HOW TO BREAK BAD NEWS

Guidelines for the Attending Physician
Reference for the Non-medical Health Provider and the Patient's Relatives

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One of the major dilemmas confronting oncological practice relates to the 'right' approach which physicians should use to reveal diagnostic and prognostic information about cancer without causing much stress or psychological damage to the patient. Due to fears regarding the psychological effects of disclosing as well as its consequences on compliance to treatment plans, telling the truth of diagnosis and prognosis has not been an easy task for many clinicians.

On the other hand, the experience of having a life-threatening illness is devastating for most patients and their families. Consequently, they have an intense need for information and emotional support.

This manual was therefore developed to present culture-appropriate guidelines for the attending physician given the task of breaking bad news to patients. It also serves as a reference for other physicians, health providers, and relatives caring for patients with life-threatening disease, like cancer. The content of this manual was derived from the results of the study done in the Philippines, which described and evaluated the modes of physician disclosure in the Philippine oncological practice and their psychological effects on cancer patients and their relatives.

Following the guidelines outlined in this document will hopefully ensure that patients who are diagnosed as having a life-threatening illness are informed of their diagnosis in an optimal manner, and are provided with the support required to deal with the news.

This manual is dedicated to the Filipino cancer patients, their relatives, and their physicians.

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SHOULD THE PATIENT BE TOLD HE/SHE HAS CANCER?

Yes.

WHO SHOULD DISCLOSE THE INFORMATION TO THE PATIENT?

The person who does the disclosure must possess the following characteristics. He/She MUST:

1. be emotionally mature and stable
2. be capable of giving empathy and encouragement
3. be reassuring
4. be intellectually mature
5. show emotional sensitiveness
6. be technically knowledgeable, and
7. be capable of imparting information in a simple way as possible.

Only one person should be responsible for breaking the bad news, preferably the first attending physician who possesses or must learn to develop the characteristic requirements as mentioned above. Due to the nature of family ties in the Philippines, it is essential that the family members be informed and consulted about the decision to be made.

WHERE MUST THE DISCLOSURE TAKE PLACE?

The physical aspect of the room where the disclosure is conducted is very important. Furnitures should be arranged appropriately. The interaction should be conducted in a suitable and comfortable private room with minimal disturbances. Make every effort to ensure privacy.

Disclosure could be done where participants are face-to-face by the bedside or across an office table. Be sure that the patient’s position is stable.
WHO SHOULD BE WITH THE PATIENT WHEN THE DISCLOSURE IS MADE?

Oftentimes the relatives, preferably first degree.

However, by all means, the patient's right to confidentiality and/or his/her request to be alone, should be respected. Other medical staff can be present but with permission from the patient and introductions made *a priori*.

WHEN SHOULD DISCLOSURE TAKE PLACE?

Disclosure should take place when conclusive test results or high suspicion of cancer exist. The 'right' time of disclosure is the time when the patient is emotionally, physically, and mentally ready to hear the 'bad news'. As such, he/she should be gradually prepared for the 'bang!'

In the Philippine setting, it might be more advantageous to reveal the information first to the family, so they can help in the initial preparation and in showing full support to the patient during disclosure time. Disclosure to the patient should preferably take place at a time when the family has shown acceptance and control over their grief. On the other hand, it might be that the patient is ready for the bad news earlier than the relatives. In such case, disclosures to the patient takes priority.

Ninety-six per cent of the relatives preferred that somebody (96% relatives; 4% friends) should be with the patients when the doctors talked to them about their illness. Others preferred that the patient should be alone. 65% of patients were not alone when they first learned about their diagnosis, although more preferred (89%) that someone, mainly relatives (98%; 85% first degree), should have been with them. Others preferred to be alone.

There was an opinion among the physicians that patients more or less have already an idea of their disease, having been exposed earlier to media or other sources of information. Twenty-seven percent of the patients indicated that they suspected they had cancer even before seeing a doctor.

Few patients and relatives preferred not to let patient know of his/her diagnosis. Reasons given were fear that the information might affect the patients emotionally and physically, leading to pessimism, loss of hope, loss of self-confidence, and fear.

Although accompanied by shock, sadness and fear, patients asked questions about hope and/or if there is anything that could still be done as well as questions that pertained to the length of time for survival. Despite their predicament, the patients can eventually become resigned or tended to accept their present crisis. Among the major factors that help them cope were - belief and trust in God and social support from family.

Take note that the relatives' initial refusal to permit the doctor to tell the patient, is probably because the relatives themselves have to go through the stages of anger, denial, grief, and acceptance, first. As observed by the physicians, relatives get very upset upon knowing about the truth regarding the patient's disease. In fact, they can become more inquisitive and irritatingly curious than the patient himself. However, doctors acknowledged the significant support that relatives can provide the patient. The dilemma of disclosing as well as the emotional costs that it could get from the doctor's own disclosure to the patient have been partially resolved by the relatives.
WHAT SHOULD BE TOLD TO THE PATIENTS?

They should be told the truth regarding diagnosis, prognosis, and treatment options. The patient has a legal and moral right to accurate, reliable information, especially in cases where informed consent is required. Telling the truth will also prepare the patient for the ultimate event.

Before breaking any bad news, the doctor must first check what had previously been told to the patient, and how he/she feels about it. The doctor cannot assume that the patient had been properly informed previously.

HOW SHOULD THE INFORMATION BE TOLD?

There is no standard way of telling the "bad news" to the patient. The person doing the disclosure must be aware that people differ in the way they receive, perceive, interpret, retrieve, and express information. As such, he/she should be sensitive to such variations not only between individuals but also within the individual as mediated by time, environment, mood, and other situational variables. A GRADUAL, REASSURING, but DIRECT, FORMAL method of disclosure is oftentimes preferred. Instilling hope may help the process, yet being aware that developing a false sense of hope and security should be avoided. The disclosure method should help the patient cope with the stress.

Indirect styles of the patient and/or the family should be acknowledged and their identities and relationships to each other should be established. Allow enough uninterrupted time for the interaction.

Prepare for the interview. Case details should be checked and all necessary information,
such as test results must be available. Provide simple, clear, and specific information. Use drawings, diagrams, models and other illustrations if necessary.

Technical jargons and euphemisms should be avoided but can be used minimally if it is felt that a frank and straightforward use of the word 'cancer' and other direct measures is disastrous to the patient's psychological and physical health.

Speak slowly and clearly. Be aware that some patients are old, hence with probable hearing defect and are emotionally disturbed.

Discuss treatment options. Involve the patient in making decisions regarding treatment plan.

After giving the information clearly and simply, one should pause and allow time for the patient to absorb the information that had just been given.

At every stage of the interview, the doctor should check that the patient had understood correctly what had been said, and encourage him/her to ask questions, using prompts, if necessary.

Repeat and write important pieces of information. These may be given to the patient and or be included in the discharge summary which goes to the patient's other physicians and to others involved when he/she leaves the hospital.

What the doctor feels as the most important aspect of the interview may not be the same as the perception of the patient. There is a need to continually check how the patient is feeling, and to provide an opportunity for the information to sink in and for questions to be asked.
Encourage patient to express his/her feelings and emotions such as crying freely. Accept the patient's feelings and concerns by letting him/her know that it is quite normal to feel this way.

ENDING THE INTERACTION

Respond to the patient's feelings with empathy. Touch can be used to convey warmth, sympathy, encouragement and reassurance.

At the end of the consultation, it is useful to summarize and to check what the patient and relatives intend to do immediately after. Make sure that there are no questions left unanswered.

Due to emotional response to bad news, patients may retain very little of the information that had been given by the doctor, which may increase their feelings of anxiety and uncertainty later. Providing relevant reading materials would thus be of great help.

Give the patient information about various support services such as cancer support groups, spiritual care groups, palliative care services, and others.

Among the needs of the patient is to make himself/herself 'presentable' again, in case they had shed tears. When in an office/clinic setting, accompany the patient to the door as he/she is leaving. A pat on the shoulder will surely be a good balm to a depressed spirit.

After the needs of the patient have been addressed, the doctor needs to check his or her own feelings, ensuring sufficient emotional control to deal with the next patient sensitively.
EXAMPLES OF ACTUAL INTERACTIONS BETWEEN PHYSICIAN AND PATIENT AT TIME OF DISCLOSURE

EXAMPLE 1:

Doctor:  "Alam mo na ba ang sakit mo?" (Do you already know your ailment?)

Patient:  (Shook head. Stared at the doctor.)

Doctor:  "Mayroon kang hindi magandang bukol na dapat tanggaliin, ooperahin ang suso, pati taba-tabaa sa kili-kili." (You have a bad mass that should be removed. An operation will be done on the breast; even fats will be removed from the axilla.)

Patient:  (Cries.)

Doctor:  "Huwag kang iiyak. Mahahabol iyan." (Don't cry. That can be remedied.)

Relative:  "Huwag ka nang umiyak. Mabuti tinapat ka." (Don’t cry. It’s good that you’re told the truth.) (Looked at the observer-researcher.) "Kasi iyan, siya lang ang naghahanapbuhay. Hiniwalayan ng asawa." (She is the only breadwinner. Her husband had separated from her.)

Doctor:  "Huwag ka nang umiyak. Maooperahan iyan para hindi na kumalat. Marami ang naoperahan diyan. Bibigyan kita ng complete test bago kita paoperahan. (Do not cry. That should be operated on so it will not spread. There are many who are being subjected to operation. I’ll give you a complete test first before I have you operated.)

In this first example, the word "cancer" was not used although there seemed to be an unspoken understanding that the disease was cancer. The doctor was formal and very explicit about the treatment plan yet at the same time reassuring the patient that everything will be done to help her, even hinted some hope for recovery. Social support was given by the relative who felt the doctor was frank enough to tell the "truth". "Ooperahin" (operation) was the term used instead of telling the patient that the breast will be "aalisin" (removed). The type of disclosure in this example was direct yet some indirect ways were practiced to cushion the impact.
EXAMPLE 2:

Patient was an unmarried young woman.

Doctor: "May masamang bukol ka." (You have a bad mass.) (Doctor was not looking at the patient. He drew a breast on a sheet of paper and explained to the patient what was to happen to the breast.)

Patient: "Di papaopera ako." (So I should be operated on.)

Doctor: (Nods and writes prescriptions).

The doctor was cold and formal and tried to be very technical about his explanations.

EXAMPLE 3:

Patient: "Doctor, kansi ba ito?" (Doctor, is this cancer?)

Doctor: "Masamang bukol. Pinsiyan ng kansi. Pero kayang tanggalin." (Bad mass. That is a cousin of cancer. But that could be removed.)

Patient: "Nag-umpisa iyan sa malili na bukol. Pinisil-pisil ko. Ngayon, kasing-laki na ng pakwan. Ilang buwan pa ba ako mabubuhay?" (This started with a small mass. Then I squeezed it. Now, it is as big as a watermelon. How many months will I still live?)

Doctor: (Did not answer. Talked to someone in the room.)

Patient: (Asked again - until when she is going to live.)

Doctor: "Ah, basta kailangang maoperahan ka. Matagal ka pa." (Ah, you should be operated on. You will still live long.)

In this sample, the patient tried to be direct and straightforward by asking if it is cancer and for how long she will still live but the doctor avoided a head-on encounter with her. He did not categorically confirm that the disease was cancer but again used euphemisms such as "bad mass" and "cousin of cancer". At the end, however, he provided some feelings of hope for the patient.

Each episode lasted for a maximum of 10 minutes.
OPENING THE VERBAL COMMUNICATION TO BREAK BAD NEWS

In reality, there is no "cook-book" approach with regard to informing patients about their diagnosis and prognosis. Initial and subsequent communications depend on a variety of factors as mentioned in the earlier sections. The most difficult portion of the communication process is at the beginning of the verbal interaction.

The following statements provide examples on how to initiate the interaction based on various scenarios.

I. When patient is emotionally stable, active, assertive and intellectually prepared, disclosure can be made directly to the patient.

A. WHEN PROGNOSIS IS GOOD:

*Ito ang mga eksamin na ginawa sa iyo. Batay sa mga resultang ito, kailangang ikaw ay mabigyan ng gamot* (Mention all options for medical care and explain the degree of effectiveness, the expected side effects, cost, safety, rate of survival of each). *Huwag kang mag-alala. Gagawin natin lahat ng paraan. Mabuti at ikaw ay nagpatingin ng maaga.*

B. WHEN PROGNOSIS IS POOR:

*Oo, ang mga resulta ng eksamen na ginawa sa iyo ay nagsasabing ikaw ay may ______ (type of disease). Ikinalulungkot ko pero ang magagawa na lamang natin ay bigyan ka ng _______ (type of treatment). Mabuti na habang maaga ay ihanda mo ang iyong sarili sa ano mang pangyayari.*

II. When patient is emotionally unprepared and psychologically unstable, disclosure is preferably coursed through the relatives. However, when there is a need to be confrontational, the following examples may be used:

A. WHEN PROGNOSIS IS GOOD:

*Ang mga resulta ng eksamin sa iyo ay nagsasabing mayroon kang nabubuonng ______ (type of disease). Mabuti at maaga pa ay napatingnan mo sa akin. Tingnan mo ang _______ (example) X-ray mo. (Explain the x-ray results, biopsy results, etc., by indicating what is actually happening to the body). Huwag kang mag-alala. Mayroon pang paraan sa sakit mo. (Mention all treatment options and explain their effectiveness, safety, side effects, cost). Kailangan lamang na sumunod ka sa gamutang gagawin natin.*
B. WHEN PROGNOSIS IS POOR:

Alam mo, lahat ng tao ay nagkakasakit. Mayroon magaan na sakit, may malala, may pangmatagalan gamutan, mayroon namang panandalian lamang ang gamutan, mayroon din mga sakit na malaki pa ang pag-asang tumagal ang buhay pero, mayroon ding iba na talagang wala ang itatagal. Kadalasan hindi natin mapipili ang sakit na kakapit sa atin.

Iyang sakit mo ay medyo malala na pero bibigyan kita ng _____ (type of treatment). Kailangan lamang na lakasan mo ang loob mo at ihanda mo na rin ang sarili mo sa ano mang mga pangyayari. (Then divert attention to unrelated light topics).