

What they don't teach you at medical school / Tips from the shop floor: Talking to patients and relatives about Dying

Key Words: Palliative; Death, Dying; Bereavement; end-of-life

Key points (5-8)

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

Introduction

In most UK medical schools, there are 8-10 weeks training of undergraduates to bring babies safely into the world through Obstetrics, but much less proportionately of this amount of teaching is in end-of-life (EOL) care.

Why talking about dying is so difficult

Freud in 1915 reflects why it is so difficult (1);

"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 us both of our 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 we rarely consider when we are 'healthy', but change when we are ill and could be viewed as spiritual anxiety or pain. We know when we are successfully communicating with a dying patient when they ask, "What will dying be like?" We cannot know and it is an unnerving question.

Tip 1 - Talk to the patient, gain their trust and keep talking. Successful palliative care is about two things; good communication and adequate symptom control

'Total Pain' and Spiritual Pain

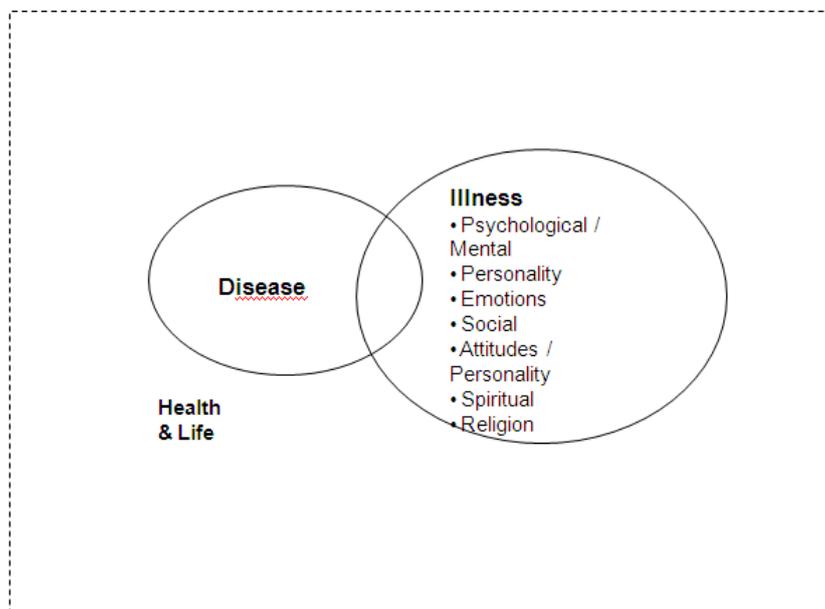
The late Dame Cicely Saunders (founder of the modern hospice movement) coined the phrase 'total pain' in the 1960s; the physical, psychological, mental, emotional, social and spiritual(2) and so a holistic and patient-centred approach to the dying.

This is included in the European Association of Palliative Care (EAPC) 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."(3)

The concept of spiritual pain or spirituality is not necessarily related to a religious faith. This is illustrated in a Venn Diagram (4) which has been annotated(5);

Tip 2- Consider the total needs of the patient and not just their symptoms. Difficult symptom control is when all aspects have not been considered eg unresolved personal conflicts



The broken line or box is meant to signify the existential element.

Move from being doctor-centred to patient-centred

In the 1950s there was 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 (6). Conversely in 1961, 219 USA physicians stated that 90% did not tell cancer patients the truth.(7) This attitude changed, as a similar study of 264 USA physicians in 1977 found that 97% always told the truth.(8). We are now more open about talking to dying patients.

Coincidentally, psychotherapist, Dr Michael Balint, who wrote about the doctor-patient relationship in his book, “The doctor, the patient, and his illness”(9) 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.

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 he was dying of cancer.(10) The theme of illness as a threat to our very being is described by Berger;

“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.” (11)

Tip 3 – Don’t neglect a patient’s spiritual pain

Subjectivity and Objectivity

A USA paper (12) considered the factors important at the EOL by patients, family, physicians and other care providers(12) 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 the following issues as important to patients at the end-of-life but not perceived important to physicians (p<0.001);

- 1) Be mentally aware
- 2) Be at peace with God
- 3) Not be a burden to family or society
- 4) Being able to help others
- 5) Prayer
- 6) Planned funeral arrangements
- 7) Feel one’s life is complete

Doctors thought the following of importance:

- Pain control
- Symptom control

- Depression
- Cure

Doctors should be aware of the difference.

Tip 4 - Never make assumptions caring for a dying patient, ask them what worries them the most

Patients reaching acceptance that they are dying

Atul Gawande, an American Surgeon in his 'Being Mortal' writes; "*Arriving at an acceptance of one's mortality is a process, not an epiphany.*" For many, death is a taboo subject. In the 1960s Kubler Ross, a Swiss born psychiatrist working in the USA is known for her proposed five stages of anticipatory grief where the last stage is moving from depression to acceptance of illness.(13) As part of the taboo it could be argued, and it is my experience, that it is not common to witness a dying patient that 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.

Tip 5 - Despite what anyone tells you, remember that many patients are not in acceptance of their fate but rather resigned to it

Medicalisation 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 'medicalised' in UK institutions where most people die and it is rare for the majority of the public to see a dead body. When communicating then with dying patients, we should be mindful of this and so as well as ameliorating symptoms, our greatest role, but least appreciated, is facilitating the transition to ideally acceptance of dying which for these reasons is difficult for the public(14).

As we attempt to communicate with our patients who are dying, in order to help them accept their fate, we also need to take into account the personal conflicts with family or friends in enabling a person to re-order their 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.

Doctors and patients contradict all that we know and so what was written as long ago as 1612 when Sir Francis Bacon wrote(15); *"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. This is the DNAR (Do Not Attempt Resuscitation form).

Inevitably palliative care pathway patients 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 driver for symptom relief of the patient and placating distressed relatives and carers.

Tip 6- Dying patients do not fit guidelines and so pathways. Talk to the patient, find out what they want.

'Conspiracy of Silence'

Elizabeth Kubler Ross also coined the phrase 'conspiracy of silence' (16) when thinking of a patient with a terminal illness where nobody is talking to each other or the patient, but everybody's talking about their terminal illness. So often is the case that a patient has a very good idea what is happening to them when they are dying, but no one is talking to them 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 them by not respecting their autonomy and confidentiality. A review states (17);

"[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."

Tip 7 – Try not to exclude a patient from conversations that affect them, matter how well-intentioned, unless that is their request. If necessary, talk with everyone present, including any close relatives. Remember the needs of the informal carer as the 24 hours a day workload can takes its toll.

Facilitating a 'good death'

Bevins and Cole describe how technology and modern medicine at the EOL may be at odds with the concept of enabling a 'good death' and overcoming spiritual pain(18);

“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.”

Tip 8- Treat every patient as an individual.

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(19), but;

"Grief is like a raging river"(20)

It is a significant life event and it is inevitable that all doctors will encounter patients who are experiencing bereavement.

Shakespeare in his play, Much ado about nothing(21), states,

"Everyone can master a grief but he that has it."

Tip 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.

Looking after yourself

Caring for the dying, if done well is exhausting. Ideally, you follow up and care 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 patients care must be made available (diagnosis, management plan and medication) to any doctor deputising for that patient care. To provide a good care is therefore physically, emotionally, psychologically and often spiritually demanding. So when a patient dies, such is the good relationship built up, it is also a personal bereavement. As in Roger Neighbour's consultation model ('The Inner consultation') a period of good housekeeping is required for you to reflect and discuss with

colleagues and to maintain contact with the grieving relatives and that you did your best.(22)

Sometimes you get invited to a patient's funeral and it is very much an individual judgement and choice whether you attend and time dependent as a busy clinician.

Conclusion

Patient Expectations of you as a doctor haven't changed;

- To be their doctor
- Accompany them on the journey
- To follow up, even when cure is not possible
- Availability
- Be there for them
- Communication, communication, communication
- Not Sympathy or Empathy but Compassion

Tip 10- Reflect on each dying patient which 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.

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