

Let's talk about it

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Normally we do not like to think about death.

We would rather think about life.

Why reflect on death?

When you start preparing for death you soon realize

that you must look into your life now...

and come to face the truth of your self

Death is like a mirror

in which the true meaning of life is reflected.

Sogyal Rinpoche

Summary

In this article I explore current attitudes to death and dying among health professionals and the public and how that impacts on our ability to come to terms with it as an inevitable part of living.

I have always been curious that so much time and effort goes in to preparing for a birth, yet so little goes into preparing for death. I have been musing on these themes for a very long time, as someone who has accompanied many people in their last days, and in my work as a nurse, midwife, counsellor and trainer. I have a special interest in creating opportunities for more people to engage in open dialogue based on the belief that 'the way we go out, is just as important as the way we come in'.

Introduction

Early in 2000 in his BMJ editorial, Richard Smith¹ reflected on the state of dying in Britain raising issues such as: the increasing 'medicalisation' of death; the paradox of creating a specialty of palliative care, when it is something that happens to us all; and the soulless experience of dying in hospital when most of us would prefer to die at home. There haven't been too many changes since he wrote and the concerns remain the same, but there is a sense that death and dying is working its way to the top of the health care agenda and progress appears to be underway.

Why don't we talk?

Our lack of engagement with the most challenging fact of life — death — inevitably comes down to fear. It is going to take some working through, for individuals, professionals and society to embrace it as a profoundly natural and normal event, sacred even. Becker suggests such deep fear has its roots in childhood: *'The child meets the terror of life and aloneness first by asserting his own omnipotence and then by using the cultural morality as the vehicle for his immortality. By the time we grow up, this confident, delegated immortality becomes a major defence in the service of the equanimity of our organism in the face of danger.'*²

Firestone and Catlett³ take this further and explore the enormously complex range

of the psychological responses to death and dying. They illustrate how our unwillingness to engage with the deepest questions of our existence leads to all kinds of compensatory and distorted behaviour: from addiction to isolationism, from cynicism to lack of direction, from magical thinking to accumulation of wealth, status or power — all to shore up the feeling of immunity to death.

The ego loves to uphold the illusion of the world as a predictable and familiar place over which it has control. When death looms, it is seen as the ultimate threat and triggers a state of primal, existential fear of the unknown. Michael Kearney describes this state of human suffering as soul pain. *'in a reaction aimed at ensuring its survival, our panicking ego ... flees from the soul, thereby alienating itself from all that is deepest in us and leaving us feeling isolated and terrified in a wasteland of meaningless and hopelessness — soul pain.'* ~

On the other hand many of us working holistically with people who have life-threatening illnesses, or are facing the end of life, have seen there is the possibility for deep inner healing at this time — though not necessarily a prolongation of life. *'If the dying person even begins to attend to the soul, it responds a thousandfold.'*⁴ There is no doubt it is the road less travelled, but accompanying someone on this journey is the most rewarding of experiences.

How good are we at talking?

Given the rough and tumble of our development from babyhood to adulthood, health and care professionals are as likely as anyone else to emerge as death-averse. If we take a moment to place ourselves in the centre of our own lives, setting aside our professional role to reflect on our humanness and our own mortality, we will recognise we are as vulnerable as the next. If we are to bring benefit and true human support to people in our work, our challenge is to attend to our own anxiety and pain. And if we consider ourselves to be in integrated, holistic practice, we have a responsibility to find a relationship with the bigger picture — God, the Divine, the Light — however we might describe it, so that we are able to be in a more enlightened relationship with death and dying. If we don't, we will find ourselves retreating in the face of others' suffering, possibly resorting to inappropriate palliation, in an effort to dampen down our own anxiety.

The culture of denying death and avoidance of discussion happens in subtle ways that are so embedded in health care culture we don't realise they are happening.

A colleague described to me his stay in hospital when the patient opposite died; the curtain was drawn around and the body later removed. This was all done with great discretion, but with no acknowledgement. It was as if the man had never existed. Not one of the staff mentioned the death to the other patients in the room.

We all know the accepted reasons for this — busyness and concern about upsetting other patients. But if we think it through honestly, more deeply, are we really protecting others or ourselves? Is this an avoidance which reflects our own anxiety about death, or at the very least our lack of confidence in talking about it? Even more, what does it say about the nature of our patient-professional relationship?

A colleague who mentors a group of hospice nurses approached me for my thoughts on a dilemma they were facing in their daycare facility. They were uncertain how to behave when one of the peer group of day patients dies; what should they say to other patients? In response I pick up the fact that in many daycare centres 'living well until you die' is an excellent way to run programmes, but safeguarding clients from the reality of other peoples death reflects a culture where staff are engaged in 'distraction from' (where does the elephant in the room go?) as opposed to an atmosphere of openness and 'preparation for' death with the people who attend.

In transactional analysis terms, our form of 'nurturing and caring' in these examples is as if from a parent to child — taking care of/taking responsibility for — rather than engaging with people in an adult-to-adult way, respecting their life experience, maturity and capacity to cope, even if it is painful. Not only that, it compounds the fundamental problem in society of not facing up to death, when in reality health professionals are in a powerful position to lead the way in changing attitudes in society especially those working in palliative care settings. If we don't talk more openly about it who will?

How much talking are we doing?

In July 2008 Professor Mike Richards launched a wide-ranging report from the DOH: *End of life care strategy — promoting high quality care for all adults at the end of life*. The report identified a major problem: 'as a society we do not talk about death and dying — this contributes to its low profile in health and social care. Most people do not discuss their own preferences for end of life care with their partner/family, hampering individual planning'.⁵

The Dying Matters Coalition, an offshoot of the National Council for Palliative Care, was formed shortly after the report and starting conversations has been one of its first objectives. The Coalition held its inaugural conference, *Dying to talk*, in March 2010 where Professor Jeff French, drawing on national surveys, highlighted attitudes to talking about death.⁶

Why I have not discussed end of life issues	Men	Women	Total
I don't feel comfortable talking about it	9%	12%	21%
<u>I am too young to discuss death</u>	<u>19%</u>	<u>16%</u>	<u>35%</u>
<u>Death seems a long way off</u>	<u>47%</u>	<u>43%</u>	<u>90%</u>
Other people don't want to talk to me about my death	6%	8%	14%
Never thought about it	3%	3%	6%

Life expectancy has certainly improved in recent years and the majority of deaths occur between age 50 and 90, yet approximately 10% of deaths (53,285) recorded in 2009 occurred between the ages of 20 and 50. Even so, 90% of us believe that death is a long way off. And interestingly of the over 75-year-olds surveyed, 3% believed they were too young to talk about death and

20% that death seems a long way off! Professionals aren't any more relaxed about talking

about death than the public. Professor Mayur Lakhani, the Dying Matters Coalition chair, recently reported that 60% of GPs rated themselves either 'not confident' or 'not very confident' in initiating conversations about end of life.⁷

A recent pilot training programme for GPs provided participants with a short focused training in how to hold and sustain conversations about dying. To support this, they were given tailored materials, including leaflets, posters, and postcards for patients. As well as increasing their confidence, it had a tangible effect on patient outcomes with people communicating more openly about their needs and preferences at the end of life.

Before the training many of the GPs made the assumption that patients would become distressed or reject the conversation. However, contrary to their concerns, the study found that 90% chose to continue the conversation when initiated by their GE Another benefit was that patients who talked about their preferences with their GP were more likely to be placed appropriately on the end of life register, and have their preferred place of death and care preferences added to their records.

Why do we need to talk?

Dying is no longer as simple as it once was. Advances in medicine mean that life-prolonging treatments present clinicians with a series of dilemmas, where they enter into difficult moral and ethical (not to mention cost-benefit) territory and which require great wisdom and emotional resilience to navigate. If we don't face up to our mortality as citizens and engage with the discussion, everyone loses: doctors may be required to make rapid decisions without full knowledge of the values or wishes of their patients; families face the distress of making choices when they are often uninformed or emotionally unprepared to be able to respond; patients may face treatment that prolongs their life when they would actually prefer nature to take its course. It is a minefield.

Talking about and preparing for it not only begins to break down the taboos, but also releases everyone from uncertainty and the fear of acting inappropriately.

A recent Demos report suggests: *'Unless we can devise ways to get people to talk about how they want to live while they are dying, our efforts to improve services will be like groping in the dark, it should become standard for people reaching the end of life to create advanced care plans with the help of friends, family, trained peers or professionals. Evidence from the USA suggests this can dramatically reduce unnecessary admissions to hospital and improve care.'*

Preparing for the end of life experience

Richard Smith suggests the following factors could be considered to contribute to a good death. To:

- know when death is coming
- be able to retain control of what happens
- be afforded dignity and privacy
- have control over pain relief and other symptom control
- have choice and control over where death occurs, who is present and who shares the end
- have access to any spiritual or emotional support required
- be able to issue advance directives which ensure wishes are respected
- have time to say goodbye and control over other aspects of timing
- be able to leave when it is time to go and not to have life prolonged pointlessly.

Each of these requires reflection and forethought from the person who is facing death, alongside communication with family, friends, carers and/or GP. There have been attempts in recent years to clarify the process of planning and to secure a legal framework around the decisions made. It is a work in progress.

ACP — Advance care planning includes something called a Statement of Preferences and Wishes. The wishes expressed during advance care planning are personal and refer to future care though they are not legally binding.

Examples:

- how any religious or spiritual beliefs held can be reflected in care
- the name of a person/people to be called on to act at a later time
- choice about preferred place of care eg at home, in hospital, nursing home or hospice
- thoughts on different treatments or types of care that might be offered
- personal ways of doing things, eg food preferences, whether night clothes are worn or not, if a shower or a bath is preferred, or sleeping with the light on or off
- concerns or solutions about practical issues, eg who will look after pets in the event of illness.

ADRT — Advance decisions about refusing treatment.

People may want to express a very specific view about a particular medical treatment which they do not want to have and this can be done through an advance decision to refuse treatment (ADRT). This will only be used if at some time in the future they lose their ability to make decisions about treatment. It needs to be very specific — sometimes people may want to refuse treatment in some circumstances but not others. If potentially life-sustaining treatment is refused an ADRT of this type must be put in writing, signed and witnessed, and discussed with a health care professional, who is fully aware of the medical history. Someone can be named as an advocate to provide information about preferences, but they cannot make proxy decisions.

This is not a legal role unless it has been specified in a lasting power of attorney (LPA) which legally gives another person the right, should you lose mental capacity to make personal welfare and care and treatment decisions.

DNR — Do not resuscitate only covers decision about withholding future cardio pulmonary resuscitation (CPR). In general it is completed by a clinician with responsibility for the patient. Patient consent is sought only if an arrest is anticipated and CPR could be successful. However if it is part of an ADRT it becomes legally binding.⁸

Getting better at talking — initiatives and changes

It is clearly incumbent on all of us, from the personal and professional perspective, to be more willing not only to talk about the inevitability of death, but also to prepare for it. This requires us to overcome any reluctance or lack of confidence so we can engage, inwardly with ourselves and outwardly with others. There have been many research studies, reports and strategic plans carried out in the last 10 years, all leading to the same set of conclusions: we

need to talk more, change attitudes, pay more attention to the needs of dying people and offer more choices.

The Dying Matters Coalition, in two years, has built its membership to 14,000. It brings together diverse groups involved in end of life care, from public, private and voluntary sectors to act together as a central resource, in raising awareness and providing the support and information needed to open up conversations, to change attitudes towards death, dying and bereavement and improve end of life care.⁹ Dying Matters Awareness Week, this year from 16—22 May, aims to raise the profile of members' work and encourage events to get people talking.

There are also the beginnings of some positive changes to practice. The North East Strategic Health Authority began a review of their end of life care and services in 2008 and concluded:

- death is becoming medicalised
- there is an over-use of expensive hospital facilities
- death is a taboo subject
- the wider role and responsibilities of non-NHS organisations and society at large is not addressed.

Their aims and strategic planning changed, following a public and organisational consultation exercise (2,500 responses). Since then they have embarked on a public awareness and social marketing campaign and have developed metrics for monitoring and measuring progress. Their aim is to create change so that death becomes:

- a normal part of life
- more than a medical responsibility
- a public health and societal issue
- a responsibility of a compassionate community

The GP training pilot showed that it takes very small simple changes to raise awareness among GPs and the public. One participant commented: 'I feel that by having the leaflets in the waiting room this gave people the opportunity to think and have "permission" to talk about death with clinicians and their family members'.⁷ And as a result of the workshop participants were more able to recognise cues that patients were willing to talk, or to initiate conversations.⁷ This meant their practice changed in the following ways:

- recording the patient's preferred place of care (30%)
- giving information (the leaflet 'To Do List' 27%)
- discussing and recording patients' wishes regarding resuscitation (25%)
- in 27 of the 155 conversations, DNAR was discussed and subsequently DNAR recorded in the patient's notes
- discussing patient's pain and discomfort, reviewing pain management

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- treatment and medication review, symptom control
- requesting involvement of district nurse(s) and others eg MacMillan nurse, night sitters to visit, to discuss options and provide information and support
- referral or offer of support to family members and carers.

Conclusion

This article has focused on how opening up conversations can lead to changes in: a) our relationships, b) the level of clarity about people's needs and wishes, c) the quality and appropriateness of care, d) perceptions about death and dying, e) the quality of the experience families have. This alone suggests talking about it more is a positive and worthy exercise to pursue. There will always be people who are so deeply in denial that dialogue will be impossible, but as the pilot with GPs demonstrated, people were far more willing to talk than they anticipated.

When it comes to addressing the issue of 'soul pain' that Kearney identifies, or the appeal from Sogyal Rinpoche: '... *you must look into your life now and come to face the truth of yourself* *Death is like a mirror in which the true meaning of life is reflected*'¹² they suggest another level of engagement is possible, which won't be for everyone. These themes are currently discussed only superficially in palliative care circles. However, the fact that the simple initiatives, described above, exist, is a positive indicator of change. There is a sense, among those closely involved in end of life care, of an emerging understanding of the need to open up conversations, to pay attention to the journey at the end of life, to make it the best it can be and to do that in a more respectful way

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