

ABC of palliative care

Communication with patients, families, and other professionals

Ann Faulkner

There is increasing awareness of the need for effective communication in health care, particularly with people who face a frightening diagnosis and an uncertain future for themselves or someone close to them.

Recent research suggests that most patients wish to know their diagnosis and the progress of treatment and disease. This may conflict with health professionals' need to protect their patients and retain an optimistic message even when the outlook is very poor.

Effective communication depends not only on the professionals but also on patients and carers. Language may be ambivalent, leading to genuine misunderstandings, and the needs of patients and carers do not always match. This may lead to health professionals feeling as though they are "pig in the middle" as they try to meet the needs of their patient and those of relatives.

When communicating with patients and relatives about incurable and life threatening disease, health professionals should remember to give attention to the environment and the physical comfort of all concerned. Standing in a corridor or a waiting room is unsatisfactory for everyone. Taking a patient or relative to a "quiet room" to discuss painful and difficult issues has the advantage of signalling the importance of the meeting and the fact that the news may be bad. Many patients, however, prefer to be in their own bed space, with the illusion of privacy given by drawn curtains. This is because the bed and surrounding space is the patient's territory, where he or she feels most in control.

Breaking bad news

Bad news cannot be broken gently, but it can be given in a sensitive manner and at the individual's pace. Many patients are well aware of the seriousness of their situation, and this may be their reason for visiting a doctor. A screening question to check a patient's perception of the situation may also show that the need is to confirm bad news rather than break it.

If bad news has to be broken, it should be at the patients' pace so that they can indicate when they wish to stop. Some individuals will not wish to hear the whole diagnosis straight away but may be more concerned with the care that is planned. If news is given too bluntly it may lead to denial.

There is always some level of shock after bad news, so some time should be given before attempting to pick up the pieces by exploring feelings and identifying concerns.

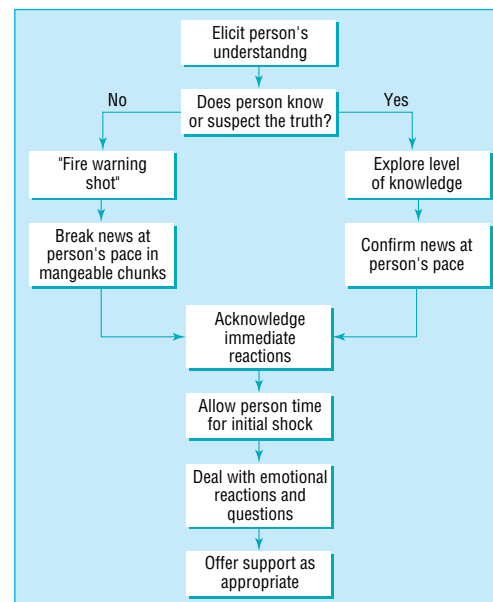
Denial

Denial may be a valid coping mechanism for those who are unable or not yet ready to adapt to the reality of a terminal illness. It can be tested by a checking question, for example: "You say you will beat this illness. Is there any time, if only for a few moments, when you are not so sure?"

This question may be answered in a way that suggests some ambivalence, such as: "Not really. Well, sometimes, if I wake early I start to wonder ... things don't add up ... but later I realise I've been silly. The early hours are a bad time." Very seldom is denial complete, though it may seem so.

Communication problems when dealing with incurable and life threatening disease

- Breaking bad news
- Denial
- Collusion
- Difficult questions
- Emotional reactions



Recommended manner of breaking bad news

Denial

- May be strong coping mechanism
- Relatives may encourage
- May be total (rare)
- May be ambivalent
- Level may change over time

Patients may also indicate a total belief in the possibility of recovery, although this may change as the disease progresses. It is important to monitor changing perceptions and to explore inconsistencies.

Relatives are often happy for a patient to be in denial, for this puts off the day when painful issues have to be faced. They may argue that there is “time enough” to face reality when the patient becomes weaker.

Most patients move towards reality and will give clear indications when they are ready to talk. At this time, relatives may try to block a patient from expressing feelings by colluding to keep the truth from the patient. While acknowledging relatives’ concerns, health professionals must work with the patient. It must be remembered that mentally competent adults have a right to make decisions about their own care, and it is unethical to keep the truth from patients when they are ready to face reality.

Collusion

Collusion is most often seen between professionals and relatives but may also occur between professionals. It is not uncommon for relatives to say, “Please don’t tell him that he has got cancer.” While the reasons behind this question should be explored, it is important to explain that the patient’s needs for an explanation of what is happening must be met.

Collusion is generally an act of love or a need to protect another from pain. Colluders will often argue that they know the patient better than the health professionals do and know “what he can take.” They may further argue that telling the truth would take away hope. Once reality has been accepted, hope can be more meaningful and based on short term, achievable goals.

Negotiation, along with acknowledging the emotional costs of collusion to carers, will generally secure access to the patient to identify his or her level of knowledge and understanding. It is very common to find that the patient is aware and also colluding, or at least suspicious of the truth, but is ready to discuss important issues.

Honest discussion allows patients to be reassured about many points of concern and helps them to be calmer and to plan and readjust hopes and aims. If collusion can be broken this can greatly enhance the quality of a patient’s life and help the patient and relatives to discharge feelings and return to a more open relationship.

Difficult questions

When the reality of bad news is accepted, difficult questions—in that the answers are tenuous or constitute further bad news—may soon follow. Questions such as “How long have I got?” need exploration. A patient may have a particular aim and need to know if it is achievable. Having sought clarification, it may be possible to answer the question in relation to particular goals or aims, but specific estimations of prognosis are best avoided.

Many of these questions are rhetorical and have no clear answers. They do, however, give the questioner the opportunity to explore feelings and can help to offload major concerns. Typically, these questions are centred on a search for meaning to make sense of the current situation and may include spiritual issues and questions on religion—beliefs may be strengthened or shaken by the thought of impending death.



Patients may give mixed messages—reading a holiday brochure does not necessarily mean that the patient is unaware of the prognosis

Dealing with collusion

- Explore reasons for collusion
- Check cost to colluder of keeping secret
- Negotiate access to patient to check their understanding of situation
- Promise not to give unwanted information
- Arrange to talk again and raise possibility of seeing couple together if both are aware of reality



Difficult questions

- Is there a cure?
- Why me?
- How long have I got?
- What happens after this? (end of life)
- Would complementary therapies help?

Dealing with difficult questions

- Check reason for questions—for example, “Why do you ask that now?”
- Show interest in patient’s ideas—for example, “I wonder how it looks to you?”
- Confirm or elaborate—for example, “You are probably right,” or “You are right in thinking that these complementary therapies don’t cure, but they seem to improve some patients’ quality of life”
- Be prepared to admit that you don’t know—for example, “The uncertainty must be hard to take, but I’m afraid we just don’t know at this moment”
- Empathise—for example, “Yes, it must seem unfair”

Emotional reactions

When people accept that they or someone they love will die in the near future, there are often strong emotional reactions, which need to be expressed and diffused.

In dealing with anger, health professionals should establish its cause, whether it is justified, and where it is focused. An individual can be encouraged to locate the true cause of anger rather than be allowed to displace feelings onto professionals. This can result in a healthy discharge of feelings rather than a continuation of unfocused anger. It may be that anger is felt towards a God that has "let me down." If a health professional feels unable to comment on this, a member of the clergy or a spiritual leader may help the patient feel able to express anger with his or her God.

Similarly, with guilt and blame, health professionals may not be able to take away guilt or comment when blame is apportioned, but, by exploring the particular issue with the patient, may help to put things in a more realistic perspective.

There are particular problems for professionals faced with strong emotions from patients or relatives whom they have never met before and may never meet again. This commonly occurs in accident and emergency departments and for house officers and general practitioners called to confirm a death, whether sudden or expected. It is rarely possible in this situation to fully elicit and address the issues, especially with a group of relatives. Acknowledging the emotion and thereby legitimising it, showing concern, and remaining calm will usually diffuse the immediate crisis. Such displays of emotion should not be seen as a personal attack. Others who are likely to see the relatives in the future should be informed.

Health professionals

Effective interaction with patients and carers is unlikely to be achieved in the absence of effective communication between professionals. Much is expected from doctors, nurses, and others as they deal with the problems of communicating with dying patients and their families. In communication workshops the emotional costs of caring are shown to be high, and a large proportion of these costs is related to communication within the team.

Common problems in communication between colleagues include defining roles, boundaries, and differing philosophies of care. Attempting to see problems from a colleague's point of view can enhance relationships within a team and lead to effective peer support. Regular team meetings where problems are discussed and potential solutions explored should lead to improved understanding between staff and a resultant improvement in concerted patient care.

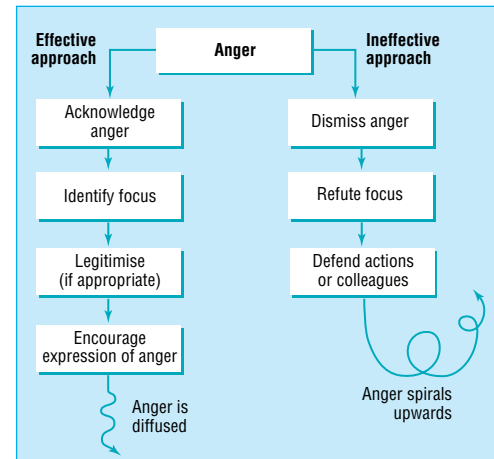
Most areas of medicine involve palliative care, but some choose to work exclusively in this specialty. Such a choice does not necessarily assure knowledge or awareness of the emotional costs of the work. Burnout, which may not necessarily be permanent, can be the cause of conflict in interprofessional communication. In common with other specialties, adequate training, peer support, and continuing education are essential.

Major emotional reactions

Anger—Often misdirected towards health professionals

Guilt—Feelings that the illness is a punishment for past sins

Blame—Belief that current situation is fault of others



Methods of dealing with anger

Costs to professionals of dealing with dying patients and their families

- Identifying patients' concerns brings professional close to patients' pain
- Feelings of helplessness when faced with insoluble problems
- Feelings of failure when patient dies
- Imbalance between work and relaxation
- Risk of emotional burnout

Further reading

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The ABC of palliative care is edited by Marie Fallon, Marie Curie senior lecturer in palliative medicine, Beatson Oncology Centre, Western Infirmary, Glasgow, and Bill O'Neill, science and research adviser, British Medical Association, BMA House, London. It will be published as a book in June 1998.