

Talking to patients and relatives about dying

In most UK medical schools, there are 8–10 weeks of undergraduate training to bring babies safely into the world through obstetrics, but proportionately much less teaching about end-of-life care.

Why talking about dying is so difficult

Freud (1959) reflected on why it is so difficult:

‘Our own death is indeed unimaginable and whenever we make the attempt to imagine it we can perceive that we really survive as spectators ... at bottom no one believes in his own death, or to put the same thing in another way, in the unconscious every one of us is convinced of his own immortality.’

When talking to a patient about dying it reminds both the doctor and the patient of their own mortality and so:

- Is it death we are frightened of or not being here?

- Is it the anxiety and fear through the anticipation of dying?

These are questions that people rarely consider when they are ‘healthy’, but which change when they are ill and could be viewed as spiritual anxiety or pain. Doctors know when they are communicating successfully with a dying patient when the patient asks: ‘What will dying be like?’ However, the doctor cannot know and it is an unnerving question.

‘Total pain’ and spiritual pain

The late Dame Cicely Saunders (founder of the modern hospice movement) coined the phrase ‘total pain’ in the 1960s; the physical, psychological, mental, emotional, social and spiritual (Saunders, 1964) and so a holistic and patient-centred approach to the dying.

This is included in the European Association of Palliative Care (2010) definition:

‘Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms,

and of social, psychological and spiritual problems is paramount.’

The concept of spiritual pain or spirituality is not necessarily related to a religious faith, as illustrated in *Figure 1* (Charlton, 2007) which has been annotated from Helman (1981).

Move from being doctor-centred to patient-centred

In the 1950s there was a movement from doctor-centred paternalistic care to patient-centred care, particularly in relation to truth disclosure. In 1950 a survey in the USA of 200 cancer and non-cancer patients revealed that 89% would prefer to know the truth if they had cancer (Kelly and Friesen, 1950). Conversely in 1961, 219 USA physicians stated that 90% did not tell cancer patients the truth (Oken, 1961). This attitude changed, as a similar study of 264 USA physicians in 1977 found that 97% always told the truth (Novack et al, 1979). Doctors are now more open about talking to dying patients.

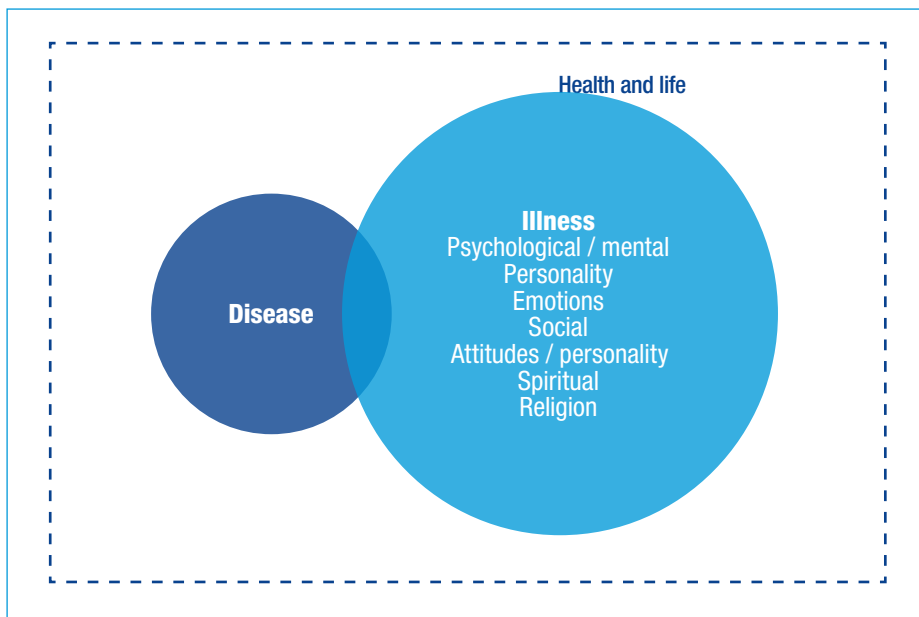
Coincidentally, psychotherapist Dr Michael Balint (1957), who wrote about the doctor–patient relationship in his book *The Doctor, The Patient, and His Illness*, described how doctors needed training to explore ideas, concerns and expectations in a consultation, hopefully coming to a shared understanding and having an agreed negotiated management plan which can only be achieved by talking to the patient.

Table 1 gives some practical tips for doctors caring for patients at the end of life.

The transition from ‘being’ to ‘un-being’

Author Gavin Maxwell recalled the great spiritual pain of the solitary moment of moving from ‘being to un-being’ when

Figure 1. The overlap of disease and illness as part of as part of life and health. The broken line of the box signifies the existential element of and so whether anything exists beyond the box.



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he was dying of cancer (Frere, 1999). The theme of illness as a threat to our very being is described by Berger and Mohr (1967):

‘As soon as we are ill we fear that our illness is unique. We argue with ourselves and rationalize, but a ghost of the fear remains. And it remains for a very good reason. The illness, as an undefined force, is a potential threat to our very being.’

Subjectivity and objectivity

A USA paper (Steinhauser et al, 2000) looked at the factors considered important at the end of life by patients, family, physicians and other care providers through a survey in 1999 of seriously ill patients ($n=340$), bereaved ($n=332$), physicians ($n=361$), other carers (nurses, social workers, chaplains, hospice volunteers; $n=429$). The key findings were that the following issues were important to patients at the end of life but were not perceived as important by physicians ($P<0.001$):

- Be mentally aware
 - Be at peace with God
 - Not be a burden to family or society
 - Being able to help others
 - Prayer
 - Planned funeral arrangements
 - Feel one’s life is complete.
- Doctors thought the following were of importance:
- Pain control
 - Symptom control
 - Depression
 - Cure.

Doctors should be aware of the difference.

Patients reaching acceptance that they are dying

Atul Gawande, an American surgeon, writes in *Being Mortal*: ‘Arriving at an acceptance of one’s mortality is a process, not an epiphany’. For many, death is a taboo subject. In the 1960s Elizabeth Kübler-Ross, a Swiss-born psychiatrist working in the USA, became known for her proposed five stages of anticipatory grief where the last stage is moving from depression to acceptance of illness (Kübler-Ross, 1969).

As part of the taboo it could be argued, and it is the author’s experience, that it is not common to witness a dying patient who reaches the stage of acceptance. Rather one watches many who are resigned to their fate and so in a state of resignation, thus adding a sixth potential stage to the original proposal.

Medicalization of death

Death has been transformed from being an accepted everyday occurrence and natural part of the life cycle into a ‘taboo subject’. This is because dying has been so professionalised and sanitised that it is now alien to many people’s daily lives. Dying has been ‘medicalized’ in UK institutions where most people die and it is rare for the majority of the public to see a dead body. When communicating with dying patients, doctors should be mindful of this. As well as ameliorating symptoms, doctors’ greatest, but least appreciated, role is facilitating the transition to ideally acceptance of dying which is difficult for the public (Smith, 2000).

As doctors attempt to communicate with patients who are dying, in order to help them accept their fate, they also need to take into account the personal conflicts with family or friends in enabling a person to re-order his/her priorities and let go. Getting involved in these conversations is something that doctors tend not to do as they do not appreciate their influence on the patient’s state of mind.

All, whether doctor or patient, contradict all that is known and so what was written as long ago as 1612 when Sir Francis Bacon wrote: ‘To die is as natural as to be born’. This is very poignant, as now one is required to have a form signed which allows you to die – the DNAR (do not attempt resuscitation form).

Often patients on the palliative care pathway seem to end up with a syringe driver in case of pain or perceived distress. Here the ‘doctrine of the double effect comes into place’ where the intention is to relieve symptoms, but unintentionally the use of opiates may hasten death. It is important to adequately communicate with patients and make sure they are aware and have consented to both a DNAR form and if indicated, the use of a syringe driver. It is all too easy to fall into the trap as a practitioner where there is a fine dividing line about the use of a syringe

Table 1. Practical tips for good care at the end of life

1. Talk to the patient, gain his/her trust and keep talking. Successful palliative care is about two things – good communication and adequate symptom control
2. Consider the total needs of the patient and not just his/her symptoms. Difficult symptom control is when all aspects have not been considered, e.g. unresolved personal conflicts
3. Don’t neglect a patient’s spiritual pain
4. Never make assumptions when caring for a dying patient – ask the patient what worries him/her the most
5. Despite what anyone tells you, remember that many patients are not in acceptance of their fate but rather resigned to it
6. Dying patients do not fit guidelines and so pathways. Talk to the patient, find out what he/she wants
7. Try not to exclude a patient from conversations that affect him/her, matter how well intentioned, unless that is the patient’s request. If necessary, talk with everyone present, including any close relatives. Remember the needs of the informal carer as the 24-hour a day workload can take its toll
8. Treat every patient as an individual
9. Palliative care does not stop with the death of a patient, but continues with the needs and care of the bereaved. It is greatly valued by those who are left
10. Reflecting on each dying patient will help with your care of future patients. Record the anniversary of their death to make contact with the relatives as a part of a good bereavement protocol

driver for symptom relief of the patient and placating distressed relatives and carers.

'Conspiracy of silence'

Kübler-Ross (1982) also coined the phrase 'conspiracy of silence' when thinking of a patient with a terminal illness where nobody is talking to each other or the patient, but when they are away from the patient, everybody is talking about his/her terminal illness. So often it is the case that a patient has a very good idea of what is happening to him/her when he/she is dying, but no one is talking to the patient about it directly. Relatives may be well intentioned by not wanting their loved one to suffer through such information. However, the spiritual pain the patient will experience is the fact that information is being kept from him/her by not respecting his/her autonomy and confidentiality.

'[Kubler-Ross's] work has vanquished the conspiracy of silence that once shrouded the hospital's terminal wards....In so doing, it has shown how, and with what quiet grace, the human spirit composes itself for extinction.' (Charlton, 2017)

Facilitating a 'good death'

Bevins and Cole (2000) describe how technology and modern medicine at the end of life may be at odds with the concept of enabling a 'good death' and overcoming spiritual pain:

'Death is the edge of a mystery, and turning our faces toward the problematic, through the persistent use of technology, at the hour of death keeps us from having to face this mystery. Death is no problem to be solved; it resists any such formulation... by keeping our attention on end-of-life problems, we ignore the mystery of the end of life.'

When a patient dies and the bereavement that follows

Communication does not finish with the death of the patient. It could be disputed whether or not bereavement is a medical problem (Charlton, 1996), but Wroblewski (1994) said: 'Grief is like a raging river'. It is a significant life event and it is inevitable that all doctors will encounter patients who are experiencing bereavement.

Shakespeare, in *Much Ado About Nothing*, states: 'Everyone can master a grief but he that has it.'

Looking after yourself

Caring for the dying, if done well, is exhausting. Ideally, the doctor follows up and cares for a patient from the time of diagnosis through to death. This means continuity of care, a named clinician who sees the person regularly to anticipate crises and avoid unnecessary emergency hospital admissions and who is available out of hours to avert crises even if just on the end of the telephone.

Full details of the patient's care must be made available (diagnosis, management plan and medication) to any doctor deputising for that patient's care. To provide good care is therefore physically, emotionally, psychologically and often spiritually demanding. So when a patient dies, such is the good relationship built up, it can also be a personal bereavement for the clinician. As in Roger Neighbour's (2004) consultation model a period of good housekeeping is required for doctors to reflect and discuss with colleagues, to maintain contact with the grieving relatives and to reflect that they did their best.

If a doctor is invited to a patient's funeral, it is very much an individual's judgement and choice whether that doctor attends, depending also on the time available to busy clinicians.

Conclusions

The patient's expectations of doctors do not change just because he/she is dying. The patient wants the clinician:

- To be his/her doctor
- To accompany him/her on the journey
- To follow up, even when cure is not possible
- To be there for the patient
- Communication, communication, communication
- Not to have sympathy or empathy but to have compassion. **BJHM**

Conflict of interest: none.

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KEY POINTS

- The science of symptom control is the easy bit, or at least it can be learnt and accessed.
- Consulting and talking to dying patients is difficult.
- This is an area of medical training which is deficient and yet is needed by all.
- Death has been medicalised and the general population has little contact with it.
- Dying is difficult as it questions our mortality resulting in 'spiritual pain'.
- Bereavement is the unintentionally neglected part of palliative care.

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