

Truth telling: Do different cultures require different attitudes?

Mohammad Mutaaz Masaarane^{1*} and Mohammed Imad Bourghli².

¹Royal Preston Hospital, Preston, England. ²Conquest Hospital, Hastings, England.

Health care professionals who are dealing with cancer are in a dilemma of whether to tell the truth to the patient or not. In clinical practice the issues include not only 'whether' but 'when', 'how' and 'how much' to tell patients about their diagnosis, treatment choices and possible prognosis. These questions have troubled doctors very much especially when they try to follow the principle of 'doing good' to their patients. Some people agree that patients have the right to be well informed and to practice their autonomy of making decision for themselves about medical care. Nevertheless, a commitment toward openness has not been achieved and is not suitable for every culture. A common reason for hiding the truth is the intention to protect affected persons from being harmed by knowing.

In North America and Western countries, clinicians' attitudes towards telling cancer patients about their diagnosis have changed remarkably in the past few decades. There has been a major shift in medical culture from an attitude of medical paternalism (doctors know best and can act in the way they believe to be in the patient's best interest), to one in which patient autonomy and informed participation in medical decisions is the predominant value. This shift is reflected in the greater willingness of doctors to disclose and to discuss cancer conditions with their patients. The survey by Oken [1] in 1961 of 219

clinicians in the United States found that 90% would not disclose a diagnosis of cancer to a patient. A repeated survey of 264 American clinicians using the same questionnaire in 1979 found that 97% would inform the patient of a diagnosis of cancer [2].

In the above countries, principles of informed consent and patient autonomy have created clear ethical and legal obligations to provide patients with as much information as they desire about their illness and potential treatment. Clinicians may not withhold medical information even if they suspect it will have a negative effect on the patient. Yet a mandate to disclose the truth, without regard or consideration for the sensitivity with which it is done or the obligation to support the patients and assist them in decision-making can result in the patients being upset as much as if they were lied to.

The disclosure of a cancer diagnosis and prognosis has been an important but still unresolved issue in cancer management and care in the Middle East and other parts of the world like the Far East, Southern Europe and South America. Doctors in these countries usually do *not* inform patients about either the diagnosis or the prognosis of cancer, although changes towards more disclosure have been reported from Japan recently. Cultural, social, ethical and religious concerns are believed to play important roles. In contrast to Western cultures, which adhere to more individually

orientated philosophies, traditional cultures place more value on the collective role of family in decision making. Discussion is more likely to take place with family members, who then filter the information that the patient receives. Some of the reasons for not telling the truth about cancer are (1) worry that patients could not take the emotional impact, (2) worry about doctors not being able to manage the patients' emotional reaction after learning the truth, (3) protecting patients from harm and (4) taboo about discussing death and related issues

Cultures in the West hold that most people are capable of making properly informed decisions about medical issues and it is usual for competent adult patients to control what information family members are given. The universal application of this disclosure model, based on very western ideas of autonomy, has raised concerns for some. In some cultures, an adequate understanding of medical data is beyond most people. To force a person to make independent choices, where he/she is socio-culturally unprepared to do so, may challenge their ability to take such decisions. This may, in turn, jeopardize the respect, integrity and human worth the principle of autonomy was meant to ensure. Western disclosure practices may make the relationship between patients and health care workers difficult and even distrustful.

Because of advances in cancer treatment in the West, telling about a cancer diagnosis is no longer equal to announcing certain and imminent death. This does not necessarily apply to other parts of the world, as there appears to be particular problems passing on information to patients in resource-poor countries. An important consideration is what medical services

a patient has access to. If the health professional assesses that the treatment is not available or the patient cannot afford a potentially useful therapy, the doctor must consider whether patients will derive greater benefit or greater suffering from being told about it.

The educational level of the patient is a significant factor in whether or not he/she is aware of his/her cancer. This correlation perhaps relates to the empowering effect of education to encourage questioning the health care professionals. Another interpretation might be that it is easier to hide the diagnosis from patients if they are uneducated.

What will happen if we continuously withhold the truth from the patient?

First, patient compliance is needed to ensure treatment efficacy and it goes without saying that patients can not fully comply with their treatment if they are not aware of the diagnosis.

Second, patients will never have a chance to make choices about their medical treatment and care. *Third*, with limited conversations and interactions, patients may feel isolated or even being abandoned. They may have sensed their physical decline and felt distressed of the disease but could not share their fears and anxieties with others. *Fourth*, it will be impossible for patients to sort out their will and fulfil their expectations before they die.

Finally, there will be a serious problem of trust, which will challenge the relationship between health care professionals and patients. Patients will probably either be suspicious or fully aware that people "lied" to them. They may choose to pretend they do not know in compliance with the family's wishes. They will have more stress from the kind intentions of their families than if they had been told truthfully.

In a survey done in Lebanon [3], 47% of doctors reported that they usually

disclose the truth to cancer patients ("tellers") and 53% reported that they usually do not ("non-tellers").

It was interesting that training abroad did not affect the disclosure policy. Doctors with U.S. training, where disclosure is considered the norm, were not more inclined to such disclosure. They believe that they had reached their current practice under the influence of their own life experience and/or personal values and convictions. Thus, regardless of what they may have been told during their formal education, those physicians seemed to be mostly influenced by trends and values predominant in the culture where they practice.

There are four recognised contexts of awareness experienced by patients with life-threatening illnesses [4]:

1. Close awareness: doctors and family try to hide the truth and engage in conversations that avoid disclosure. They keep conversations to the minimum and steer away from talking about the future, especially when a patient is in a very advanced stage of cancer. Nevertheless, the patient may move to either suspicion awareness or to full awareness of their diagnosis at a later stage.

2. Suspicion awareness: is a situation where patient begins to suspect the seriousness of their condition. The patient may attempt to confirm their suspicion by direct or indirect measure, such as sneaking a look at medical records, making direct requests of the staff or family, and inducing families and staff to adopt different strategies in response. As a result, the relationships between patient, staff and their families are strained.

3. Mutual pretence: at a later time, when staff, families and patients

themselves all know that the patient is dying, but choose to pretend that the patient is going to be all right. The drama between them could last for a long time; and as a consequence the patient will die without ever knowing the truth from family or staff, although they may have full awareness of their condition.

4. Open awareness: open awareness results from when staff, families and patients know and choose to acknowledge in their actions that the patient is seriously ill.

The biggest challenge for doctors facing patients with cancer is how to break bad news and not to devastate the patient. The skills of communication and interaction with these patients are most important for health care professionals who carry out the mission of truth telling. A careless telling may cause more damage, which is against the principle of do not harm. The bearer of bad news often experiences strong emotions such as anxiety, a burden of responsibility for the news and fear of negative evaluation. This stress creates a reluctance to deliver bad news. When clinicians are uncomfortable in giving bad news they may avoid discussing distressing information, such as a poor prognosis, or convey unwarranted optimism to the patient. A plan for the way of disclosing bad news can increase physician confidence in the task of delivering unfavourable medical information. The authors of several papers [5, 6, 7] have advised that interviews about breaking bad news should include a number of key communication techniques that facilitate the flow of information and alleviate the impact these news may have on patients. The process of disclosing bad news can be viewed as an attempt to achieve

four essential goals. The first is gathering information from the patient. This allows the clinician to determine the patient's knowledge and expectations and readiness to hear the news. The second goal is to provide intelligible information in accordance with the patient's needs and desires. The third goal is to support the patient by employing skills to reduce the emotional impact and isolation experienced by the recipient of bad news. The final goal is to develop a strategy in the form of a treatment plan with the input and cooperation of the patient.

STEP 1: Setting up the Interview

Mental rehearsal is a useful way for preparing for stressful tasks. This can be accomplished by reviewing the plan for telling the patient and how one will respond to patients' emotional reactions or difficult questions. As the messenger of bad news, one should expect to have negative feelings and to feel anxious and responsible. It is helpful to be reminded that, although bad news may be very sad for the patients, the information may be important in allowing them to plan for the future.

STEP 2: Assessing the patient's perception

Steps 2 follows the role "before you tell, ask." That is, before discussing the medical findings, the clinician uses open-ended questions to create a reasonably accurate picture of how the patient perceives the medical situation. For example, "What have you been told about your medical situation so far?" or "What is your understanding of the reasons we did the scan?". Based on this information you can correct misinformation and tailor the bad news to what the patient understands. It can also accomplish the

important task of determining if the patient is engaging in any illness denial, wishful thinking or unrealistic expectations of treatment.

STEP 3: Giving knowledge and information to the patient

Warning the patient that bad news is coming may lessen the shock that can follow the disclosure and may facilitate information processing. Examples of phrases that can be used include, "Unfortunately I've got some bad news to tell you" or "I'm sorry to tell you that...".

Giving medical facts may be improved by a few simple tips.

First, start at the level of comprehension and vocabulary of the patient. Second, try to use nontechnical words such as "spread" instead of "metastasized" and "sample of tissue" instead of "biopsy." Third, avoid excessive bluntness (e.g., "You have very bad cancer and unless you get treatment immediately you are going to die") as it is likely to leave the patient isolated and angry, with a tendency to blame the messenger for the bad news. Fourth, give information in small chunks and check periodically his/her understanding. Lastly, when the prognosis is poor, avoid using phrases such as "There is nothing more we can do for you"

STEP 4: Strategy and summary

Patients who have a clear plan for the future are less likely to feel anxious and uncertain. Also sharing responsibility for decision-making with the patient may also reduce any sense of failure on the part of the physician when treatment is not successful. Checking the patient's misunderstanding of the discussion can prevent the tendency of patients to overestimate the efficacy or misunderstand the purpose of treatment.

Conclusion:

What is needed from doctors is a consideration of each patient's situation and needs, an appropriate prioritising of ethical and cultural principles and the selection of effective methods for achieving these.

Clinicians who are convinced that communicating the diagnosis of cancer is beneficial should inform patients who ask to be told and even those who would have preferred not to know about their diagnosis.

In societies where important personal decisions are left to senior family members, it may be inappropriate to inform just the patient. In fact, in clinical settings where family members are continuously present, it may not even be possible. There may be a very important role for family members to play in providing the necessary support for their patients provided that there are given the appropriate guidance by the care professionals.

References:

1. Oken D. What to tell cancer patients. A study of medical attitudes. Journal of the American

Medical Association 1961; 175:1120–8.

2. Novack DH, Plumer R, Smith RL, et al. Changes in physicians' attitudes toward telling the cancer patient. Journal of the American Medical Association 1979; 241: 897–900.
3. Hamadeh NG, Adib SM. cancer truth disclosure by Lebanese doctors. Soc Sci Med 1998; 47:1289-1294.
4. Seale CJ, Addington-Hall, McCarthy M. "Awareness of dying: prevalence, causes and consequences. Soc Sci Med 1997; 45:477-84.
5. Ptacek JT, Ptacek JJ, Ellison NM. "I'm sorry to tell you": physicians' reports of breaking bad news. J Behav Med 2001; 24:205–217.
6. Buckman R. How To Break Bad News: A Guide for Health Care Professionals. Baltimore, MD: Johns Hopkins University Press; 1992:15.
7. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. Oncologist 2000; 5:302–311.

*Corresponding author.
mmasaarane@yahoo.co.uk .