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Diagnosis Disclosure in Cancer Patients – when the Family says "No!"

A Lee, H Y Wu

ABSTRACT

It is not uncommon for family members to thwart a doctor's attempt at disclosure of cancer diagnosis to the patient. This stems from concern and love as well as fear of the negative psychological impact of such revelation. Indeed, collusion of this nature was the norm in medical practice till the not too distant past. In this era of patient autonomy and the right to information, we must be careful not to allow attitudes of medical staff or patients' families, language difficulties and organisational issues become barriers to patient's access to information and their psychological coping of the illness. At the same time, we also need to be acutely aware of the unique cultural environment we work in and the families' emotional needs even as we aim to match the patient's desire for information.

Keywords: collusion, patient autonomy

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SCENARIO 1

Mr C, an elderly Chinese, was admitted with terminal cancer of the lung. His relatives informed the attending doctor that Mr C had not been told of the diagnosis. Written in bold and red ink on the front of his case record and medical charts were "DO NOT REVEAL CANCER DIAGNOSIS TO PATIENT." During the course of his stay, patient did not initiate any discussion regarding his diagnosis with the medical or nursing team. Medical decisions were made after discussion with the relatives. He died in hospital one week later.

SCENARIO 2

Mdm T was newly diagnosed with metastatic carcinoma of the pancreas. A palliative endoscopic insertion of a biliary stent was deemed essential in relieving her of progressive jaundice and pruritus. Her family refused an open discussion of the illness with the patient and suggested that the doctor tell the patient she had gallstones and needed a simple procedure to "remove the stones". When the doctor advised the family on the need for "more open discussion with the patient", Mdm T's family threatened to bring the patient to another hospital and accused the doctor of being "uncaring" and "cruel".

The above situations are experienced at one time or another by most doctors practising locally. Despite medical advances, cancer is unique amongst illnesses that it continues to evoke a deep-rooted fear and a sense of helplessness. It has a reputation tantamount to a death sentence, accompanied by a grim image of immense pain and suffering. It is little wonder that there is considerable anguish when such a diagnosis is made. There are worries that the patient may lose hope and the will to live, as well as plunge into depression. Even though advanced cardiovascular disease, end-stage renal and liver diseases may have the same prognosis, it does not evoke the same emotions as the diagnosis of cancer. It is not surprising that well-meaning relatives would want to withhold the news from patients.

A local survey carried out by the authors in 1994 showed that 40% of the terminally-ill patients had not been informed of the diagnosis(1). Many doctors would have gladly colluded with the relatives in the two situations mentioned above. A local study by Tan et al in 1993 showed that 84.0% will accede to the family's request not to tell the patient(2). Non-disclosure of "bad" news is not a local or Asian cultural anomaly. The world over, diagnosis disclosure in life-threatening illnesses such as cancer was the exception rather than the rule up till the not too distant past.

CHANGING TREND OF DIAGNOSIS DISCLOSURE

"DON'T TELL!"

There have been great strides and changes in the medical field over the last quarter of a century. Other than advances in the "hard" science of medicine, amongst the changes that we see is the doctor-patient relationship. For centuries before this, doctors have treated patients with strict paternalism. The doctor was accorded special status and respect. In most cultures, the modern physician has "priest-clergy" origins(3). The intimate relationship between physician, the patient and their God(s) made any critical questioning of the doctor's

Palliative Care Service
Department of Geriatric Medicine
Tan Tock Seng Hospital
11 Jalan Tan Tock Seng
Singapore 308433

A Lee, FRCP (Edin), FAMS
Consultant

H Y Wu, MRCP (UK)
Registrar

Correspondence to:
Dr Angel Lee
Tel: (65) 6357 7851
Fax: (65) 6357 7837
Email: lee_angel@ttsh.com.sg

practices by patients difficult. Not only would patients find it difficult to question their physicians, who are considered divinely ordained, but the latter would also disdain explaining themselves and their practices. The relationship was based on the principle of beneficence and non-maleficence with the doctor making decisions for the patients, in his best interest, based on their knowledge, divinely obtained or otherwise. Patients, too, accept their role and the advice of the doctor with much stoic passivity. The duty of the doctor to aim for the best for the patient was expected and seldom put in doubt. Despite the secularisation of medicine through the ages, the doctor-patient relationship was still based on "doctor knows best" and "do no harm" principles. The general belief in the past was that bad news as in a bad prognosis could lead to increase in mental anguish and psychological distress. Hippocrates encouraged physicians to "conceal most things from the patient while attending to him. Give necessary orders with cheerfulness and serenity, turning his attention away from what is being done to him; sometimes reprove sharply and emphatically, and sometimes comfort with solicitude and attention, revealing nothing of the patient's future or present condition(4)". A noted physician in Jena and Berlin, Christoph Wilhelm Hufeland (1762-1836), said, "to prophesy death is to cause it". The first code of ethics of the American Medical Association (1847) included the following: "A physician should not be forward to make gloomy prognostications...But he should not fail, on proper occasions, to give notice to the friends of the patient timely notice of danger when it really occurs; and even to the patient himself, *if absolutely necessary*. This office, however, is so peculiarly alarming when executed by him, that *it ought to be declined whenever it can be assigned to any other person of sufficient judgement and delicacy* (italics authors' own). It went on to advise the physician to "avoid all things which have a tendency to discourage the patient and depress his spirits". Up till 1989, the Deontology Code written by the Italian Medical Association stated that "a serious or lethal prognosis can be hidden from the patient, but not from the family(5)".

From the foregoing, it can be seen that the general belief was that bad news was detrimental to the patient and this led to the withholding of life-threatening diagnoses and prognoses from patients. In 1950s, a survey in America showed that approximately 90% of physicians preferred not to inform the patients when the diagnosis was cancer(6). Slightly more than 20 years ago, Cartwright et al in a survey of cancer deaths found that only 49% of patients knew their condition(7). McIntosh also found that doctors dealing with cancer patients adopted a policy of not disclosing information unless it was absolutely necessary(8). A 1969 study in Great Britain showed that only 29% of patients suffering from terminal cancer knew the diagnosis, 16% knew certainly that they were going to die and 21% knew that they were probably going to die(9).

"TELL!"

However, the last quarter of a century saw a rapid shift in this policy in Anglo-American (popularly termed "western") cultures. Novack et al repeated Oken's study(6) in 1971. The results were dramatically different – 90% of physicians would (as a general policy) disclose the truth to cancer patients as opposed to 10% in the previous study(10). The findings were similar in Great Britain. In 1987, the proportion of patients who knew their diagnosis had increased to 60%(9).

In a survey of oncologists from 20 countries carried out in 1987, 90% agreed that truthful disclosure appears to be increasing(11). Several factors could have influenced this changing trend in the doctor-patient relationship.

(1) Patient self-determination as an emerging force

Many attribute the rise of patient autonomy as a pillar in the doctor-patient relationship to the Nuremberg code of the Helsinki trials. The belief that doctors could be the trusted caretakers of patients' well-being was debunked in these trials after World War II. As the court heard the atrocities performed or supervised by German doctors who were respected teachers and researchers of world-wide renown, a judgement resulted that gave central importance to the principle of patient autonomy and made it an ideal that should govern the doctor-patient relationship(12). Even before Nuremberg, there had been rumblings of dissatisfaction over the unilateral decision-making process with the resultant perceived harm to patients. Several lawsuits were brought before American courts by disgruntled patients since the early 1900s. These culminated in the concept of "informed consent" in the *Salgo vs Leland Stanford Jr University Board of Trustees* (1957) case. Martin Salgo was a 55-year-old with intermittent claudication. His doctor performed an aortography. However, Salgo woke up the following morning with lower limb paralysis. He attributed this to negligence on the part of the Stanford University Hospital staff. He later appended the claim to state that the physician had failed to warn him of the risk of paralysis in the translumbar aortography. In awarding judgement to Salgo, Judge Brady's pronouncement were, "A physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by his patient to the proposed treatment... In discussing the element of risk a certain amount of discretion must be employed consistent with the full disclosure of facts necessary to an *informed consent*(3)".

To obtain "informed consent" for diagnostic interventions and therapeutic procedures, there is a need for discussions between the patient and the doctor. Disclosure of information, the diagnosis being part of it, forms the basis of the discussion process. At the same time, better educated patients, with increase in access to medical knowledge, wanted more information, better emotional support and greater participation in decision making(13-17). Even in traditionally non-disclosure societies, it has been noted that younger patients and those who are better educated demanded a greater role in therapeutic decision-making(18).

In America, the legislation of the Patient Self-determination Act, effective in 1991(19), reinforces the patient's right to decide on health care matters. Every health care facility that receives Medicare or Medicaid funding is required to ensure that patients are informed of their right to accept or refuse medical care. The attempts to increase the use of advance directives through the Act place an emphasis on discussion of end-of-life matters. Increasingly, the standard of care is to tell the patients the diagnosis even in life-threatening illnesses, to obtain informed consent for all procedures and to involve them in therapeutic decisions as well as withdrawal of resuscitative efforts(20,21).

The patient's right to information and self-determination became enshrined in the ethical framework of medicine. The basis of patient autonomy and the freedom to make informed choices came from explaining diagnosis, prognosis and treatment options.

(2) Changing medical scene

Concomitant with changes in the ethical arena was the rapid explosion in knowledge in various fields of medicine. The increasing complexity of diagnostic and therapeutic procedures demanded patient cooperation. Improved outcomes of care from therapeutic interventions also meant that the prognosis was often not as guarded. With time, the patient with cancer can expect better surgical techniques, improved radiation outcomes, chemotherapy with manageable morbidity and exciting advances in his care from gene therapy.

Even as medical science began to give hope of the possible conquering of many dreaded diseases, another revolution in medicine was taking place. In 1967, St Christopher's Hospice, founded by Dame Cicely Saunders, opened its doors in Sydenhem, England. It marked the beginning of the modern hospice movement. The focus of hospice and palliative care is to improve the quality of life and to help patients with terminal illnesses live life to the fullest until death occurs. The emphasis was on symptom control, whether they are physical, psychological, social or spiritual. Patients and their families were assisted in their search for meaning and hope despite the dismal prognosis of the physical illness. Death became less of a taboo subject. Within years, the principles and practice of hospice care had spread across the world. With the availability of palliative care and emphasis on improved end-of-life care, a doctor can no longer tell a patient, "There is nothing else I can do for you...."

(3) Benefits of disclosure

Research into diagnosis disclosure also revealed little convincing data that truth-telling or awareness of a grave situation does serious harm, such as inducing despair or suicide(22). Instead, much has been written about the benefits of diagnosis disclosure(23-25). In a study by Centeno-Cortes et al(26), there was no increase in perceived symptoms of anxiety, despair, sadness, depression, insomnia or fear in the group of informed patients compared to the uninformed patients. In fact, one-third of those who were not informed had wanted more information regarding their illness but had not been told. There were also clear benefits in those who had been told – 75% of informed patients were able to share their concerns about the illness and its consequences' with their relatives whereas only 25% of those who had not been informed were able to do that. Gerle et al found that patients who were not informed of the diagnosis tended to be more anxious and at times, felt desperate. On the contrary, families of informed patients felt that they were in a better position to care for the patient(27). Opening channels of communication helps to maintain trust between the patient and the doctor. Therapeutic decisions can be discussed with the patient and carried out with his or her full consent and knowledge. It gives the opportunity for the patient to clarify doubts and fears and hence reduce uncertainty. It also allows the patient to make practical (e.g. making a will, settling bank accounts and mortgages) and emotional adjustments to the illness; thereby providing closure to his or her life.

Diagnosis disclosure in cancer is also correlated with improved symptom control and patient satisfaction with care. Lin conducted a study amongst cancer patients in the oncology departments of three Taiwanese teaching hospitals. Patients who were aware of the cancer diagnosis experienced lower levels of "worst pain", had lower levels of pain interference with daily life, and were more satisfied with cancer pain management provided by nurses and physicians(28).

Faced with the purported benefits of diagnosis disclosure, the change in ethical ethos and increasing patient advocacy, the veil of secrecy around the cancer diagnosis has been gradually lifted.

"TELL, BUT..."

However, disclosure of diagnosis in life-threatening illnesses like cancer is not an end in itself. Without emphatic communication, a physician may increase feelings of despair and hopelessness, or even deepen any mistrust the family or patient may have of the health care system.

Evidence suggests that it is more important to determine how much patients wants to know, to deliver the information in a supportive manner and to confirm that patients have understood the information they sought, than to determine objectively the amount of information presented. Although patients have the right to full disclosure of truthful information, some may not want to know certain types of information or be party to certain decisions concerning their own health. Just as it is against the principle of patient autonomy to withhold information sought by patients, to thrust the full "truth" onto patients who are not up to facing it may be against their interest(29).

In addition, the sense of family remains very strong in many societies. Families often believe it is their duty to protect the patient from burdensome information and their filial responsibility to make end-of-life decisions on behalf of the patient. In Japan, family members are often the first to be informed by physicians of the cancer patient's diagnosis, condition and therapeutic programme. The family members then discuss whether the diagnosis should be disclosed(30,31). The family's decision is greatly respected, often in deference to that of the patient. In Blackhall et al's study on the attitudes of elderly of different ethnic groups toward disclosure of diagnosis and prognosis in the terminally ill, Korean-Americans and Mexican-Americans were less likely (35% and 48% respectively) than African-Americans (63%) and European-Americans (69%) to believe that a patient should be told the diagnosis. They were also less likely to believe that a patient should make decisions about the use of lifesupporting technology (28% and 41% vs 60% and 65%), preferring that the family should make the decisions(32). As in the first patient illustrated at the beginning, the patient often accepts his passive role in this process. Pellegrino, an American bioethicist, considered the delegation of decision making authority culturally implicit in many ethnic groups of the world. "...autonomous patients are free to use their autonomy as they see fit – even to delegate it when this fits their own concept of baneficence....To thrust the truth or the decision on a patient who expects to be buffered against news of impending death is a gratuitous and harmful misinterpretation of the moral foundations for respect of autonomy(33)".

It has been suggested that informing a patient with cancer may not necessary be dependent on explicit verbal communication. Even though there may not be open discussion between the patient and the physician, experienced oncologists realise that many whose relatives report not knowing the diagnosis actually know. In the survey carried out in 11 prefectures of Japan by the Japanese Ministry of Health and Welfare in 1992, bereaved families of cancer patients were interviewed. Of 1918 respondents, 81.3% responded that the patient was not informed of the cancer diagnosis. Of these, 42.5% of the caregivers felt that the patient might have suspected the diagnosis(34). In Japan and many cultures, ambiguity and use of euphemism are accepted in discussion with patients. The negative stigma attached to the word "cancer" is so strong that to mention it may be considered callous, rude and even disrespectful. To be too direct in topics such as death, may be considered insensitive and cruel(35). The patient plays into the charade of non-disclosure and in so doing, protects the family from open discussion of a taboo subject.

Hence, rather than aim for complete disclosure in all patients, it is important to be sensitive to the patient's needs, desire for information and respect cultural expectations on communication in the terminally ill.

FINALLY...

With time, it is likely that fewer patients will have their diagnosis withheld from them by concerned family; members. It is envisaged that with better education, more people will want to be in control of their own health. In Turkey, patients with higher educational levels were informed more often than those with lower educational levels. The younger patients were also noticed to desire a greater role in therapeutic decision-making(36). Doctors better trained in the skills of communication will also be more willing to address the issues of diagnosis disclosure in the face of dissenting relatives.

DEALING WITH FAMILY COLLUSION

Collusion occurs out of love and concern. So, how can we deal with the relatives who insists on keeping the diagnosis from the patient?

1. Acknowledge that they (family) know the patient better.

   This helps to break down defences and makes you their advocate, rather than appear as an arrogant doctor who "does not understand my mother".

2. Find out reason for keeping the news from the patient. Has the patient mentioned anything regarding cancer in the past (e.g. “I will rather die than have cancer.”)? Does the personality of the patient make the family fear that knowledge of the disease will aggravate the situation?
   Has there been anyone in the family who had cancer? Had there been a ‘difficult’ death?
3. Determine the cost of keeping the news from the patient.
   “Are there things that had to be settled but is difficult without the patient’s knowledge (will, bank, mortgage)?”
   “Do you find it difficult speaking to your mother now?”
   “Do you have to lie in order to keep up the facade?”
4. Ask for permission to speak to patient alone. Assure them that your aim is to determine what the patient wants to know rather than to force the bad news on the patient.
5. Acknowledge any identified emotional or psychological distress in the family. This may include guilt over delay in bringing the patient for medical advice, anger over missed or delay in diagnosis, anxiety over the future, feelings of helplessness and financial concerns. Suggest referral to other professionals (e.g. social worker) if appropriate.
6. Reassure the family that you will update them with details of your conversation with the patient (similarly when speaking with the patient, ask for permission to discuss details of the conversation with the family).

It is worthwhile to remember that communication should be more than a disclosure of diagnosis or the dispensing of information. It involves the communication of respect, support, care, concern and availability. It is not only verbal but also consists of the universal language of signs, gestures and attitudes. It involves more than the patient but also his social support system, which is often the family. It is an on-going process that involves follow-through plans and actions. It is also pertinent to note that bad news is best broken by someone who has some degree of continuity of care with the patient and preferably by one who has a rapport with the patient and family. It is not appropriate to “break a bombshell” and walk away from the scene. Ethical norms have changed through the ages. In our attempt to fulfil the new ethical and/or legal obligation, we must not overlook the individual patient’s true wishes and best interests. Health care providers need to continuously assess whether the patient wants only limited information or whether external circumstances such as attitudes of staff or relatives, language barriers and organisational barriers are limiting patient access to the information they want.

It is beyond the scope of this paper to go into a lengthy step-by-step guide on breaking bad news. For this we refer the reader to several excellent books(23,24,37). Communication skills are increasingly recognised as important aspects of medical curriculum. Such skills have been found to improve doctor-patient relationship, satisfaction with care and patient health outcomes(38-40). It is no longer thought to be a skill you either have or do not have. It is pertinent to take note of what Robert Buckman, an acknowledged authority on doctor-patient communication, had to say, “An expert in breaking bad news is not someone who gets it right everytime – he or she is merely someone who gets it wrong less often, and who is less flustered when things do not go smoothly(24)”.

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