# COMMUNICATING BAD NEWS

BEHAVIOURAL SCIENCE LEARNING MODULES



DIVISION OF MENTAL HEALTH

WORLD HEALTH ORGANIZATION

**GENEVA** 

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### COMMUNICATING BAD NEWS

#### Introduction

These modules are produced as part of a series of such modules for the teaching of behavioural science to medical students. The aim of the modules is primarily to provide behavioural skills to students, and provide knowledge only in so far as it is directly necessary to do this. The skills concern those activities in which a physician interacts with patients or with groups in the community in whom he/she wishes to promote healthy behaviour.

Some skills are more "generic" in nature and apply to a broad range of interventions. These include interviewing skills, listening skills, observational skills and other communication skills. Some skills are more focused but still apply fairly broadly, such as skills in obtaining compliance with treatment or prevention programmes. Finally, certain skills dealt with in these modules are focused on dealing with a very specific problem, such as this one on communicating bad news, together with a second part which is an even more focused module on introducing parents to their abnormal baby.

There are two different modules dealing with communicating bad news. These modules reflect the fact that different approaches to teaching behavioural skills exist. It is up to the medical school to decide which of these two modules fits its teaching philosophy.

This skills teaching approach differs from that taken in many other programmes, since within the modules there is no provision for the teaching of the psychological or social science theories underlying the interventions proposed. However, each module is accompanied by a background paper providing a short summary of theoretical knowledge relevant to the intervention. This places emphasis on presenting the rationales and the empirical evidence for the effectiveness of a proposed intervention. The module itself provides very practical guidelines on how to learn the skill and how to put it into practice.

#### Breaking Bad News (I)

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Few responsibilities demand more of the doctor than that of breaking bad news to patients. It calls for sensitivity, gentleness, honesty and willingness to be available and to be vulnerable. done in the right way, it can facilitate the patient's adjustment to his/her situation by relief of uncertainty, in itself therapeutic¹, and by clarification of what must be faced. It can plant seeds of genuine hope that life is still wroth living and that, however bad the situation, there is always something which can be done; and it can so strengthen the relationship between patient and doctor that it becomes an important source of mutual support during the illness.

## When the news is bad, what information should be disclosed?

The last three decades have seen a significant change in the attitudes of doctors to disclosure of the news of cancer. In 1961, 90% of 219 US physicians surveyed stated that they did not usually disclose the diagnosis of cancer to their patients<sup>2</sup>. A similar survey in the US in 1979 revealed that 98% favoured telling patients the diagnosis and that all would want to be told if

they had cancer themselves3. However, one study of a group of oncologists showed that stated attitudes and actual behaviour towards patients did not always tally4. There is also evidence that although doctors may think that they have broken the news, the message may not have been received or,a t least, retained by the The truth may bbbe marked by patient<sup>5</sup>. euphemisms or language may be too technical for the patient to understand. Again, a single communication may be insufficient for a listener distracted by pain or anxiety to take in7. A recent study of a group of dying patients who were aware of their condition revealed that only 13% had received the news from their doctor8. Thus, there is reason to believe that doctors may not be communicating as much to patients as the literature suggests or as they imagine themselves

#### Disclosure models

The literature reveals basically three models, each reflecting different doctor-patient relationship and, accordingly, a different style of management decision making (see Table 1).

Table 1: Comparison Between Models (Relationships and decision making)

Model	Doctor- patient relationship	Management decision making style	Doctor- patient communicati on
Non-disclose	Paternalistic	Physician only	Poor
Full disclosure	Paternalistic	Patient only	Fair
Individual disclosure	Partnership	Joint	Good

#### Model 1: Non-disclosure

This was the traditional model particularly used in the case of cancer, presumably because of the fear and anxiety which that disease uniquely generates<sup>1</sup>. News of the diagnosis was usually given to a responsible relative who colluded with the doctor to keep the news from the patient<sup>9,10</sup>. Underlying this model are three assumptions:

Assumption 1 This it is appropriate for the doctor to decide "what is best" for the patient without reference to him/her.

It is argued that the doctor, as the expert, is best placed to decide what is in the patient best While the doctor's capacity to interests. determine treatment modalities most likely to be effective is not in question, the competent patient has a fundamental right firstly, to information about him/herself and, secondly, to make choices about his/her own management based on accurate information from the doctor about probabilities<sup>11</sup>. While this does not exclude a patient's right to delegate the responsibility for such decision making to somemone else, particularly the doctor, as many still do6, there is evidence that doctors re poor predictors of patients' wants<sup>12</sup>. Only the patient knows "whether the game is worth the candle" when it comes to decision about management 13. Moreover, as evidenced by the growth of the consumer movement, patient attitudes are changing14, and it has been pointed out that, unless the profession is prepared to change its practice accordingly, governments will almost certainly legislate to compel such a change<sup>15</sup>.

In summary, the weight of evidence is that the doctor, however expert medically and however well-intentioned, should not in these days *unilaterally* decide what is best for the patient.

Assumption 2 That patients do not want to know bad news about themselves.

In Table 2 the results of nine studies of the attitude of patients to receiving bad news are summarized 16-24. Most suggest that most patients do want to know bad news about themselves, whether it be diagnosis of cancer 18-21, diagnosis of terminal illness 22-23 or full information about cancer 14. In fact, other studies reviewed by Ley 6 indicate that most people want to know as much as possible about their illnesses including cause, treatment and prognosis and that usually, they want to know more than their physicians are prepared to tell 5-25-26. This is supported by evidence that 85% of malpractice litigation in the USA is based on the physician's alleged failure to sufficiently inform the patient 15.

Assumption 3 That patients need to be protected from bad news.

It has been suggested that undesirable emotional reactions with long term harmful consequences re likely to follow the giving of bad news<sup>5</sup>. Again, evidence from the literature does not support this<sup>20,27-30</sup> (see Table 2). While disclosure will have short term negative emotional impact, especially if made abruptly<sup>31</sup>, in the long term most patients adjust well<sup>25</sup>. Several studies have demonstrated that uncertainty is a major cause of emotional distress in cancer patients<sup>1,2,31</sup>. Even though the news was bad, disclosing it to this group resulted in better overall adjustment and less anxiety<sup>20,27</sup>.

Table 2: Effects of giving patients bad news (adapted from Ley, 1982, p.353)

Investigators	News	Effects
Gerle et al. 1986	Diagnosis of incurable cancer	Those told adjusted better than those who were not
Gilbertsen & Wangesteen, 1962	Diagnosis of cancer	Gratitude and peace of mind
Cassem & Stewart, 1970	Prognosis in dying patients	Positive attitudes and lack of negative effects
Molleman et al, 1984	Diagnosis of cancer	Reduction of uncertainty and anxiety
Still and Todd, 1986	Diagnosis and prognosis in terminally ill	No increase in state or trait anxiety compared with controls

In summary, the evidence from the literature is that patients do not need to be protected from bad news and many arrive at the conclusion that they have cancer whether they are given the news or not. Their sources of information include the media<sup>32</sup>, the implications of the particular diagnostic work-up and treatment they are given, the fact that they are not told any diagnosis, the demeanour of their care-givers, the progress of patients with similar symptoms and information from other patients<sup>25</sup>.

#### Conclusion

The non-disclosure model is untenable in these days of increasing consumer pressure for information, besides being a violation of the right of human beings for information about themselves. While it may have temporary value int he small group of patients using denial as an important coping strategy, it functions by encouraging the kind of hope which in the end proves false. Further, it denies patients and their relatives opportunity to work through their grief and to resolve issues related to their loss together<sup>33</sup>; it dehumanizes patients, denying them the opportunity to come to terms with their situation and face death with courage and it undermines the doctor-patient relationship since honest communication and mutual trust and impossible; it precludes patient participation in their own treatment with the therapeutic advantage that that is known to confer1; it creates barriers within the family unit and so obstructs vital mutual support<sup>34</sup>; it leads to information gathering from uninformed sources and the likelihood of non-compliance with treatment; it leads to avoidance of the patient by health staff and thus to development of an increasing sense of having been rejected. For these reasons, this model is not recommended.

#### Model 2: Full disclosure

This model involves giving full information to every patient as soon as it is known. It is argued that it promotes doctor-patient trust and communication and facilitates mutual support within the family unit. It is based on three assumptions.

Assumption 1: That the patient has a right to full information about him/herself and that therefore the doctor has an obligation to give it.

While the principle of the patient's right to full information about his/herself cannot be denied, it may also be argued that the patient has a right to decide not to receive that information, in part or in whole. Some patients prefer to exercise their freedom of choice at the level of selecting a physician in whom they have confidence and giving that person a mandate to choose what is best for them<sup>35</sup>. It may also be argued that the patient has a right to determine the timing of the receipt of information. Some appear to need to use denial for varying periods and will signal their readiness to hear information when they can handle it. the full disclosure model does not allow for these individual choices.

Table 3: Do patients want to know bad news? (adapted from Ley, 1982, p.353)

Investigators	Information	Preference
Kelly & Friesen, 1984	Diagnosis of cancer	89% approved of being told
Aitken-Swan & Easson, 1959	Diagnosis of cancer	66% approved of being told
Gilbertsen & Wangensteen, 1962	Diagnosis of cancer	87% of incurable and 93% of curable approved of being told
Alfidi, 1975	Diagnosis of cancer	Many did not want to know
McIntosh, 1976	Incurability in undisclosed cancer	68% of those who suspected it did not want diagnosis confirmed
Veatch, 1978 (review of nine studies)	Terminal illness	60-98% approved of being told
Hinton, 1980	Terminal illness	Over 75% preferred to know
Henriques et al., 1980	Diagnosis of cancer	76% definitely or probably approved
Reynolds et al., 1981	Diagnosis, treatment and prognosis of cancer	91% wanted full information about diagnosis; 97% about treatment; 88% about prognosis

Assumption 2: That all patients want to know bad news about themselves

Reference to table 3 will show that while most people want the truth and are better off for knowing it<sup>1</sup>, there is evidence that a small but significant group do not want to be given the truth<sup>16,17</sup>. This model makes no provision for such people and denies them freedom of choice<sup>12</sup>. Clearly this assumption is not tenable.

Assumption 3: That it is appropriate for patients to determine what treatment is best for them since they have to live with the consequences and therefore must have full information.

While it is true that unilateral doctor decision making falls down because of inadequate knowledge of the patient's whole life situation, it is equally true that unilateral patient decision making falls down because of their inadequate medical expertise. For the doctor, a laissez faire attitude towards patient autonomy must stop short of taking no action to prevent acts which are self-destructive or against the interests of the community. To fail to act in such a situation is to behave unethically in terms of the doctorpatient contract<sup>36</sup>.

In summary, while it may be argued that only the patient has the right ultimately to make decisions affecting his/her own body, it seems highly desirable that such decisions be made in the light of the best available medical advice.

#### Conclusion

The full disclosure model is a paternalistic model taking no account of the patient desires about the timing and amount of information disclosed. While most patients may want to hear broad outlines of their diagnosis, treatment and

prognosis, a significant number do not want detailed disclosure. To discuss options at length with a patient who is already frightened and confused and not ready to hear them is neither kind nor helpful. For these reasons, it is a model which is not recommended.

#### Model 3: Individualized disclosure

In this model, the amount of information disclosed and the rate of its disclosure are tailored to the desires of the individual patient by doctor-patient negotiation. Together they will clarify what information the patient wants and then it will become the doctor's task to impart it in a way which the patient understands. This will be an on-going and developing process. It implies a level of mutual trust and communication which will take time and work to develop<sup>13</sup>. Management decision making will usually involve both parties, using the doctor's medical expertise and the patient's knowledge of his/her own needs and values. The precise model will be somewhere on a spectrum between somewhat somewhat paternalistic and autonomous depending on the patient's choice. The model is based on three assumptions.

Assumption 1: That people are different in the amount of information they want and in their methods of coping

Evidence supporting the first part of this statement has already been mentioned in the earlier sections (e.g. see Table 3). In a recent study of methods used, to deal with uncertainty and anxiety by cancer patients, it was found that a range of coping methods was used including problem solving, information getting and avoidance or denial. It was concluded that the approach to each patient needed to suit his/her coping method<sup>25</sup>.

Assumption 2: That, for most people, time is needed to absorb and adjust to bad news and therefore disclosure should be a process over time

Parkes (1974), on the basis of his clinical experience as a psychiatrist at St Christopher's Hospice in London, believes that there are dangers in breaking bad news too abruptly. Uncontrollable anxiety or depression can be precipitated, together with panicky attempts to escape from an intolerable situation. These can lead to refusal of further contact with the physician and turning to alternative therapy. Lasting depression and disorganization of personality can result<sup>31</sup>. Others experienced in relating to cancer patients also underline the importance of disclosure being perceived as a

process taking place over time, with the physician constantly monitoring the patient's desire for and capacity to absorb new information, as well as checking the degree to which earlier messages have been received<sup>7,37</sup>.

Another important factor in the concept of disclosure as a process over time is that patients may take time to develop sufficient confidence in the relationship with their physician to feel free to ask questions. One study of patients who had had mastectomy for cancer found that 86% had questions about their treatment which they had not asked38. A study of 501 primary care physicians and 1100 patients found that only 2-4% of patients asked questions of the physician about the medicines they were prescribed. The doctors thought that the patients were satisfied because they did not ask questions but in fact this was not so38. In his extensive review of literature, McIntosh (1974) identifies nine reasons why patients do not ask questions of their physicians, including their perception of them as too busy and too remote and their desire not to be nuisances25. Also contributing is the effect of the patient role. Being a patient, and particularly being in hospital, results in loss of control over virtually every area in which the individual normally functions. This amounts to depersonalization, and to this loss of control people generally react by assuming either the good patient or the bad patient role. Most people assume the good patient role and become compliant, uncomplaining, undemanding, passive and willing to submit to all manner of indignities. They are helpless and anxious, wanting information, but at the same time not asking questions lest they upset the staff39.

Clearly, it will take time for the average patient to gain sufficient confidence to overcome his/her disinclination to ask questions even though they may be questions upon the answers to which the patient's life may hang.

In summary there is good evidence from the literature that adequate disclosure takes time.

Assumption 3: That a partnership relationship between doctor and patient as basis for decision making and abased on mutual confidence, trust and respect is in the patient's best interests

Such a partnership will be based on joint acknowledgement of the truth about the patient's situation. The physician needs help from the patient in order to give effective help in return<sup>40</sup>. In particular, there needs to be mutual understanding of the amount of information desired and the rate at which it is to be given.

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	ŊĊ	Non-disclosure	Full disclosure	Individualized disclosure
Underlying assumptions	3. 2. 1.	Appropriate for doctor to decide what is best for patient Patients do not want to hear bad news about themselves Patients need to be protected from bad news	<ol> <li>Patient has right to full information about self and doctor has obligation to give it</li> <li>All patients want to know bad news about themselves</li> <li>Patients should decide what treatment is best for them</li> </ol>	<ol> <li>People are different</li> <li>It takes time to absorb and adjust to bad news</li> <li>Partnership relationship as basis for decision making is in patient's best interests</li> </ol>
Disadvantages	다 다 다 다 다 오 오 오 오 오 오 오 오 오 오 오 오 오 오 오	Opportunity to adjust denied Trust in doctor undermined Opportunities for helpful interventions lost Patient compliance less likely Barriers between partners May acquire wrong information Leads to avoidance, isolation and perception of rejection Patient sese of control lost	<ol> <li>Discussion of options in detail frighten and confuse some</li> <li>Insisting on informing may undermine defences e.g. denial</li> <li>Full information may have negative emotional consequences for some</li> </ol>	It is a very time consuming process     It drains caregivers' emotional resources
Advantages	7 7	Easier and less time consuming for doctor Suits those people who prefer not to know their condition	<ol> <li>Promotes doctor-patient trust</li> <li>Promotes family support and allows time to put affairs in order</li> <li>Helps those who cope by finding out maximum information</li> </ol>	Amount of information given and rate of disclosure tailored to needs of the individual     Supportive relationship with doctor is developed
Summing up	7 7	Assumptions cannot be supported from literature Negative impact on lives of most patients	<ol> <li>Assumptions are no valid for a significant group</li> <li>Could be harmful to some especially if done abruptly</li> <li>Ethical problems in medicine</li> </ol>	1. Appears to be the ideal model

Crucial is the patient's awareness of the doctor's confidence in his/her capacity to bear with courage the painful reality of the situation and of the doctor's commitment to help him/her enjoy the rest of his/her life. It is suggested that a relationship of this kind will provide the atmosphere in which the patient will have courage to ask questions freely<sup>34,42</sup>. It has been shown that the doctor who supplies information, gives attention and shows understanding has a positive influence on the patient's coping process<sup>27</sup>. This model requires that the doctor abandon unilateral decision making, exchanging if for the more time consuming process of exploring alternatives with the patient in an atmosphere of mutual trust<sup>43</sup>.

#### Conclusion

While individualized disclosure model does take time and skills which the busy physician may feel that he/she does not have, it is the model of choice because its underlying assumptions can be supported from the literature. Further, it is appropriate in these days of consumerism and emphasis on consensus and it has the capacity to maximize quality of life for the patient.

## When the News is Bad, What Information Should be Disclosed and How Should it be Done?

The individualized disclosure model is recommended (see Table 4). This means that the amount and rate of disclosure will be determined by negotiation based on a relationships of mutual trust and confidence between doctor and patient.

The key questions to be addressed by the doctor are "How much information does this patient want?" and "How should I break the news?".

## How much information does the patient want?

The way to discover this is to ask the patient, and to do so in an atmosphere which encourages an honest answer i.e. within the context of a non-threatening partnership relationship.

When the patient first presents to the general practitioner, it is wise to raise the question of a serious diagnosis. A patient with a breast lump or who has coughed or passed blood has, in these days, almost always thought about cancer, and it is sensible to acknowledge this as a possibility at the outset, while at the

same time giving a perspective on other possible causes. At this stage, the doctor can begin dialogue with the patient about his/her life situation and the meaning that a diagnosis of cancer would have for the family unit. At the same time a cancer education programme aimed at dealing with any frightening misconceptions about cancer which the patient may have can be introduced in a low key way. At some point, the patient should be asked how much information he/she would want to be given in the event of the diagnosis being cancer. By honest sharing and evaluation of probabilities in these ways, a relationship of mutual confidence and trust can be initiated. This will provide a foundation on which to build later.

At the time of positive diagnosis, the patient should again be asked what he/she wishes to be told and his/her wishes in the matter should be respected. For example, there may be a desire to hear the diagnosis but nothing more - at least at that time. Where a patient chooses not to be informed or delegates to another the responsibility of treatment decision making, the legal position with regard to the requirement of informed consent needs to be considered.

Informed consent is that which is obtained after a patient has been given sufficient explanation about a treatment or procedure to understand its possible risks and benefits. In contrast to North America (see Section on Patients' Rights), it is a notion which has not been discussed very much. However, as Mr Justice Michael Kirby interprets it, behind it is the patient's right of self-determination. If a patient does not wish to be informed and makes this quite clear, a doctor need not force information upon him. A doctor may also modify the extent of the disclosure to avoid causing the patient "unnecessary anxiety, apprehension or distress". In North America the concept of "therapeutic privilege" covers the situation where informing a patient is judged likely to cause him/her physical or mental harm<sup>44</sup>.

#### How should I break the news?

What is the doctor's role?

The doctor should be:

- 1. available
  - as a source of honest and clear information to the patient
  - as a person prepared to give whatever time is necessary to inform the patient to whatever extent he/she wants to be informed

- as a source of continuing support and encouragement as long as is needed, letting it be known that grief, anger and despair are normal and can be safely expressed in his/her presence
- as a person who will listen, encourage questions and encourage legitimate hope that a full valuable life can still be lived
- as a person prepared to spend time exploring alternatives with the patient in an atmosphere of security and mutual trust
- as a person prepared to see the patient through, even when cure is not likely

#### 2. vulnerable, i.e.

- prepared to receive the patient's anger, pain and grief, which may be echoed in his/her own life
- prepared to have his/her professional competence challenged
- prepared not to have all the answers.

Parkes (1974) summed up the role of the physician as "to help people to live until they die by creating a situation in which fear of dying doesn't spoil joy at living" (p190:29).

#### When should it be done?

As soon as the diagnosis is certain, the news should be given to the patient. Waiting at this stage can be very distressing<sup>35</sup>.

#### Where should it be done?

In a place that is quiet and private. It should not be done at the patient's bedside in the presence of other patients.

#### Who should be present?

The patient has the fundamental right to control access to information about him/herself and therefore should be told first. Whether or not the partner and/or others are present is for the patient to choose. If the partner is not present, it is highly desirable that he/she be informed and involved as soon as possible. The purpose of this is partly so that patient and partner can support one another from the time of diagnosis onwards. The other advantage is that the partner may well recall or understand information which the patient misses.

#### How should the patient be told?

#### 1. Aim

- to break the initial news gently, honestly and with sensitivity
- to avoid technical jargon or euphemisms which would obscure the truth
- to give as much further information as the patient wants
- to implant genuine hope
- to convey to the patient that you have plenty of time for discussion and/or simply to be available

#### 2. Method

- This depends on the patient. Some will immediately ask whether the diagnosis is cancer. Others will come around to the question more slowly. Others will need to be drawn out. A useful way of doing this is to go over the sequence of events which have preceded this interview and then ask the patient what he/she would like to know. The more the possibility of cancer and its implications for the patient have been discussed earlier, the more readily the issue can be faced. While there is no way of escaping the realities of the information, "Yes, I'm afraid it is cancer", to convey at the same time that you really care will help
- Allow the patient to express his/her feelings freely, making it clear that it is all right to do so. Don't try to stop the flow of emotion or to provide pat answers. Where appropriate, an arm around the shoulder or a hand on an arm will speak much more effectively
- Give as much or as little further information as the patient asks for. Don't try to give a precise prognosis. They are almost always wrong and this can be very distressing<sup>41</sup>. Speak honestly in terms of the range of possibilities
- Begin to instil hope as soon as possible
  i.e. that a full and valuable remaining
  life is possible and that you will do all
  you can for as long as you are needed
  to help make this possible.
- Do not allow the patient to go without making arrangements to see him/her again soon and without giving him/her your telephone number and permission to contact you at any time with questions

#### 3. What further can be done?

It is important for the patient emotional well-being that this be seen as the beginning of a partnership characterized by continuing dialogue, mutual confidence, trust and respect. Begin as early as possible to encourage the patient to talk about the meaning of the illness for the whole of his/her life and that of the family. Remember that the quality of the patient's life has not only physical but emotional, social and spiritual dimensions. All of these need to be patiently worked through as part of the disclosure process.

Referral to others able to offer help in particular areas may be needed but the primary physician will remain the anchor person. All this takes time and it take work. However, the physician who perseveres in such a partnership will find him/herself in a very privileged position, being not only able to offer support to a person in great need but also to learn a great deal from the patient.

## Patients' Rights - The Legal Position

Whereas in North America doctors are bound by law to disclose all information which might conceivably affect a patient's decision making except in the case of therapeutic privilege mentioned earlier44, in Australia the law is much less well developed in the area of patients' rights  $^{15}$ . Australian law courts, moreover, tend to follow the English model in interpretation of existing law. That is, they use the principle that the test of what ought to be explained to a patient is wether or not most doctors int eh same field would have explained it<sup>45</sup>. However, it is likely that this will change as community awareness of rights grows and as the means to exercise those rights become more fully developed. In the Departments of Health in Victoria and NSW Complaints units have been set up. The NSW Complaints unit reports that it is handling an increasing number of complaints<sup>45</sup>. At the same time consumer group involvement in health policy decision making is being encouraged by the Federal government<sup>44</sup>.

The NSW Health Department Complaints unit has developed a statement of Rights and Responsibilities of Consumers of Health Services which it proposes should become the framework upon which a future amendment of the Medical Practitioners Act be based.

## Taken from *Consuming Interest*, 1986, 29:4-7.

## Summary of rights and responsibilities\*

The following is a list of the rights and responsibilities of consumer of health services:

#### Right to "informed consent"

The consumer of health services has the right to have a doctor or other health professional explain in terms the consumer understands:

- (i) The condition, problem or disease
- (ii) The treatment or procedure to be followed, including details of alternative procedures, and all the risks or side-effects involved
- (iii) The costs of any procedure proposed, including any further costs associated with rehabilitation
- (iv) The health care system, including details of support services

#### Other rights

The consumer of health care services also has the right to:

- (i) Withdraw consent at any time
- (ii) Refuse experimental or research treatment
- (iii) Obtain a second opinion
- (iv) Have details of a condition and treatment kept confidential by medical and hospital staff
- (v) Leave a hospital at any time (except in the cases of infectious diseases or certain psychiatric conditions). If the patient leaves without hospital consent the patient is liable for any injury or illness caused or aggravated by their action
- (vi) Be treated with care, consideration and dignity
- (vii) Request medical files from the doctor
- (viii) Obtain legal advice regarding any matter arising from the treatment
- (ix) Contact friends, relatives, solicitors, members of the clergy or ward if he or she is the parent or guardian
- (x) Ask to stay with a child at all times except where separation is necessary for medical reasons
- (xi) Inform nursing staff if he or she does not want to see, or speak to. a visitor or caller

#### Responsibilities

Consumers of health care services have a responsibility to:

- (i) Know their own medical history including medications taken
- (ii) Keep appointments or advise those concerned if they are unable to do so
- (iii) Comply with the treatment supplied
- (iv) Inform the doctor if they are receiving treatment from another health professional
- (v) Know what their private insurance will cover because private patients are responsible for doctors' and hospital charges
- (vi) conduct themselves in a manner which will not interfere with the well-being or rights of other patients or staff
- prepared by the NSW Department of Health Complaints Unit

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Those with a (\*) are especially recommended for reading.

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#### COMMUNICATING BAD NEWS TO PATIENTS (II)

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#### Summary

This article reviews the literature on doctor/patient communication, emphasizing the communication of bad news. Available information supports the view that patients want more information than they generally receive and that, contrary to popular belief, patients who are better informed benefit from the information they receive. Physicians are seen as taking a less professional approach to communication activities than to clinical problem solving. Some strategies for approaching the problems identified are outlined.

No physician likes to detect the presence of potentially lethal disease. Such a discovery brings with it the unpleasant reminder of human vulnerability and the equally unpleasant question as to what to do with the newly found information. The question extends far beyond simply "telling" or "not telling" to how much to tell, when, and to whom. "How will the patient react?" "Can he handle this information?" "Who is the best person to tell first - the patient or a relative?" "Am I certain enough of my findings and my interpretation to tell now?" are just a few of the questions and uncertainties that arise under such circumstances. Notwithstanding the unpleasantness or difficulties of these situations, the discovery of serious disease is a fact of clinical life, a fact with which every practicing clinician will be repeatedly confronted.

Given that the communication of bad news is an integral part of medical practice, how does the student or practicing physician acquire the requisite knowledge to manage these situations? A search of the literature in the area is discouraging; little seems to be known about the actual process of giving bad news. There is, however, much more information concerning the needs and wants of patients and the effect that receiving bad news has on them. Little of this information seems to have been incorporated into the clinical practice of medicine; the debates that rage are not over **how** to give bad news but whether it is appropriate to do so at all.

#### Three Positions

There are at least three distinct positions on what information to convey to patients who have a serious illness. The first position is that patients should always be given full information regardless of their individual perceptions or needs.1 Another view states exactly the opposite; that under no circumstances should patients be informed that they have acquired a lethal disease, and that falsehood and deception should be used if necessary, on the basis that the patient needs protection from the terrible reality of terminal illness.<sup>2</sup> A third view suggests a more flexible approach, with a variety of psychological and sociological factors to be taken into consideration, but without guidelines as to how this might be done.3 As Waitzkin and Stoeckle4 point out, however, all three positions share one thing in common: they all lack any supporting objective evidence, seeming to be based on the authors' ethical positions and evaluative judgments.

Surveys of practising physicians reveal that this debate is not carried out at a solely academic level, but is reflected in clinical practice as well. Two surveys, 2,5 similar in nature but carried out at different times and in different venues, reveal some very interesting material. Whereas in 1961 the majority of surveyed physicians indicated a preference for not telling patients they had cancer, in 1977 a preponderance of those surveyed indicated a preference for exactly the opposite. What is most interesting and revealing is that the basis on which these judgments were made was the same in both situations, and related more to the physicians' personal preferences and beliefs than to objective scientific evidence. The data base used in communication skills is apparently not subjected to the same academic scrutiny and other clinical skills.

Why the difference? Why would clinicians who pride themselves on their meticulous scientific approach to clinical problem-solving abandon these principles when dealing with the communication of bad news? If there are no firm data to explain this phenomenon, there is certainly no lack of speculation on the matter. It has been suggested that physicians avoid discussing serious illness

with their patients because they have a subconscious fear of illness and death. it is further speculated that it is this characteristic which predetermines their entry into medical school, ostensibly to provide themselves with additional control over these factors. It has also been suggested that another major reason for withholding information from patients is to maintain additional control over their behaviour, since patients are much more dependent on their physicians when they do not have sufficient information to make their own decisions.

The temptations to scoff at such explanations, and to disregard the whole area as being unimportant and unworthy of further scrutiny is great. But the fact remains that poor communication is the most frequent source of patients' dissatisfaction with physicians, and therefore cannot be too lightly dismissed. 4.8

#### Acquiring communication skills

Perhaps the question has not been posed appropriately. Rather than ask why they do not perform well, might it not be better to ask why it would be expected that physicians should perform well under such difficult circumstances? It seems to be assumed that physicians will automatically be able to cope with the unpleasant situations they will meet. Fantasies of medical students are more likely to centre around doing great deeds with the knowledge they have acquired, than uncovering problems that cannot be pleasantly or amicably resolved. Furthermore, topics such as the communication of bad news do not usually appear in the formal curriculum of the undergraduate or postgraduate student.

In the absence of formal training it is likely that whatever communication skills physicians have acquired by the time they enter practice have either been self taught or patterned on those of their clinical teachers. Opportunities to observe instructors communicating bad news are rare. Further more, it is likely that these teachers learned their skills in the same way one generation earlier. Considering the issues in this perspective it may not seem quite so unreasonable that patients do not see their physicians as possessing adequate communication skills.

Without formal training or an awareness of the scientific information that exists in the area, there is little else left to do than improvise and develop strategies based on personal social experiences acquired before becoming a professional. Comoroff makes some important observations on the manner in which physicians approach communication with patients and how it differs from their approach to clinical problem

solving. The latter is much more likely to be managed through the use of rational strategies that depend on the conscious mobilization of scientific knowledge than the former. Professional communications are often managed in the same way as social communications, using rules of thumb that were developed prior to professional training and without reference to scientific information.

A physician's behaviour is likely to reflect his training. If there has been no training, the individual must improvise and use his own ingenuity or fall back on skills already developed. Without formal training in communication of bad news many physicians apparently adopt their previously developed ritualized social responses.<sup>10</sup>

#### Doing "The Right Thing"

Physicians want to do the right thing for their patients. The problem is that the right thing is not always easy to determine and there is always the frightening possibility of doing harm. These issues are basic in the communication of bad news and the uncertainty generated by them is often the major determinant in the development of clinical strategies. While uncertainty cannot be totally eliminated from any clinical situation, a review of the literature on the needs, wants and responses of patients being told they have serious disease is reassuring. It strongly suggests that there is room for a considerable margin of error and that it is difficult to cause any lasting damage. Given sufficient time, almost anyone, it seems can mobilize their coping mechanisms to deal with even blunt or sudden disclosure of painful information.11, 12

Further more, patients do want to know what is wrong with them and are dissatisfied with the level of information they generally receive. The state of information they generally receive. However, they have difficulty in initiating requests for information (those in the lower socioeconomic groups have greater difficulty than others). Considering this information, a patient's failure to ask - often interpreted as an unwillingness to know - may instead indicate a reluctance to initiate the process. Differentiation between these two states may only be made by providing an opportunity and a milieu for the patient to ask.

Cassileth<sup>15</sup> et al. found that not only did patients want to know their diagnosis, but most of them wanted to continue to be informed, and further, to participate in the decision-making about their ongoing care. Contrary to what many would expect, this group of investigators found that those who were best informed and most involved were more hopeful than those

who were not. While it is not possible to say from this that disclosure of information always promotes hopefulness, it is reassuring to know that it does not exclude or diminish it.

In actuality, the question for physicians is not whether to tell the patient, but rather how to have the patient find out. It seems that when patients are not informed directly about their disease, they are able to acquire the information in other ways. Often the observation and interpretation of non-verbal behaviour by the health professionals caring for them, gives many cancer patients the cues from which they will deduce their problem.<sup>16</sup> But it is obvious that patients have many other ways of acquiring information and can be very proficient in this activity. In an interesting comparative study between cardiac and cancer patients Hackett and Weissman<sup>17</sup> found that cancer patients knew more about their disease than the cardiac patients, even though they had been told less.

#### No news is bad news

Problems do arise, however, when patients are left to their own designs to acquire information. The interpretation of such things as non-verbal behaviour and nuances of language is open to considerable error unless some means of validation is available. Many people misinterpret unclear information in such a way as to make it worse than it really is. In a study aptly titled "No News is Bad News", Reynolds18 describes the anxiety and fear generated in patients when they were given insufficient information, and makes a plea for better doctor patient communication. She cites a situation in which a patient who was told to expect the worst before her surgery thought the message was that she would not survive the procedure, rather than the intended message that her lesion was probably malignant. Evidently failure to communicate information clearly under such circumstances can produce its own set of unwanted problems.

On the other hand, many physicians express a concern about how patients will cope with bad news and how they will cope with the patient if things do not go well. No one wants to cause unnecessary discomfort by revealing too much at one time - more than the patient wants to hear or can manage. While the concern is understandable, and in may ways laudable, it does not seem to be founded on fact. Oken<sup>2</sup> points out in his study that while many stories circulated about the disastrous results of informing patients about their diagnoses, they were all hearsay and could not be documented by those relating them. It also seems that

receiving information in a very blunt fashion is not a major problem for most patients, because they are quite able to cope with it in one way or another.<sup>11</sup>

The weight of available evidence then seems to support a position that disclosure of bad news is not harmful to patients, with some evidence suggesting that failure to communicate clearly may be. However it does not seem sensible to recommend a course of action simply because it may not cause harm. Is there any evidence available to suggest that such a policy may be of benefit?

## What happens when patients are better informed?

It has been demonstrated that patients with cancer have difficulty with relationships and that some of this at least is caused by the ambivalent feelings and behaviour to which they are subjected in their relationships.<sup>10</sup> It has also been shown that better informed patients cope better with their disease, are more compliant to treatment, less anxious and generally more functional.<sup>15</sup> On the basis of the available evidence, open communication appears to be of great benefit, giving the patient an avenue for information and support.

Two studies deal with the effects of giving preoperative patients information on their possible postoperative course; while the studies do not address themselves directly to the issue of giving bad news, their findings seem relevant enough to be taken into consideration. Thus Egbert et al<sup>19</sup> found that when patients were instructed preoperatively about what to expect in the postoperative period, they were both more comfortable and required less analgesia in this period than a comparable group of patients who were not so instructed. In a more elaborate study, Janis<sup>20</sup> found that providing information preoperatively to patients who had either low or moderate anxiety increased their anxiety somewhat in that period but reduced it postoperatively. Even more important, however, patients with low anxiety in the preoperative period who were not instructed had a more stormy postoperative period than would have been expected from their preoperative assessment. Again the weight of the evidence suggests that provision of information is likely to be both psychologically and medically helpful to the patient.

#### Not a simple problem

How does one differentiate between those who want to know and those who do not? How does one approach the problem even if the patient has signalled his willingness to know? It is here that there is the greatest deficiency in research and knowledge: only two references in my entire literature review address themselves to the problems of educating health professionals in this area. Of those, one described a physician's experience in teaching medical students about he delivery of bad news,<sup>21</sup> the other gave some common sense advice on how to approach the problem clinically.<sup>22</sup> Neither provided any scientific evidence for what was offered.

With or without scientific evidence, however, the practicing physician must have an approach for managing those clinical situations in which serious disease is discovered. What can be distilled from the information available to direct the physician who wished to become more effective in this area?

It is clear that he circumstances surrounding the provision of bad news are not nearly as volatile as is generally believed. Patients cope with bad news rather well; setbacks are infrequent, and, as a rule, not serious. Placed in the perspective of the variety of volume of clinical tasks undertaken by physicians, the communication of bad news has to be seen as a comparatively low risk activity. Physicians probably take greater risks, for example, each time they write a prescription.

It is also clear that patients will signal their willingness to be informed and involved if given the opportunity to do so. Armed with basic interviewing skills a physician can use the patient as a regulatory agent who will define the limits about how much information to give and when to give it. Based on the literature cited, there is no doubt that patients have opinions about what they and others should learn about their condition and will share this with anyone if given the opportunity.

Beyond this however, little more has been documented. Nonetheless, a series of strategies based on general experience and conventional wisdom can be used to provide the foundation for an approach to the communication of bad news. The fact that many of these strategies have not been subjected to scientific testing in the classical sense does not make them less useful. Many of the thoughts and maneuvers outlined below have proved to be a useful way to think about and approach communication problems encountered in clinical medicine.

#### **Strategies**

1. Have a plan in mind before starting. The communication of bad news is a difficult activity and cannot be properly executed by relying on the rules of communication utilized in social encounters. Patient will almost certainly be handicapped to some degree during the encounter because of fear, and the introduction of uncertainty into their lives. The patient will likely look to the physician to provide support and guidance to a greater degree than usual. Indeed, a few patients may require very directive advice until they regina their equilibrium.

Emotions are contagious, and intense emotions interfere with clear thinking. In the face of a very upset patient the physician who has not thought through his management plan before introducing the bad news begins to feel the pressure of having to solve problems as well as attend to a distressed patient. Having a set of general rules about how to manage communication of bad news and having a tentative management plan for the specific problem before beginning the process leaves the physician free to deal with what happens in the here and now, rather than having to think about routine matters.

For example, if a breast lump is encountered during examination of a well woman, the patient will very likely be upset as the specter of cancer will be raised in her mind.23, What should she be told? How certain is the diagnosis? What further information will be required? A mammogram? A biopsy? Or a repeat examination after the next period? If this decision is made before beginning the dialogue, the physician will appear much more confident of what is to be done. The management plan can be changed if the patient is not satisfied or if new information comes up - but it will likely be changed less using this approach than if the problem is thought through while the process of informing is underway.

It is, however, probably very important to provide the patient with a management plan of some kind during an encounter in which bad news is broken. Recent evidence<sup>29</sup> suggests that health related problems favour emotion-focussed coping, and that situations assessed as unalterable - or where no action can be taken - also favour this kind of response. On the other hand situations assessed as requiring more information or in which something constructive can be done favour problem-focussed response.

Based on this information, a physician may be able to direct a patient's coping response toward problem-solving activities and away from emotional reactions by identifying and emphasizing those aspects of the problem that lend themselves to action or to information gathering.

2. Give the patient control over the quantity and timing of the information he receives. Even the patient who wants to know everything usually does not want to hear it all at once. A strategy commonly used by experienced physicians is to start the communication with very vague or euphemistic terms and become more specific as the patient asks for more information.<sup>23</sup> Such an exchange may go as follows:

"During my examination I found a thickening (lump, mass) in your rectum that I think requires further attention."

"Oh, is it serious?"

"I don't know yet, but it could be."

"Well what do you think it is?"

"I can't be sure yet, but it feels very much like a tumor."

"A tumor' What kind of tumor?"

"I'll have to arrange some further tests before I can answer that for certain, but it could be a malignant tumor."

"Are you telling me I have cancer?"

"No. But I am telling you you might have cancer."  $\,$ 

This particular conversation took place in the space of a few minutes but it could stop anywhere along the way and be resumed a day or a week later. Some patients don't want to know until the physician is certain of the diagnosis. The essential point is, however, that the patient will respond to the physician's lead and will give the clues as to how the physician should proceed.

Another strategy that can be very useful is to ask the patient how much he wants to know before the investigation is started. If a man has hemoptysis he may indicate his wish to discuss the findings of his bronchoscopy fully or may indicate his willingness to take whatever suggestions are made for treatment without hearing about the specifics of the diagnosis. Knowing the patient's wishes before the investigation starts makes the subsequent course of action much easier to develop.

It is also important to tailor information to each patient's concerns, knowledge and experience, because this reduces the risk of causing unnecessary worry or discomfort. A patient who is told he has a carcinoma of the transverse colon may have more concerns about having a colostomy than having cancer per se. It is only by asking the patient about his specific concerns that this can be determined.

3. Allow the patient time to integrate information. Even in situations where non-fatal illness is being discussed, there is a limit to the amount of information that patients can incorporate at any given time. <sup>26, 27</sup> As the seriousness of the illness becomes greater, so does the potential impact on the patient which in turn will diminish the individual's ability to hear and incorporate new information.

It is a common experience for physicians that having informed a patient of the possibility of a malignant lesion, and having then fully explained the implications of the illness and recommended course of action, to discover the next day that the patient is asking the same questions, often giving the impression that the matter has not been discussed at all.

In the uncomfortable circumstances of telling bad news, there is a tendency to tell it all in the first encounter and "get it over with". Such a strategy is often not only inefficient because repetition will be necessary, but sometimes counter-productive - the patient may selectively hear the negative aspects of the information and retain a gloomier picture than is warranted by the facts.

4. Soften the bad news with good news - or at least hope. It seems difficult if not impossible when confronted with having to tell someone they have cancer that anything good would be conveyed. It is indeed rare, however, even with the most serious illness that there is not something about which to be hopeful. A malignant lesion in the breast is never good news, but it is not as bad as a malignant lesion with axillary lymph node involvement, or if lymph nodes are involved this is not so bad as secondary disease in distant sites. In her classical descriptive study, Kübler-Ross<sup>16</sup> found that patients wanted and were appreciative of any information that provided hope.

Certainly, the more advanced the disease the poorer the prognosis, but no one can be sure which patient will do well in spite of the severity of the disease. Boyd describes a patient with carcinoma of the rectum who survived for 17 years after the lesion was judged to be inoperable.<sup>28</sup> While the patient must be allowed

the awareness of the severity of his illness, he is also entitled to know that there are exceptions to the rule.

For each individual, the distance between being and not being on this earth is infinite. While everyone knows that those who are born must also die, this remains essentially academic until one is confronted directly with one's own mortality. Making the journey from immortality to mortality is painful and takes time. One of the commonly used mechanisms to butter this process is denial.

Denial is an adaptive mechanism sometimes seen by physicians as being universally bad and therefore a maneuver that is not permitted under any circumstances. Admittedly, denial can be pernicious mechanism when it becomes the major adaptive maneuver for coping with the everyday world. But as Kübler-Ross<sup>16</sup> has described and Lazarus<sup>12</sup> points out, denial is an essential and normal adaptive mechanism under certain circumstances. It can buy time and comfort for the patient while he completes his underlying grief work and is thereby better able to confront the realities of the situation. Supporting a patient's denial while he is incorporating bad news may be not only humanitarian, but also constructive.

5. Never tell the patient a falsehood. At first glance this particular recommendation seems to be contradictory to what has already been said, particularly in regard to the comments on denial. But further scrutiny will reveal that this is not so.

Not telling a falsehood must not be equated with unsolicited full disclosure of all the known facts. A question of initiative is raised, as well as the consideration of whose needs are to be served by the information.

Patients need information to make intelligent decisions about their own treatment, but they do not need to know all the details about he course and prognosis of their disease to do so. Patients also need more general information about their illness and how it might affect them, so that they can plan for the future.

Physicians feel a responsibility to provide sufficient information so that the patient will be able to take the responsibility for these decisions. Physicians also frequently express a need to provide more information so that they will not be held accountable if the course of illness is worse than originally predicted. Unfortunately, the only way to be absolutely certain that this does not occur is to predict the worst possible prognosis for all patients, a course of action few physicians would care to follow.

One way to avoid this apparent bind is to differentiate between the prognosis for the

disease in question and for the patient in particular. it can be made clear to the patient that one can only speculate, and not accurately predict, the course of his own illness and that the information being offered is about the natural history of his disease and not him. Within this framework it is possible to respond to even the most pointed questions truthfully and still leave room for hope. If most patients with carcinoma of the rectum have colostomies, not all do. If the prognosis for carcinoma of the stomach is less than five percent survival at five years, there are still some individuals with the disease who are alive at the end of five years.

A more general perspective of this point is encompassed in the story about he difference between optimists and pessimists. A pessimist sees a half glass of water as half empty while the optimist sees it as half full. While half of a glass of water is a finite quantity, there are choices in the way in which it can be described and the choice made by the physician can have a real impact on the patient's morale.

#### No golden rules

Bernard Shaw is supposed to have said that "the only golden rule is that there are no golden rules". This seems particularly relevant to the communication of bad news. Each patient, each physician, and each situation is different and the flexible use of any strategy will be the only appropriate basis on which to approach the problem. The communication of bad news will never be pleasant, but it can be rewarding for the physician who knows that his planning, and his communication skills have made the situation a little less unpleasant for the patient.

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#### **Learning Module**

#### **Communicating Bad News**

#### **Purpose**

This educational programme for medical students has been developed to help in the teaching and learning of interpersonal skills. It deals with the complex problem of communicating bad news.

#### Specific objectives

- To provide a set of principles and guidelines which can be used by the students to formulate their own personal approach to communicating bad news;
- To provide the students with an opportunity to apply this knowledge to specific clinical problems so that they have an opportunity to combine this knowledge, together with their newly acquired skills, with their other biomedical knowledge in order to be able to take a unified clinical approach;
- To provide the students with examples of other physicians using these basic principles, often using a simulated clinical encounter, so that they can have clinical models upon which they can build their own behaviour.

#### The materials

- A written learning module outlining the principles that can be used as guidelines when communicating bad news;
- 2. It is suggested that each medical school (or group of medical schools) develops a set of videotapes if possible, in which they can see a skilled physician communicating bad news to a simulated patient. This should provide a model on which the students can base their own way of doing this.
- A set of articles describing scientific work and various programmes in this field.
- 4. A number of short modules dealing with specific situations in which bad news has to be communicated by the physician.

#### Method of proceeding

- The students should be given time to read the scientific literature made available (one hour);
- The students should see one or two videotaped examples of a physician communicating bad news (15 minutes); alternatively an experienced physician can give a demonstration of this, using a "simulated patient".
- 3. A course tutor should go through this module with the students to ensure that they understand the process.
- The students should be divided up into small groups of say 4 or 5 each. The course tutor should give each group a "scenario" to role play in which a patient has to be told that he/she has some life threatening condition. One student plays the part of the patient, another the physician and the others observe, rate the "performance" and provide feed back to the "physician" according to the adequacy with which they followed the steps set out below. Each student should have an opportunity to play the physician. "Simulated patients" may be used instead of students to play the part of the patient (depending on the number in the group, this should take no more than one hour).

#### Principles of communicating bad news (focussing specifically on communicating with patients themselves)

- 1. Have a plan before starting
- Give the patients control over how much they hear and the timing of what they hear
- 3. Find out what the patients themselves understand about their condition
- Allow the patient time to take in the information

- Give some good news, or at least some hope, as well as the bad news
- Provide the patients with a specific management plan
- 7. Never tell a falsehood to the patient

#### Expansion of the steps above

#### 1. The plan

Physicians should follow some kind of plan when they communicate bad news to patients. The above steps can help the physician to make out such a plan, but in addition it is sensible to take account of the following in doing so:

- What is the minimum amount of information that this patient or his family needs to know to make intelligent decisions about his future
- . What is the most that can be told to the patient at this time, and how much more information and investigation is required before going further
- Is there any good new or positive information that can be given right now to help soften the blow of the bad news and give the patient some hope.

#### 2. How much to tell, and when

Evidence suggests that the great majority of patients want to know when they have a serious illness and those patients who get such information usually do better because of it. However, there are few patients who do not want to hear the bad news and physicians must be sensitive to this. The simplest way to find out what a patient already knows and what a patient wants to know is simply to ask the patient. (Frequently physicians fail to do this, and yet it is easy.)

There is ample evidence both from the literature and from clinical experience that shows that when patients are provided with the opportunity, they will say how much information they want and will also say when they want it. Contrary to widespread belief amongst physicians, there seems to be little or no danger of doing harm to patients by talking to them about a potentially lethal disease that they might have.

## 3. Finding out what the patient thinks

With a patient who has been ill for some time, one can ask the patient to tell the physician what he understands about his own particular illness.

When a physician discovers a new or unexpected illness, he can introduce the subject to the patient by indicating that he has made a discovery. For example "I have discovered an abnormality in your abdomen that should have some further investigation" or "I have found a lump in your abdomen that should be investigated further". The patient may respond to this either by allowing the physician to describe the investigation or by pressing the physician for further information.

This same technique should be used in a similar sort of way on further consultations, since it may well be that a patient who has indicated that he does not wish to hear more on the first occasion, may, when given an opportunity, press for further information at a later time.

Finding out what the patient understands by asking the patient to say what he thinks, will sometimes help the physician to find the right terms to use in talking to the patient. If the patient uses a term such as "cancer", then it becomes easier for the physician to take this up in his own explanations. Allowing a patient to explain what he thinks may also show that the patient has some unfounded fears that can be dispelled.

Often physicians assume that the patient's main concern is that he is going to die, whereas in reality it may be that the concern is about a painful death and not with death itself. This may provide a physician with an excellent opportunity to give reassurance and support to a patient in a situation that otherwise seems to be hopeless.

There are many ways of phrasing questions or statements that help to explore this and students should work these out for themselves. Examples that have been used are "What have you been telling yourself about these symptoms that you have?", "What are you especially worried about when you think about these particular problems?"

## 4. Allow the patient time to take in the information

When a patient has been told that he has a fatal illness, such as cancer, he may not really hear anything of the rest of that session, despite the fact that he may seem to carry on an intelligent, normal conversation. There is a danger that physicians, because they feel uncomfortable about communicating bad news, will, once they have started, want to get it all over with in one session. It is important however that patients are not overloaded with information at this time.

#### 5. Give some good news

It has been an important finding in studies of this question that dying patients have a need for some kind of good news or some kind of hope. Even if we know that 95% of patients with a particular condition will be dead at the end of five years, the fact of the matter is that 5% of the patients will not be dead, and the patient being seen at that moment may be one of those 5%. A patient with a lump in the breast may not have palpable lumps in the axilla and this can offered as good news, even those with lumps in the axilla may have no clinical evidence of more distant spread, and this should be told to the patient. The physician may need to be cautious under these circumstances but nevertheless can say "Based on the information I have today there is no sign of spread ....".

#### 6. Provide a plan for the patient

If the physician cannot provide very specific information about what is going on, he can at least provide specific information about how investigations will proceed and what he intends to do. Patients often describe how grateful they felt when they knew that something was being done and that someone seemed to be in control and seemed to know what to do next.

#### 7. Never tell a falsehood

It takes a very long time to develop a trusting relationship with a patient but it may only take a minute to destroy it. Once a patient has been told a falsehood, it puts into question every bit of information that has been or will be communicated to him. As patients are very dependent on health professionals to interpret complicated medical information, the trust of one's physician becomes a precious possession. This does not mean that patients have to be forced to know everything that is going on, but they should be told as much as they want, and they should be given an opportunity to say how much they want to know. The purpose of this module is to provide the medical student with the skills to allow the patient to say how much they want to know and to provide the student with the skills to enable him to give this information in a sensitive and caring way. A number of modules have been prepared which deal with specific situations in which bad news is communicated to patients and their families, in order that the students may learn the necessary skills in order to do this.

#### Role playing exercise

The course tutor will need to prepare a number of scenarios which can be given to the groups (e.g. a woman, married, age 45, with one daughter of 14, who has had a lump removed from her breast, which on biopsy is seen to be malignant, and who has/has not, palpable axillary nodes). Other life-threatening diagnoses can be chosen for other scenarios, such as multiple sclerosis or Hodgkin's lymphoma. The observers should be asked to check that the "physician" follows all the steps set out above. At the end of each role play, the "patient" and observers tell the "physician" how he did, and the "physician" can say how he feels about his own performance.