A Patient-Centred Approach to the Ethical Dilemma of Breaking Bad News to Cancer Patients: Recommendation for Better Communication Strategy

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Introduction

It is important to start this article with a vignette that clearly expresses the impetus behind taking the time and effort to do this research work. Two years ago, my mother-in-law was diagnosed with cancer and had to visit a well-known surgical oncologist to confirm the diagnosis. As we walked into the clinic, I noticed the physician's title in the sign as “Surgeon” without reference to his oncology specialization. After I seated her, I walked to the medical secretary and asked about the reason for not including “oncology” in the doctor's title. He explained that many families of cancer patients particularly from lower socioeconomic classes, or those coming from rural areas do not disclose the bad news to the patients in fear of damaging their morale. He claimed that this practice works well in several cases and actually helps recovery. This incident raised many questions in my mind as this casual observer spotted a pattern worthy of triggering interesting research that is interdisciplinary among many fields of study where insights of psychologists, communication specialists, clinical pharmacists (responsible for patient education), oncologists, lawyers and ethicists could lead to better recommendations for communicating the first diagnosis to cancer patients. I embarked on an extensive literature review to find that many original manuscripts are in languages other than English and that the most recent review was published more than a decade ago.

The literature review process was also meant as an attempt to answer the questions raised in my mind; Is this practice really effective? Acceptable? Can it be redressed? Are there cases where this practice can be more justified (based on culture, race, education or psychological disposition)? From an ethical point of view, is the doctor in a position to make that decision alone? If the doctor chooses to inform a responsible relative with full disclosure as a proxy to the patient, does this relieve the doctor from the dilemma? If the patient has a close relative who is a physician, could that be a viable solution to designate them as case owners? If the physician chooses not to tell the patient directly, does this breach the trust and fiduciary responsibility in the patient-doctor relationship? The literature review answered some questions but stimulated even more questions and untested hypotheses. This research work is a recent review and foresight for a better strategy of communicating a diagnosis to cancer patients and/or their families that will trigger streams of interdisciplinary research in a new direction.

The Ethical Dilemma of Communicating Cancer Diagnosis

Most patients with malignancy want to be told about the nature of their disease and its prognosis [1]. A review of studies on patient preferences regarding disclosure of a terminal diagnosis found that 50 to 90 percent of patients desired full disclosure [2]. Another study was conducted to assess patients’ preferences and expectations about physicians’ disclosure of a prostate cancer diagnosis, and patients’ preferred participation in medical decision-making. The results of this study revealed that men expect physicians to disclose the diagnosis and wish to participate in making treatment decisions [3]. One more study investigated whether the knowledge of a diagnosis of cancer in eastern societies increases the anxiety and depression where newly diagnosed, untreated cancer patients were evaluated with standardized questionnaires. Authors of this study reported that, although patient relatives’ perceive that diagnosis of cancer is preferred not be disclosed or patients could suffer from psychiatric problems, the resultant anxiety and depression scores of informed and non-informed patients did not show statistically significant difference. The authors suggested that decreased anxiety of informed patients may be caused by the acceptance of the cancer, and the elevated anxiety and depression...
levels of non-informed patients may be caused by the expectation of bad news [4]. In addition, results of a study where 50 patients underwent a semi-structured interview with a social worker within one week of having been told the diagnosis of lung cancer showed that patients wanted to be told their diagnosis truthfully and required a high level of information [5]. Because a sizable minority of patients still may not want full disclosure, the physician needs to ascertain how the patient would like to have bad news addressed. In fact, the belief that breaking the bad news of cancer diagnosis to the patient is culturally ingrained in several societies to potentially create great psychological burden that the patient may lose all hope to live [6]. Awareness of prognosis may negatively impact survival and quality of life in terminally ill cancer patients. Therefore, the patient’s preference for and individual susceptibility to receiving such information should be assessed carefully before breaking the bad news [7]. The literature also suggests that information provision needs to be tailored to the individual needs of the patient which may be influenced by different factors such as disease status, age and gender, coping style and values. Those with higher trait anxiety scores were more likely to prefer the physician to tell a loved one the prognosis. Healthcare professionals should respect those patients who do not want to know, and they need to realize what impact the news may have on the patient.

Medical ethics should also be acknowledged, placing emphasis on the patients’ rights. Physicians’ attitudes towards truth telling varied according to their specialty and the stage of the disease [8]. The majority of physicians tell the truth more often today than in the past, in both developed and developing countries, but most of them prefer to disclose the truth to the next of kin [9,10]. The American College of Physicians ethics manual affirms the importance of truth-telling based on the principle of autonomy [11]. The four ethical principles of “autonomy (respect for persons), beneficence (a duty to promote good and act in the best interest of the patient and the health of society), non-maleficeance (do no harm) and justice (fairness in distribution of life-enhancing opportunities) shape our current understanding of medical ethics” [11]. Nevertheless, the medical principle of primum non nocere may be threatened if a blanket policy of full disclosure is adopted, since not all patients wish to be given all the details of their illness [12,13]. Nurses’ attitudes towards truth telling of terminal cancer were influenced by their educational level and work experience. Oncology nurses differed in their attitudes towards truth telling of different stages of cancer. Nurses who preferred disclosure reported that cancer patients should be informed by the doctor in charge immediately after the diagnosis and in a quiet and undisturbed room [14]. Highly educated and more experienced nurses were less likely to want patients with terminal illness to be informed of their diagnosis. Married nurses were more likely than unmarried colleagues to want patients to be informed of their terminal illness. Another study reported that the attitude of nurses towards truth telling was influenced by the exact disease stage of cancer patients [8]. 55-80% of oncology nurses reported that terminal cancer patients should not be informed of their diagnosis. Medical students and law students differed in their attitude toward disclosing cancer diagnosis and/or prognosis. One study aimed at comparing the attitudes of 127 medical students and 168 law students toward informing a cancer patient about diagnosis and prognosis. Results showed that all medical students and 96% of law students favored information about the diagnosis of cancer if the patient requests it. Seventy-four per cent of medical students and 82% of law students favored informing a cancer patient about his/her prognosis. Thirty-five per cent of law students and 11.7% of medical students favored communicating the diagnosis and 25.6% of law students and 7% of medical students favored communicating the prognosis even if the patient had clearly expressed his/her wish not to be informed [15]. Collectively, the issue of whether, how and how much to tell cancer patients about diagnosis is still approached differently depending on country and culture. So, culture influences the decision of whether or not to break the bad news to cancer patients. In a study involving European, African, Mexican, and Korean Americans, researchers demonstrated a wide variation in patients’ willingness to discuss a diagnosis of metastatic cancer openly. Thus, it may be particularly important for physicians to address cross-cultural differences in patients’ preferences about the delivery of bad news [16]. Ethical approaches to information disclosure are influenced by the Western principle of individual autonomy rights in which the patient is responsible for making decisions regarding his/her health. This model is probably at its most advanced in the US, where truth telling has become part of the culture. But there is still strong resistance against disclosure of cancer diagnosis and prognosis in many cultures. Some patients are not ready for the truth or are not willing to know the truth. Instead, they prefer their family to receive the initial diagnostic cancer disclosure, a common practice in China, which highlights the importance of personalized disclosure. Withholding information from cancer patients is a common practice in many Asian countries, including not only China, but also Japan, and Singapore, as well as in some Western countries, such as Spain, Greece, and Italy [17]. Although fear of causing psychological damage to patients and their reluctance to find out the truth are two main justifications of non-disclosure attitudes, there are other important contributing factors that need to be better understood including those related to the relatives, physicians and healthcare systems. Cultural differences in attitudes towards truth-telling exist; however, these differences should not be used as excuses not to respect individual rights and preferences of cancer patients by making assumptions based on their age, sex, type of cancer, language and/or cultural background [18]. It has been found that physicians from Japan agree upon the concealment of the truth [19] and similar attitudes of patient non-disclosure have been observed in Singapore [20].

Nevertheless, guidelines for transparent and truthful communication of the diagnosis with cancer patients were established and started to be used at the National Cancer Centre in Japan in 1996 [21]. Five hundred and twenty-nine Japanese cancer outpatients were surveyed regarding their preferences for disclosure of bad news to find that more than 90% of them strongly preferred to discuss their medical condition and treatment options with their physician and to have their physicians take the feelings of their family into consideration as well [22]. Some physicians in Portugal or China believed that disclosure might damage the patients psychologically. Nearly 50% of the Chinese questioned believed that patients with terminal illness should not know
their diagnosis, which may be a cultural issue [8]. Many Chinese doctors, patients and their relatives also believed that patients with terminal illnesses should not know their diagnosis and therefore, oncology nurses need more training to deal with this situation [23]. In a Greek study conducted in 146 relatives, few chose the disclosure of diagnosis or prognosis (23%) to the patient [24]. However, a significant proportion (56%) argued that only in special cases should the diagnosis be disclosed. They were fairly certain as to their opinion and attitude on informing the patient about possible treatment options (71%). Another study investigated the communication context through which health care professionals and families with cancer patients interact in Greece to find that the decision of information disclosure lies with the treating physician who has the tendency to tell the truth more often today than in the past, although the majority still disclose the truth to the next of kin. So, in Greek society, the patient’s family plays an important role in the provision of care and information disclosure. They often decide on the patient’s behalf. It is to be noted that one of the major causes of physicians’ attitudes regarding non-disclosure is the lack of education in communication skills [25].

On the other hand, another study examined whether awareness of diagnosis had any impact on hundred Greek cancer patients. The results revealed that patients exhibited a great desire for information overall. Greek cancer patients needed more factual information about their condition and management particularly when they were receiving chemotherapy [26]. Yet, results of one study in Iran showed that almost half of the terminally ill cancer patients were not aware of their diagnosis and only one out of six knew that their disease was metastatic or terminal; however, none of them had a ‘breaking bad news’ session with their physician [18]. Another study demonstrated that Iranian patients who did not know their cancer diagnosis had a better physical, social and emotional quality of life [27]. In Turkey, more than 50% of families did not agree with disclosing a cancer diagnosis to patients, whereas the majority agreed with disclosing it to the relative [28]. In India, two studies reported a higher prevalence of psychiatric disorders, especially depression, in cancer patients aware of their diagnosis while in another study on lung cancer patients, the disclosure of cancer diagnosis, or lack of it, had no significant impact on health-related quality of life assessment in these patients [29]. Results of a study evaluating Norwegian cancer patients’ awareness of their prior cancer diagnosis, in a general population-based study, revealed that 20% of the patients denied their prior cancer diagnosis. This group consisted mainly of men (54%) and those who were diagnosed as very young or as elderly. More smokers than non-smokers were unaware of their prior malignancy [30]. One recent study assessed the attitudes of the public people toward the disclosure of cancer diagnosis to patients in Saudi Arabia and the majority of participants prefer to inform the patients about cancer diagnosis to help in treatment [31]. The social background in Lebanese society is the main obstacle to revealing the truth to cancer patients. Lebanese patients seem to prefer direct communication of the truth, but families take the opposite approach. Physicians also prefer to communicate the truth at the time of diagnosis, but in actuality, they instead disclose it progressively during treatment [32]. An Israeli study indicated that doctors and nurses were not trained in medical ethics [33]. However, there is an obvious shift towards disclosure observed in all the previously mentioned nations following trends set in the US and the UK. A large study of 2331 heterogeneous cancer patients conducted in the UK by Jenkins et al. [34] found that 87% of patients wanted “all information good and bad”.

Families have strong bonds within themselves in many societies and it is a duty for every family to protect its members. In cultures where there is a belief that disclosure produces more harm than good, hiding information can be ethically rationalised by the ethical principle of beneficence that urges doing good for the patient or by an assumption that in some cultures the majority of patients want to practice their right to confer decision-making to their families or the physician [35]. Therefore, it is believed that diagnosis with cancer is not a personal issue; since the whole family is involved and affected by such incident. Therefore, it may not be important to know the attitudes of physicians, pharmacists (as patient educators), nurses, lawyers, or ethicists toward the issue of cancer diagnosis disclosure. Instead, it is important to understand that it is the right of the closest mature/responsible family member to be engaged in the decision of whether to break the bad news to the patient or not. Family members are well aware of the patient phenotype/personality traits and they can expect the patient’s reaction to such news. If patient harm is expected, they have the right to intervene and inform to hide the bad news. In a Patient-Centred approach, the physician should respect and appreciate such an attempt for the best interest of the family experiencing the disease ramifications together with the patient.

**Better Strategy for Communicating Cancer Diagnosis**

The literature review revealed that communication strategies used with cancer patients are crucial for their emotional response which can affect treatment outcome and prognosis [10]. In 1847, the American Medical Association’s first code of medical ethics stated, “The life of a sick person can be shortened not only by the acts, but also by the words or the manner of a physician. It is, therefore, a sacred duty to guard himself carefully in this respect, and to avoid all things which have a tendency to discourage the patient and to depress his spirits.” [36]. The ability to communicate “bad news” to a patient and family is also essential to the provision of quality care particularly for terminally-ill patients [37]. Unfortunately, there are no randomized trials conducted to define optimum methods of communicating cancer diagnosis. This was justified by some researchers considering it unethical to randomize patients at vulnerable times such as waiting for a diagnosis [38]. Moreover, papers in clinical journals dealing with how to tell cancer patients bad news rely mostly on the opinion of the physician [39]. A systematic review was performed to assess the effectiveness of various methods of communicating the first diagnosis of breast cancer. The review examined how this affected what the patient recalled, the satisfaction with the received information, coping strategies and the impact of the information on the patient’s quality of life. The review authors retrieved 23 original reports of trials for further review but finally no trial could be included since a number of trials focused on communication at the first treatment
consultation rather than the method of delivering the diagnosis. The authors then suggested that a review that focuses on various methods of communication at the first consultation visit may be useful to define which methods are more effective and beneficial for this group of patients [38].

One study provided a self-administered questionnaire to a total of 460 oncology patients of the National Cancer Institute (NCI) being treated at one NIH Clinical Centre [40]. Of the 437 patients who completed the survey, 54% were told their diagnosis in-person in the physician’s office, 18% by phone, and 28% in the hospital. The authors of this study concluded a recommendation that the diagnosis should be given face-to-face in a personal setting rather than on the phone or in an impersonal setting and physicians should plan to talk for longer than 10 minutes discussing the diagnosis and treatment options whenever possible [40]. Many physicians report that they have difficulty disclosing a cancer diagnosis. Poor doctor-patient communication may lead to psychological distress including anxiety, depression and ill psychological adjustment to cancer. Consensus guidelines have been developed to assist physicians to a cancer diagnosis. Important aspects include “exploring the patient’s expectations, warning him/her of bad news, delivering the news at the patient’s own pace, allowing time for the patient to react, and eliciting the patient’s concerns”. There is little evidence about the best methods for giving bad news and most recommendations/guidelines are not recent and are based on opinion [41,42]. Several professional groups have published consensus guidelines on how to discuss bad news; however, few of those guidelines are evidence-based and they generally recommend individualized disclosure by tailoring the interview to the individual patient [43]. The clinical efficacy of many standard recommendations has not been empirically demonstrated. Lack of legal and ethical guidelines in some developing countries, or unclear guidelines, also contribute to the physician’s state of confusion.

Some risk factors were reported to be associated with stress reactions of patients after being told the diagnosis [45]: “1- Patients with many symptoms at the time of diagnosis. 2- Patients with family problems, e.g. marital. 3- Poor support from surrounding people. 4- Patients feeling their physicians be unsupportive. 5- Patients with a history of psychiatric disorder (especially depression). 6- Patients who tend to be anxious. 7- Pessimistic patients”. Therefore, evaluation of these factors may be useful before disclosing cancer diagnosis. In addition, to improve the quality of doctor-patient communication, guidelines were developed focusing on two major perspectives, i.e. general matters requiring attention at the time of explaining the diagnosis and understanding the patient’s psychological reactions and offering the necessary support [44]. In general, patients prefer emotional support from physicians when physicians deliver a cancer diagnosis [45]. It is also recommended that when communicating bad news, ‘physicians should use supportive expressions to relieve patients’ emotional distress’ [46]. Some patients are anxious for comprehensive and transparent cancer disclosure to reduce their stress [47]. When patients desire the truth and are not fully disclosed, their sense of hope will decrease. Treatment options are of great concern to cancer patients, and the way of disclosing treatment plans may influence patients’ levels of hope. One study found that one of the most hopeful disclosure strategies is that doctors mention the availability of multiple treatment plans [48].

Multiple international studies involving oncologists have identified communication barriers such as cultural differences, paternalistic views and family dynamics. Understanding barriers for communicating bad news and applying general tactics of communication improvement, such as avoiding jargon and active listening, are initial steps in grasping the physicians’ task of communicating bad news to their patients. Bad news should be communicated to a patient in a supportive environment and in simple, but not blunt, terms.

The amount of news delivered at any one time must be judged by a patient’s response/reaction. It may be preferable to deliver bad news in smaller portions to allow time for a patient to digest and cope. The use of a “warning shot” can be helpful to alert patients to forthcoming bad news. Common patient responses to bad news include shock, denial, fear, anger, and guilt. Doctors and nurses need to be sensitive to verbal and non-verbal cues and to improve their communication skills [49]. Physicians need to individualize their manner of breaking bad news based on the patient’s needs [36]. Rabow and McPhee [50] documented ABCDE Mnemonic for Breaking Bad News that has different stages; “the first stage is: Advance preparation that includes: Arrange for adequate time, privacy and no interruptions (turn pager off or to silent mode). Review relevant clinical information. Mentally rehearse, identify words or phrases to use and avoid. Prepare yourself emotionally. The second stage is: Build a therapeutic environment/relationship that includes: Determine what and how much the patient wants to know. Have family or support persons present. Introduce yourself to everyone. Warn the patient that bad news is coming. Use touch when appropriate. Schedule follow-up appointments. The third stage is: Communicate well which includes: Ask what the patient or family already knows. Be frank but compassionate; avoid euphemisms and medical jargon. Allow for silence and tears; proceed at the patient’s pace. Have the patient describe his or her understanding of the news; repeat this information at subsequent visits. Allow time to answer questions; write things down and provide written information. Conclude each visit with a summary and follow-up plan. The fourth stage is: Deal with patient and family reactions which includes: Assess and respond to the patient and the family’s emotional reaction; repeat at each visit. Be empathetic. Do not argue with or criticize colleagues. Encourage and validate emotions. Explore what the news means to the patient. Offer realistic hope according to the patient’s goals. Use interdisciplinary resources. Take care of your own needs; be attuned to the needs of involved house staff and office or hospital personnel”. Another protocol (SPIKES) for disclosing unfavorable information “breaking bad news” to cancer patients about their illness has been developed. It consists of six steps: “gathering information from the patient, transmitting the medical information, providing support to the patient, and eliciting the patient’s collaboration in developing a strategy or treatment plan for the future” [51]. It is true that cultural differences are important determinants of physician–patient communication on the issue of truth-telling, but
physicians should manage their communication based on ethical principles including the preferences of each individual patient not on their own assumptions. Health professionals must also consider specific issues including social, cultural and emotional aspects and understand the role that the family members play in the disease experience particularly of elderly patients [52].

To understand communication as a complex human activity also requires knowledge of older patients’ experience of cancer and their need for honest and compassionate care. Research findings on physician–older cancer patient communication need to be translated into medical education, training and practice to improve an important dimension of healthcare service to older cancer patient [53]. The design of ethically sensitive research to assess the impact of various methods of communicating cancer diagnosis needs to be explored to advance future practice. In addition, since the strategy of how bad news should be communicated to patients constitutes a major area of interest in medicine, more studies need to be conducted focusing on patients’ perspectives to better serve the customer and really provide Patient-Centred care. Doctor-patient communication can be improved by including training courses in communication skills for medical students and clinicians. Professional training programs on improving doctors’ communicating a bad cancer diagnosis are needed, and emphasis might be placed on providing emotional support to cancer patients. Doctors could involve family to find out ways of personalized disclosure. What a patient wants to know, not what a patient’s family wants to know, and determines the disclosure strategy [54]. The task of delivering bad news is an important task that, if done well, improves patients’ ability to cope with their disease [55].

Finally, it is believed that good communication offers the most rewarding aspect of total patient care and that communication specialists and clinical psychologists are the main role players in defining the optimum cognitive communication strategy that improves Patient-Centred healthcare service and disease outcome.

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Conflict of Interest

No conflict of interest.

References


