Reactions to loss

Isobel Bremner

Abstract

Facing potential loss (of health, bodily functions, independence, a future, hope for a cure, control) can be overwhelming for all individuals involved, including healthcare professionals. However, understanding the profound impact of loss and how it can be managed enables those involved to gain a sense of control and hopefulness. Doctors can use their relationship with patient and family to help individuals facing loss to feel heard, understood and less worried about themselves, their family and their future. Isolating specific responses to a complex psychosocial event and conducting research into these is difficult, but many retrospective and prospective analyses and studies of clinical practice highlight the significant issues for those working with individuals managing their reaction to a loss.

Keywords bereavement; children's needs; giving bad news; loss

Giving bad news

Patient and family reactions to bad news

Various models of reaction to bad news have been proposed, including:

- 'five stages of dying' — Kübler-Ross's interviews with over 200 dying people found that they passed through stages of denial, anger, bargaining, depression and acceptance[1]
- 'hive of affect' — Schneidman suggests that individuals experience a constant 'coming and going of feeling', including acceptance and denial[1]
- 'three-stage model' — individuals pass through stages of facing the threat, being ill and acceptance.[2]

Regardless of which model or research is accepted, healthcare professionals must be prepared for several common reactions to bad news (Figure 1). However patients react, it is likely that their experience of being told bad news will be less traumatic if their doctors are thoughtful, prepared and self-aware.[2] It is a mistake to believe that patients can be made to 'feel better', but individuals whose doctors demonstrate their awareness of the profound impact of this conversation will feel understood and valued.[3]

Approaches to the giving of bad news

Research continues to show that healthcare professionals and patients find giving and receiving bad news very stressful.[4] Professionals are reluctant to give detailed and truthful information if the news is not good.[5] Research shows, however, that patients want more information, for example about palliative and end-of-life decisions, than doctors generally provide.[6] Relatively small changes to practice can improve patient's experience.[7]

- Initially, determine what patients already know or believe about their illness. Recipients are more likely to understand, and it leads the patient towards the bad news. The 'forecasting style', which provides consistent information in a staged format, is recommended by many training programmes and supported by research. However it was only used in 45% of 'bad news interactions' in research.[8]
- Give patients a warning shot that they are about to receive significant information, so they can choose to prepare themselves. Evidence suggests that preparation improves the likelihood of 'making a smooth transition', and the use of forewarning words such as 'unfortunately' helps patients to assess whether they want more information. Research suggests that it is important to convey bad news clearly, consistently without ambiguity and without switching topics or the recipient will become confused, anxious and distressed.[8]
- Allow patients to have someone with them, if they wish. Research suggests that about two-thirds of individuals would want a loved one with them when being told about a terminal diagnosis.[9]
- Be aware of patients' non-verbal communication, the speed at which they speak, their tone of voice and the emotions they exhibit (sadness, irritability, anxiety, resignation), and make use of this information to assess how they are and to respond with a sensitivity that reflects their emotional and physical state. Patients are then more likely to regard the healthcare professional as an ally.

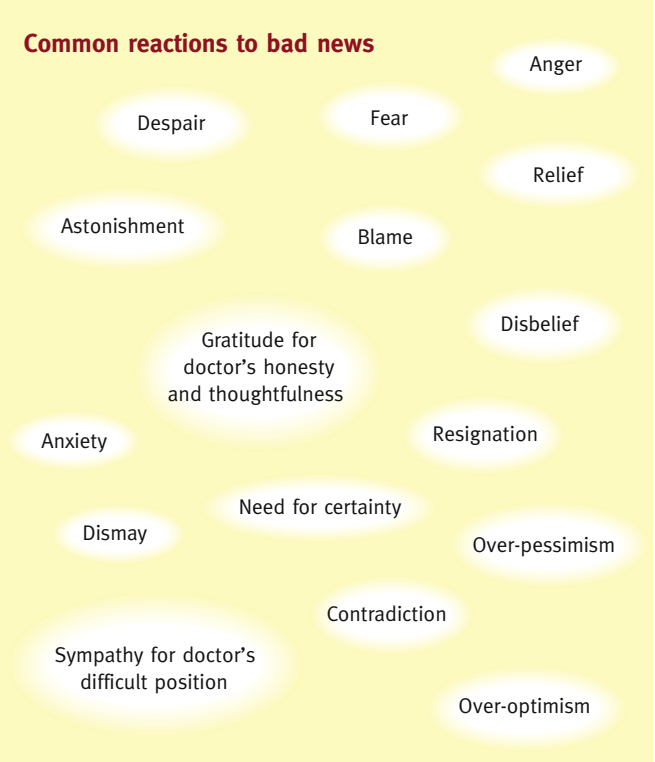

Figure 1

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- Determine what patients want to know before you tell them. Research suggests that most individuals want to know the truth and want detailed information regarding their illness,[10] but the level and detail of information required may vary. Patients also do not want the decision of how much they are told to be made by their family,[11] despite the fact that some families insist on deciding whether a patient should be told the truth. The healthcare practitioner then faces a dilemma of not wanting to alienate the family, but needing to honour the patient's right to autonomy. It is good practice to ask patients, using an interpreter if necessary, whether they wish their family to mediate for them with healthcare professionals or whether they want to be communicated with directly.
- Remember that, even in the least stressful situations, individuals remember only a small proportion of what they are told. Patients receiving bad news will probably need to have information repeated, and are likely to feel too shocked and bewildered to make informed decisions about treatment or care plans at that time.
- Determine and respond to patients' key concerns and hopes, without being unrealistic or falsely reassuring — 'preparing for the worst does not stop us hoping for the best'.[2] There is evidence that being told bad news with concern, clarity and a caring attitude, and being given the time to talk and ask questions in a private setting, is beneficial.[12]
- If possible, arrange a follow-up appointment at which questions can be asked and decisions made.
- Provide further sources of patient information (e.g. in the UK, Macmillan Cancer Support, Motor Neurone Disease Association).
- When giving further bad news to patients who are seriously ill, healthcare professionals must be aware that such patients and their families are likely to be already managing feelings of grief about, for example, loss of income, loss of independence, loss of status and changes in body image (e.g. loss of feeling sexually attractive).

Bereavement

The grief process

There is much debate about the nature of grief, for example whether it helps individuals to 'let go' or to 'hold on', whether models of grief for men and women should be different, and whether grief is a universal experience. Some key concepts useful when working with bereaved individuals are that:

- grief is a process, not an event
- grieving takes time — usually longer than expected or hoped
- grief is energy-consuming and exhausting. Four 'tasks of mourning' have been identified — accepting the reality of the loss, processing the pain of grief, adjusting to the world without the deceased, and finding an enduring connection with the deceased in the midst of embarking on a new life[13]
- both too much grief and too little grief can be harmful; bereaved individuals need times when they face their grief, and times when they look to the future and avoid it[14]
- common feelings and experiences have been described as the 'phases of mourning' — initial shock, numbness and disbelief, intense and overwhelming pangs of grief (sadness, guilt, pining, searching, anger, fear, anxiety, panic), disorganization, despair, depression and loss of meaning, and final reorganization and adjustment[15]
- the grief process can be facilitated when bereaved individuals construct a positive connection with the deceased by remembering them, retaining keepsakes, initiating conversations with them and locating them in their lives.[16,17] However, this will not be helpful if it causes emotional pain without any sense of relief.

Risk factors in bereavement

Most individuals face the loss of a significant person at some time in their life. Grief is a common experience and carries a high risk. After a major loss, such as the death of a spouse or child, up to one-third of individuals suffer impaired physical or mental health or both. There is also clear evidence those who are bereaved are at greater risk of dying, particularly by suicide, than those who are not.[18] Healthcare professionals must be aware of the situations in which bereavement carries a greater risk (Table 1).[18–20]

Managing bereaved individuals at risk: there is evidence that bereavement counselling is effective and can prevent some of the psychiatric and physical complications of grieving. There is less clear evidence on which type of counselling is most effective.[18,19] However, the strongest evidence is that targeted and specific interventions effectively diminish complicated grief symptoms, grief-related depressions and post-traumatic disorders.[20–22]

Bereavement counselling and support services are available in many countries and are often staffed by specially trained volunteers. Many hospices and palliative care teams have risk assessment processes and bereavement follow-up systems; in the UK, Hospice UK (www.hospiceuk.org) provides an online directory of these. Some hospitals now provide a bereavement officer or counselling service.

In the UK, Cruse Bereavement Care (www.cruse.org.uk) provides national and local services which include: telephone, face to face and group support as well as an excellent website (Hope Again) for bereaved young people. Other organizations provide support for particular deaths, for example, SANDS (www.uk-sands.org) for those bereaved by a stillbirth or neonatal death, SAMM (www.samm.org.uk) for murder or manslaughter, SOBS (www.uk-sobs.org.uk) for those bereaved by a suicide, the Child Death Helpline (www.childdeathhelpline.org.uk) and Compassionate Friends (www.tcf.org.uk) for bereaved parents and others affected by the death of a child, and Road Peace (www.roadpeace.org) for those bereaved by a road traffic crash.

How can those who are bereaved be helped?

- Use clear, unambiguous language (e.g. do not say 'lost' when the meaning is 'died').
- Help those who are bereaved to obtain the information that they need to understand why their loved one died, and (having prepared them for what they may see) to say goodbye to the body of the deceased if they wish. There is