants were within the 30-39 age range, and 58.3% (186) were women (Table 1).

74% (236) of the participants stated that "the doctor's way of communicating information to them" is of absolute importance (Figure 1).

49.2% (157) of the participants stated that "to whom the doctor will communicate a bad news/malignant illness about oneself" was also of absolute importance (Figure 2).

We found no significant differences, based on age and gender between groups, in the way doctors' communicate information and to whom the information would be provided. In terms of the substatements, the 1st and 3rd sub-statements, which ask if only the patient is to be notified in case of a malignant illness, were adopted more commonly by the participants compared to the other three statements (Figure 3).

In comparison to the married participants, single participants stated the doctors' way of communicating information was most important, and these patients more commonly held the view that bad news should be communicated to themselves rather than to their relatives (Figure 4).



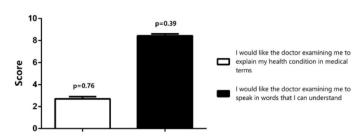


Figure 1. Distribution of the participants' responses to the statement the doctor's way of communicating

The statement is "Doctors' way of communicating information"p≤0.05

Table 1. Baseline demographic features of the participants (gender, marital status, and age)

Age		<30	30-39	40-50	>50	Total	
F1-	Single	46	14	4	3	67	185
Female	Married	24	62	22	10	118	
Male	Single	29	8	1	3	41	134
Maie	Married	8	40	35	10	93	
Total		107	124	62	26	319	

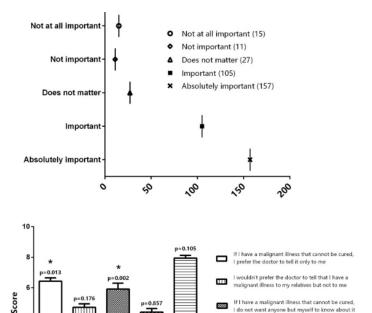


Figure 2. Distribution of the participants' responses to the statement to whom the doctor will communicate a bad news/malignant illness about oneself. The statement is "To whom the doctor will break a bad news/malignant illness about me"1st and 3rd statements were statistically significant (p<0.05) by Kruskal-Wallis Test

If I have a malignant illness that cannot be cu

If I have a manignant illness that cannot be cured, I do not want to know about it. I prefer to live with my loved ones until the last moment as if nothing was wrong rather than living with this pain

No matter what, I believe anything that happen en me and my doctor will re en us and stay confidential

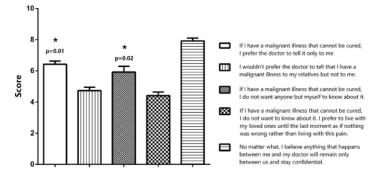


Figure 3. Distribution of the responses obtained in reply to the statement suggest only the patient to be notified in case of a malignant illness. 1st and 3rd statements were statistically significant (p<0.05) by Kruskal-Wallis Test

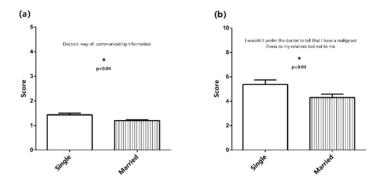


Figure 4. Distribution of marital status for respondents asked how bad news should be communicated

The statement on doctors' way of communication and the sub-theme on breaking bad news on malignant illness were statistically significant (p<0.05) by Kruskal-

Discussion

In healthcare settings, bad news generally means information that negatively affects the patient's view on the future and can result in persistent cognitive, behavioural, and emotional responses in the patient [15,16]. Hence, providing healthcare is, at its essence, a communication process and healthcare workers are the professional side of this process. In a doctor-patient relationship, the expectation of patients from doctors, in terms of communication, is to establish a bilateral relationship based on honest, simple, and clear language that makes patients feel understood [3,16-18]. This is also an expectation of effective communication. The humanitarian aspects of this relationship must, of course, be taken into consideration in each case. In terms of clinical ethics, it is an important practice to inform the patient about his/her clinical condition in adequate, appropriate, and understandable language based on the medical facts [19,20]. Thus, this practice reinforces patient autonomy, which is one of the basic principles of medical ethics. According to this principle, the patient has the right to accept or reject any treatment, diagnostic method, or medical procedure. Although with limitations, all information regarding the patient's medical condition should be provided to the patient for this right to be upheld [21,22].

In our study, 74.1% of the participants stated that the doctor's way of communicating information to the patient is of absolute importance. Patients who refer to a health institution for modern medical service expect such information from the very outset. Considering basic requirements of communication, the act of notifying the patient should be performed in a calm environment with words the patient can understand and by taking the patient's cultural characteristics into account [12,23]. When the 23.7% participants who stated that the way information is communicated is important are added into this analysis, 97.8% of the patients in this study attach importance to the method of notification concerning their clinical condition.

Contrary to an outmoded, paternalistic approach to the practice of medicine, patient autonomy is now accepted as an important ethical approach in today's clinical decision-making processes [24,25]. In the current approach, while the patient is informed before making any decision, there are important details to consider such as information related to this process, the content and the extent of this information, and with whom it can be shared. However, among these details, the issue that requires clarification from the very outset is the determination of whom information concerning the patient will be shared with. Various protocols such as SPIKES, BREAKS and ABCDE have been developed to address the issue [26-28]. In some countries where these protocols are widely used, there are studies that outline objections, as well as some suggestions to address the shortcomings of these methods [15].

In the context of the principle of respect for patient autonomy, the main, and perhaps the only, decision-maker on who to share information with is the patient himself/herself. The physician is expected to talk to the patient about this subject matter in a clear and constructive manner [29]. Considering that the patient has likely already adopted an outlook of his/her own on this issue before visiting the doctor, 83.4% of the participants in our study regarded as important the issue of whom bad news concerning their illness will be shared. In such circumstances, which may also be affected by socio-cultural characteristics, a significant portion of the patients stated that this news should only be shared with them. Since poor prognosis commonly evokes negative views such as long-term nursing, death and despair, this issue has a direct link to religion, beliefs, and culture [26,30]. Therefore, it is often not surprising that a subject matter which involves social institutions and interactions, family or relatives may also be involved in the process. Especially in patients diagnosed with cancer, the approach to share such news with their family or relatives and to make decisions together constitutes a common approach [31]. However, in current study, patients wished for only themselves to be informed in the event of such illnesses, at least initially. In a society where family bonds are regarded as strongly as they are in Turkey, such views are worthy of attention. A reason for this change might be the increasing individualization within society.

In this study, although the participants above the age of 50 stated, with the highest average, that only they should be notified, no statistical difference was found between the ages of the participants in terms of to whom the facts regarding their illness should be told. However, it is an important finding that the participants responded with the highest average to the seventh statement, which was a reflection of the trust relationship between the doctor and the patient. Patients who adopted the statement that "No matter what, I believe anything that happens between me and my doctor will remain only between us and stay confidential", appear to have an attitude of strong trust with their doctor. In today's modern medicine, this trust relationship is an important issue [32]. In accordance with other studies, our findings show that this trust element continues to exist strongly in current doctor-patient communication. Accompanied by high technology, doctor-patient communication based on trust still maintains an important place in the practice of medicine.

While breaking bad news within a clinical setting, providing emotional support to the patient, in addition to providing correct and sufficient information, is of significance [17,33]. This emotional support, its content and application to be offered to patients, is a topic that also concerns cultural elements besides the medical application, procedure, and approaches. In some societies, emotional support of this type is carried out within an approach that involves the patient's family together with professionals involved in this process. Similarly, some studies recommend the involvement of nurses in the process of breaking bad news [34]. In this scenario, sharing of the burden by the healthcare team can be seen as an appropriate approach, rather than placing all the responsibility on the doctor. A more important position can be attributed to the patient's family in cases of bad news, since the process does not take place only between the doctor and the patient. Family is an important factor especially in the process of coping with an illness with a poor prognosis [31,35]. In addition to the fact that the trust in doctor-patient relationship is a crucial clinical ethical practice, the support of family or patient relatives is also considered valuable in the process of coping with such illnesses [36-38].

In our study, it is also noteworthy that the participants who wished only to be informed when they have a malignant illness took an undecided approach to a statement which queries attitudes that include sharing information regarding the illness with patient relatives. Of note, our findings are in accordance with the findings of the Aminiahisashti et al. study [39]. Specifically, participants in the current study prefer to hear bad news concerning their illness personally, before their families, and to have families join the conversation possibly after an initial briefing. Two possible explanations can be possible to the participants' seemingly contradictory statements. Firstly, the statement was specified with a negation particle that might have caused indecision in the participants. Secondly, and more likely rationale, was that the participants may have considered their preference to be informed about their illness first and then to inform the relatives. Considering the cultural characteristics and healthcare system's structure, this second rationale seen as more conceivable. However, in any case, when informing patients about disease with poor prognosis, it may seem usual for people to adopt an indecisive approach, at least at first. In a situation that would highly affect the person's life and future plans, waiting for him/her to make a decision quickly would not be easy from the viewpoint of human psychology.

Breaking bad news to patients is also a complex and multidimensional issue process for physicians. As part of the medical practice in some societies, hiding bad news from the patient or sharing the seriousness of the illness with the patient relatives rather than directly with the patient is not an uncommon practice [18]. Such an approach also means that this process involves a separate challenge for physicians in terms of medical practice. Knowledge on the attitude of patients regarding informing them about poor prognosis would be a guiding element for medical practice. In our study, the patients had a very clear attitude towards being notified. However, this clarity differs slightly for single participants because, compared to married participants, single participants stated that the doctor's way of communicating information is more important. Similarly, compared to married participants, single participants more embraced the view that bad news should be communicated to them rather than to relatives. The importance of the family in dealing with a bad illness cannot be denied; however, it is possible that this different attitude among singles has a dimension that is nourished not only by the concept of family but also from cultural elements [40].

Conclusion

Several general conclusions can be drawn from this study providing new data for doctors and the healthcare system in breaking bad news to patients. This study contributes to the importance of the communication process and patients' perspective on breaking bad news. Patients consider it very important to be notified about their illness in clear and honest terms. This shows that the classical idea that patients may be affected by bad news and that this will disrupt his/her treatment should no longer be taken into consideration. At the end of the communication process, most patients wish to be informed concerning their health situation or illness from the doctor, even if it is bad news. Although their relatives may be involved in the process a later time, patients wish to be the first to hear the news. At this point, notification of patients and the method of this communication by physicians is highly important and it is critical how doctors' communicate with patients.

Patients expect a good communication process from doctors. They expect doctors to explain the medical facts in lay terms, and provide clear and explicit explanations regarding their diagnosis and prognosis. Nowadays, given the increase in individualization, patients wish to hear bad news themselves. Thus, they take an approach to involve their relatives in this process at later stages. Patients have strong expectations for healthcare service provided by caring healthcare professionals who are equipped with advanced communication skills, and communication with patients has become more important than before in both medical education and practice. It is clear that various protocols and practices regarding breaking bad news should be effectively included in medical education.

This study contributes to the understanding that healthcare is a personal issue. Even if relatives want to share responsibility in this regard, patients prefer hearing hear bad news personally. This may give rise to an ethical conflict for physicians between their professional role in healthcare regarding breaking bad news and their personal approaches on this issue. Obviously, more studies need be done on breaking bad news and taking into account cultural characteristics, and more attention should be paid to this issue in medical education.

Conflict of interests

The authors declare that there is no conflict of interest in the study.

Financial Disclosure

The authors declare that they have received no financial support for the study.

Ethical approval

Prior approval of the data collection form was obtained from hospital administration and the local ethics committee, and data were collected between May 2017 and August 2017

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