Counselling the terminally ill - Can we prepare for death?

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Abstract

The family medical practitioner is a key player when care of the patient becomes palliative. The practitioner's ability to be present to the psychological, spiritual and social needs - in addition to the physical -gives reassurance and affirmation of life up to the point of death. Counselling in the medical field and the approach to opening up a conversation with a patient or family member is discussed.

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Introduction

In the 1960s in the USA Dr. Elizabeth Kübler-Ross[1] demonstrated to medical staff and students that some terminally ill patients wanted to be able to talk to someone about what was happening to their bodies, about the meaning of their illness, their relationships, their fears and hopes, their spirituality. The family doctor is well placed in the care team to facilitate such discussion with the patient. The doctor can develop such counselling skills whilst at the same time respecting the various defence mechanisms (such as denial, avoidance) which the patient may need to use from time to time in order to maintain his or her psychological health during the process of preparation for dying.

What is counselling?

Counselling in palliative care is defined as skilled consultation between professional and patient in which each draws on the expertise and knowledge of the other in order to assist the patient with any physical, psychosocial or spiritual issues he would like to explore. The expertise and knowledge of the counsellor exists as a result of training and experience, self-awareness and awareness of his culture and value system. The expertise of the patient lies in his knowledge of his own body, his past life experience and acquired skills and wisdom, and his knowledge of his culture, history and belief systems.

The doctor is able to move between two styles of care:

- The prescriptive doctor-centred authority role
- The holding of conversations in which the patient's power and knowledge of himself and his body is recognised and encouraged.

The counselling conversation is a journey of discovery with the patient - a co-searching or 'co-researching'[2,3] with the person of what is important to her or him in the context of the illness and the cultural context of the life. This conversation is between doctor and patient/family members and can include others significant to the patient.

Maintaining hope

Conversations between patient and doctor should endeavour to maintain hope. As the hope for cure recedes, other hopes may be explored. Hopeful discussions might include attending to relationships, helping the partner prepare for life without the patient and allowing the patient to feel included in decision-making regarding all aspects of his care. Sharing knowledge of the illness and treatments can empower a patient to make appropriate decisions in the context of his life - thus restoring to him some elements of control in a life where he may feel he has lost control and independence. The patient will take courage in the reassurance given by the doctor that the latter will remain actively involved and supportive in all aspects of the terminal care of the patient.

Barriers to counselling a patient or family

Below are some of the possible concerns which might prevent medical practitioners from using a counselling approach:

- The doctor may lack confidence in his/her ability to engage with the patient in this way
- The doctor may have painful unresolved issues of personal loss
- At some level s/he may hold a belief that the death of a patient is a failure on the part of the medical profession
- 'Cancer silence' - "We won't talk about it so as to avoid painful interactions"
- The doctor is worried that s/he will not sufficiently understand the patient's culture

The approach to counselling

The following aspects should be considered to take the conversation from the medical model to the counselling mode:

- The doctor (or other member of the multi-disciplinary team) listens carefully and respectfully to the patient's story in the context and culture of the patient's life situation. Where necessary s/he uses an interpreter and cultural advisor.
- Permission should be sought from the patient to open up issues for discussion
- The doctor asks open-ended questions to elicit more detail or to deepen and enrich the discussion
  - thus creating openings for exploration of thoughts, feelings, behaviour, relationships. These questions are asked in a tentative even hesitant way giving space and time for the other to think and reply.
- The object is to be with the other on an equal basis in a journey of discovery about the following:
  - The effects of the illness on the life of the patient and those around him and hopes for the future of the family

- The meaning of the illness for him/her
- Expectations and spiritual hopes in the present and the future
- Fears and anxieties

The patient is being treated holistically rather than according to the bio-medical model. Now emotional, cognitive, spiritual, social and financial issues are recognised.

Questions to facilitate the counselling conversation:

1. Starting the conversation

- *"We've talked about the possible options for treatment but I also wondered if there are other things you would like to talk about such as how this illness is affecting you as a person?"* (the doctor is asking permission to move into other areas of discussion.)
- *"I am wondering what effect this illness is having on your life generally?"*
- *"Do you find the illness is creating any stresses in the family?"*

The reply to any one of the above questions will give clues as to what would be a useful follow-up question. Other useful statements or questions might be some of the following:

- I am wondering if anything is especially on your mind today
- I am wondering whether you see any particular meaning in this illness
- How is the illness affecting your view of the past/ the future?
- Is this conversation helpful or would you prefer to be talking about something else?

The practitioner is communicating that anything may be discussed. By careful listening he or she becomes sensitive to what may be important to the patient rather than to the doctor.

2. Discussing possible fears

- Are there any particular fears about what may happen?
- Do you have any concerns about home circumstances at the moment or in the future?
- Would you like to talk about how things might change over the time ahead?

3. Exploring support for the patient on a physical and emotional level

- Who would you say are the people who support you - the people you can count on?
- How are they coping?
- Are they helping with your care - how is this going?
- Only one question is asked at a time.
- You seem particularly concerned about your wife (husband) today. Is there something on your mind?
- How do you think those left behind will manage?
- What would you say your wife (husband) most appreciates about you?[4]

The latter question opens up discoveries for the patient or nearest other of their personal resources in terms of qualities and also encourages review of the relationship. The doctor is communicating recognition of the person's relationships and how they might be impacting on the situation. It also helps to assess the person's people resources and potential practical help as the patient becomes less independent.

4. Assessing emotional preparedness for dying

The following set of questions can help the patient and doctor to gain insight into the preparedness for dying.

- What crises have you had before in your life? What was it that helped you to get through? (This may indicate how the future emotional journey may go and encourages people to think about how they have met previous challenges in their life - what has helped them to get through - can this ability empower them now?)

5. Spiritual preparedness

- Do you have any particular belief systems?
- How are those beliefs helping you?
- Do you have any questions around this?
- Is there someone in the spiritual line that you would like to talk to?
- Do you see any particular spiritual significance in this illness?
- What have been the high points in your life? What are you particularly proud of?

6. Concluding or ending a conversation

- What you have just brought up sounds really important. We have to stop now but maybe we should spend some time following this up at our next session?

How can counselling help us to prepare for death?

It has to be born in mind that in order to prepare for death we need to become aware that we have only a limited time to live. It is a person's individual choice of whether to prepare or whether to put awareness of impending death out of his or her mind.

By reviewing one's life and making peace with the past one can move more fully into the present and the realisation of approaching death. Counselling can help us prepare in the following way:

- The person receives help in adjusting thoughts and emotions in order to move from the belief that he/she will be cured to the realisation that time on earth is limited
- Someone is alongside - the patient no longer feels isolated. This person provides a sounding board for whatever the patient wishes to discuss and explore
- The person hears his/her own voice and becomes aware of what he/she is thinking - that which was maybe not previously consciously apparent
- Sometimes counselling is not verbal but just silent companionship.[4] As patients we need hope, reassurance, good care. We need to know that all medical, nursing, social work and related professionals working with us are liaising for our benefit. We need to feel listened to and respected and to know that we are allowed some control and independence

Conclusion

It is a patient's right to choose to prepare for death or not to do so. If he wishes to talk about his dying and death and issues which concern him, a helping medical person alongside can facilitate this process enormously. Including the counselling conversation within the medical consultation provides opportunities for holistic preparation for living with the illness in the present, for the process of dying and for death itself. Benefits to the doctor are in recognising that s/he does not always have to provide curative answers. Contrary to what one might expect, the anxieties of the patient are not stilled by easy reassurance but by the doctor's honesty, the sharing of empathy and the readiness to listen to the patient's concerns.

See CPD Questionnaire, page 42

(P) This article has been peer reviewed

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