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Truth Disclosure at The End-of-Life Situation-a Practical Method for Professionals.

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Abstract

Breaking bad news is a difficult task, and it is even more difficult on an end-of-life situation when a truthful prognostication should be given to a dying patient or to his/ her significant other people. A congruent, empathetic approach with an unconditional positive regard, thoroughly based on client centred counselling principles is the way forward. Honest disclosure of diagnosis and prognosis to patients and relatives is beneficial and much appreciated by them, for reorienting the life choices based on realistic hope.

Keywords: Truth disclosure, End of life Communication, BREAKS protocol

Introduction and Review of Literature:

The 'patronising attitude' of the doctors dominates the domain of medical science dealing with death and dying. The health care professionals involved in the care of terminally ill patients tend to withhold the truth from their patients due to a variety of reasons. Oncologists feel that the patients hope and the 'Will to live' will be in peril if they disclose the truth to the patient. Reasons for withholding information or being reticent to discuss prognosis and end of life issues by the health care professionals from Anglo Saxon descent were identified as: a) Discomfort of the health care Professional b) Uncertainty about the illness trajectory c) Too little time in consultation d) Patient requests for more information e) Concerns for negative impact on patient f) Family/ caregiver request for withholding of information. Minor variations observed in other cultures [1].

Health care professionals' reluctance to broach the information concerning the prognosis and life expectancy of a terminally ill patient usually end up in greater difficulties for patients, their friends and relatives and other members of the health care team [2]. This failure to have an open and honest discussion with the patient and relatives about the nature of disease and prognosis will ultimately deny the opportunity for the terminally ill patient and the family to reorient the remaining life based on realistic hopes. The patient may be subjected to costly and ineffective treatment in the absence of proper prognostic awareness. A survey among 714 practising oncologists in US to know their own preferences of prognostic information if they are afflicted with a terminal cancer, seventy four percent expressed the desire to know the medical estimate or time frame as to when the death can be expected [3].

Some family members and even the treating physician refrain from delivering the bad news to patients on account of 'cultural' issues. For them, truth disclosure is culturally unacceptable. This argument is inappropriate, as the family may be acting in their own, rather than the patients' best interest. Also, such nondisclosure requests are not stemming from ethical grounds, but from historical and social circumstances [4].

A family member who is insisting the physician not to tell the truth to patient most often try to wear the pseudo image of a guardian angel and persuade the physician to engage in collusion. They are acting at their own, and not at the interest of the patient. They may be informed about the ethical obligation of the physician to answer honestly to the queries levelled by the patient. Physician has to respect the patient autonomy. Hence, he /she is ethically bound to disclose the diagnosis and prognosis, if demanded by the patient. Patients who kept in darkness about their diagnosis and prognosis suffer more psychological distress than other patients [5]. hey may feel as if they were deceived. Detailed, realistic and individualised approach for disclosing the prognostic information is preferred by the patients. A patient's self -determination is respected if the truth is told, and that is liked by patients themselves, even it is the bad news [6].

The basis of a physician patient relationship is Trust. Patients rely on the information's given to them by their physician to make

a proper decision on their course of therapy and disease journey. If the medical information is permanently withheld from a patient, a clear violation of Trust will happen and should be avoided in clinical practice. If the physician feels that the full disclosure of truth is not appropriate in a given time, he/she should continue offering the adequate care to patient and monitor them to identify the right opportunity to deliver the bad news to the patient. The truth disclosure should not be withheld permanently [7].

The revised palliative care information act of February 2011 by the New York state ensured adequate information to terminally ill patients about their end-of-life options. All patients with terminal illness with a reasonable life expectancy less than six months must be counselled and informed the palliative care and end of life care options. The law thus allows the terminally ill patients to empower themselves to make choices for an optimal quality of care. The attending health care practitioner should offer information and counselling about the prognosis, range of options available and their risks and benefits. It also emphasizes the legal right of patient to have comprehensive pain and symptom management at the end of life. The law also gives the option to the attending physician to entrust another colleague to carry out the said function of information delivery [8]. In recent times, due to increased patient autonomy and empowerment, truth telling attitudes improved [9]. More and more patients in end stage diseases are being recruited for clinical trials. Enrolment of such trials essentially involves the disclosure of the entire truth to the patient. Breaking bad news is a difficult task. It is not about telling the truth alone. It requires adequate communication skills to address the patient's and family members' emotions. If the information is not conveyed properly, intense negative feelings will continue to harbour in the family members [10]. Health care providers may choose to avoid difficult conversations as they are not adequately trained. When a health care worker embarks upon difficult conversations with the patient, the/she suffers significant anxiety. They will be subjected to self-validation of their own vulnerability.

Prior education in prognosis communication was surveyed and was found that fifty eight percent did not receive any formal training in prognosis communication. Also, ninety six percent wanted to include communication training in oncology curriculum [3]. The medical students will be aware of the real issues of truth telling through an interventional approach, which engages them into a realistic situation [11].

The BREAKS Protocol for Truth Disclosure in End-of-Life Situation

In 2010, author and co-authors proposed a protocol for breaking bad news with an acronym BREAKS [12]. (Background, Rapport, Explore, Announce, Kindling, Summarize) This protocol was based on a Rogerian client centred approach. A positive outcome in cognitive, evaluative, and emotional level can be expected if the approach is client centred [13]. Empathy and support are very much needed for the terminally ill patients and their family towards the end of life. Cold, detached professionalism is counterproductive in such circumstances [14].

The following are the 6 steps of the BREAKS Protocol:

1. Background preparation
2. Rapport establishment
3. Exploration of what the patient knows and their support system
4. Announce the bad news
5. Kindling to vent out the emotions
6. Summarize the information given.

Background

In-depth knowledge of the patient's problem is essential for an effective therapeutic communication. A list of possible questions from the patient has to be prepared. Even though the physician cannot answer all questions, reasonable doubts of the patient and family must be cleared. Session should begin only if the physician has prepared adequately. It is desirable to have a detailed information regarding the patients' cultural and ethnic background, educational status, coping skills, support system, along with an in-depth knowledge about the disease status. The physical set up is very important in accomplishing this difficult task. The conference room should be quiet. There must not be any interruptions. The mobile phone must be switched off. All physical barriers must be removed to maintain eye contact. A co-worker's help for transcribing the conversation is helpful. It is preferable to avoid translation by a family member. Emotional breakdown can be expected; hence, the physician may have to console the patient as well. Regressive behaviours need to be tackled with a complimentary transaction. The appointment length should be sufficient to complete the task.

Rapport

Unless the patient feels a sense of having connection with the physician, they are most unlikely to co-operate with the physician. Building rapport is fundamental to continuous professional relationship. The physician should establish a good rapport with the patient. Being aware of who the patient was before contracting a terminal illness and remaining respectful throughout the conversation is very important. The physician needs to have an unconditional positive regard but has to stay away from the temptation of developing a patronizing attitude. The ease with which the rapport is being built is the key to continue conversation. A hostile attitude has disastrous outcome, so is a hurried manner. It is necessary to provide ample space for the windows of self-disclosure to open up. The patient should be placed in a comfortable position. A brief introduction of the purpose of the meeting should be outlined. Present condition of

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the patient can be enquired through open questions. If the patient is not prepared for the bad news, especially after getting his /her symptoms well palliated, let him finish the reports of wellbeing, and then try to take cues from his conversation to initiate the process of breaking bad news.

Explore

Whenever attempting to break the bad news, it is easier for the physician to start from what the patient knows about his/her illness. Most of the patients will be aware of the seriousness of the condition, and some may even know their diagnosis. The physician is then in a position of confirming bad news rather than breaking it. The history, the investigations, the difficulties met in the process etc need to be explored. What he/she thinks about the disease and even the diagnosis itself can be explored, and the potential conflicts between the patient's beliefs and possible diagnosis can be identified. The dynamics of the family and the coping reservoir of the patient are very important in delivering the bad news. Try to involve the significant other people of the patient in the decision-making process, if allowed by the patient. At least few patients may respond in a bizarre way to the bad news. Hence, a careful exploration of all these points should be carried out. A common tendency from the physicians is that they jump into premature re assurances. Premature reassurance occurs when a physician responds to a patient concern with reassurance before exploring and understanding the concerns [15]. Absolute certainties about longevity cannot be given to a patient. The prognosis can be explained in detail, with all available data. A reasonable conclusion based on the facts can be presented. Practice 'active listening', where the patient also feels that he/she is well heard by the physician. Paraphrasing the patient's words and reflecting them make the patient feels that he/ she was heard properly. The physician can ask questions to the patient if he is not clear with what the patient is trying to express, but those questions should be tailored and thoughtfully processed.

Announce

A warning shot is desirable, so that the news will not explode like a bomb. Euphemisms are welcome, but they should not create confusion. The patient has the right to know the diagnosis, at the same time he has the right to refrain from knowing it. Hence, announcement of diagnosis has to be made after getting consent. The body language of both the physician and patient is very important, and the physician is supposedly a mirror image of the patient. The embarrassment, agony, and fear of the patient should be reflected in the physician (mirroring the emotions), so that the patient will identify the physician as one close to himself. Announcement of the bad news must be in straightforward terms, avoiding the medical jargon completely. Lengthy monolog, elaborate explanations, and stories of patients who had similar plight are not desirable. Information should be given in short, easily comprehensible sentences. A useful rule of thumb is not to give more than three pieces of information at a time [16]. If a patient asks a question, "can I still hope for a miracle cure?", "well, you can hope that too" may be a better answer than bluntly challenging the traumatised person with medical facts.

Kindling

During this process, the physician essentially set the emotions of the patient on fire. People listen to their diagnosis differently. They may break down in tears. Some may remain completely silent, some of them try to get up and pace round the room. Sometimes the response will be a denial of reality, as it protects the ego from a potential shatter. A gallows humour is also an expected behaviour. These are all predictable responses. Adequate space for the free flow of emotions has to be given. Most of the time, patients will not actively listen to what the physician say after the pronouncement of the status. An overwhelming feeling of a grim fate can ignore further explanations and narratives from the physician's part. Hence, it is advisable to ensure that the patient listens to what is being told, by asking them questions like "are you there?", "do you listen to me?" etc. It involves asking the patient to recount what they have understood. Be clear that the patient did not misunderstand the nature of disease, the gravity of situation, or the realistic course of disease with or without treatment options. While trying to kindle the emotions, care has to be taken not to utter any unrealistic treatment options.

The patient and their relatives will cling on to it, and subsequently feel embarrassed because of its unrealistic nature. Answers have to be tailored to the question, and physician should stay away from lecturing to the patient. Lecturing occurs when a physician delivers a large chunk of information without giving the patient a chance to respond or ask questions [17]. Beware of the "differential listening," as the patient will listen to only *the* information that he/she wants to hear. Dealing with denial is another difficult task. It may be necessary to challenge denial because the patient may have some important unfinished business to conduct, or because the patient is refusing treatment that might alleviate symptoms. In such situations, attempts to break the defence without mutilating the ego should be attempted.

Summarize

The physician has to summarize the session and the concerns expressed by the patient during the session. It essentially highlights the main points of their transaction. Treatment/care plans for the future has to be put in nutshell. The necessary adjustments that have to be made both emotionally and practically need to be stressed. A written summary is appreciable, as the patients usually take in very little when they are anxious. Offering availability round the clock and encouraging the patient to call for any reasons are very helpful. An optimistic outlook has to be maintained, and volunteer if asked by the patient for disseminating the information to the relatives.

The review date also has to be fixed before concluding the session. At the end of the session, make sure that the patient's

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safety is ensured once they leave the room. He/she should not be permitted to drive back home all alone and find whether someone at home can provide support. Patient may even try to commit suicide if he/she feels extremely desperate. Patient should be assured that the physician will be actively participating in all ongoing care plans. Physician should not give false promises, or nurture unrealistic hopes. At the same time, the patient must feel that the physician or his team is compassionate and will be available for the patient to complete the possible tasks that are left behind. There should not be a sense of abandonment.

Conclusion

Breaking bad news is part of the art of medicine. Bad news is always the bad news, however well it is said. But the manner in which it is conveyed can have a profound effect on both the recipient (the patient) and the giver (the physician). If done badly, it will hamper the wellbeing of patient, impair the quality of life and future contact with the health care professional will be thwarted. It is a skill that has to be learnt by the physicians and other caregivers and effective methods of communication skills training are available [18]. Lack of proper training will lead to emotional disengagement of the physician from his patients. Good communication has a therapeutic effect on patient and bad communication leads to a detrimental outcome. Communication skills can be improved through structured training programs with appropriate feedback to the trainees. Curricula for teaching the task of breaking bad news include didactic lectures, small-group discussions, role-playing, and teaching in the context of patient care [19]. Role plays and video tapes of the same with constructive suggestions to improve the skills are very much effective. It should be noted that the evidence base of the current practice and training of breaking bad news is not sound. Education and practice in breaking bad news may be ineffective for improving patients' well-being unless it is informed by a strong evidence base [20]. The above-mentioned protocol-BREAKS (background, rapport, explore, announce, kindle, summarize) had been taken up successfully for training the health care professionals dealing with terminally ill patients. Truth disclosure at the end-of-life situations is a difficult task. Adherence to the protocol can make the task a simple one.

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