

COMET seminar lecture

Quality of life to the end

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What is quality of life?

Quality of life is a complex personal construct. Various tools have been created to attempt to measure or quantify quality of life. They have each had their place in care delivery as the onus on a broader dimension has entered care than simply weeks or months of life lived after a particular treatment. It was in oncology that the measurements really began to take shape, probably because the chemotherapy regimes that were instigated for those with advanced cancer were so terrible, caused so much nausea and vomiting and had such poor survival rates that the compassionate began to question whether there really was any overall benefit. The first measures were very crude, but the Karnovsky¹ index, which assessed functioning based on what the physician saw, set the scene for a wider exploration of the issues for these patients.

The domains covered by such measures vary from measure to measure, often including physical, psychological and spiritual domains. The McGill short form looks at the patients' perception of existential distress and at feeling of being a burden and being supported by others². Others such as the EORTC QLQ C-30 has 30 items to look at quality of life and takes a more physical checklist approach³. One model that is particularly appealing is the Calman's concept of a gap between the patients hopes and aspiration and their reality⁴. The wider the gap, the greater the deficit in the person's quality of life. So, efforts in care need to be directed to enhancing the patients experience of reality, through good symptom control, and also at helping the difficult adjustment to realistic goals within the parameters of the disease.

It can be easy to see the distressed patient and seek to solve the distress with medication. But perhaps the greatest danger is to use a tranquilliser drug indiscriminately, throwing blanket of suppression over the manifestation of distress without addressing the underlying causes of it. Such management can make those providing care feel better, leaving the patient more isolated with concerns that have not been worked through and are not being explored.

Distress is not only seen in patients. Relatives are often 'out of step' with the patient, wanting to protect the person they love from upset. This benevolent intention can often result in pressure on staff to withhold information from the patient, although the advent of open communication with patients in the last ten years has made this much less frequent than it used to be.

Making decisions

Difficult decisions often have to be taken when someone is dying. Firstly, the state of 'dying' needs to be accurately diagnosed. Often patients can look as if they are dying when they are very ill, for example with hypercalcaemia, but the condition is eminently treatable with bisphosphonates and the patient rapidly returned to independent living for weeks or months. Decisions that are good for the family may not always be the ones that are best for the patient. As an extreme example, if a fixed term life insurance is about to expire, the continued survival of the patient for weeks may not be in the inheritor's interest.

The clinician is bound, within codes of ethical conduct, to always act in the patient's best interest⁵. Such a principle is even being recognised in draft legislation before Parliament⁶. The tenets underpinning a good decision are the four main principles of medical ethics⁷, namely autonomy, beneficence, non-maleficence and justice, with the addition of the concept of scope⁸. Autonomy is taken to be synonymous with choice, but the autonomy of one person cannot override the autonomy of another. Hence the personal beliefs and values of the doctor must always come into the equation; a patient cannot demand that something be done that the doctor feels is of harm, of unproven benefit or is immoral.

In this context the term 'Advance Directives' is a misnomer as the advance decision is and can only be a decision, in advance of the predicted event, to refuse treatment. Thus the term Advance Refusal is less misleading. If the legal status of Advance Decisions to Refuse Treatment is strengthened, then physicians and others providing care will have to have careful verification procedures in place to ensure that the person is indeed now incompetent to take a decision. They will also need to verify that as far as they can ascertain, the wish described in the document remains the current wish of the patient, for people change their minds so often as their clinical situation changes.

When considering justice, most are familiar with the concept of the right of a patient to the best treatment within the resources available. But the concept of justice also demands the just allocation of resources - the principle of equity. It is on this basis that the rationing of healthcare services is determined and the balance between these two arms of the principle of justice demands health treatment is prioritised on the basis of need, not demand⁹.

A patient's experience

When considering the validity of consent, whether current or expressed in advance of an event, the consent is only valid if it was given freely (voluntariness), based on accurate information that the person could understand, retain and process for decision making. But competence in decision making demands more than just this. The person must be able to understand the implications of the decision, including the option to do nothing, and understand the likely consequences of each course of action. The last phase of competent decision making is that the decision must be communicated to others, where by words, sign language or other signals that can be verified.

What is a good death?

The issues that are considered in Western culture to constitute a Good Death include being pain-free, with open acknowledgement of the imminence of death, at home

surrounded by family & friends, according to personal preference and in a manner that resonates with the person's individuality. Patients wish to remain "aware", even in the last stages of life. Death is viewed as potentially a time of personal growth, so that conflicts and unfinished business are resolved prior to a peaceful demise¹⁰.

The hospice movement has changed the face of dying in this country and around the world¹¹. A recent edition of the BMJ was dedicated to discussions of 'A Good Death'. It considered how to provide better care in the last 48 hours of life¹², and debated the lack of evidence from patients themselves over questions concerning euthanasia¹³.

Desiring death - euthanasia

Several recent high-profile cases have thrust the question of euthanasia and physician assisted suicide forward again. The Patient Assisted Dying Bill, introduced as a private members bill to the House of Lords by Lord Joffe, has re-opened the question of legalisation in the UK following Holland. This is a complex issue for society. It is easy to make the case for the individual, but very difficult to establish the impact on (potentially) vulnerable people in the community. People with disability are very fearful of any such moves; they already feel society views their plight as meaning they are to be pitied and that their lives are easily judged as being of less worth. A very moving description by Jane Campbell in the Guardian of her struggle to be treated and resuscitated rather than left to die makes salutary reading for anyone who tends to a utilitarian view of life¹⁴.

Our living and our dying have an effect on those around us. That is an inescapable truth. If as a society those who are ill and with disability are judged as a burden on resources their dignity is undermined; it is not surprising that those waiting weeks or months for social care improvements to their home end up feeling that they are of less worth. For that is the stark and cruel subliminal message they receive.

The motive behind any action to end life requires careful scrutiny. Are we seeking to affirm autonomy, reduce suffering, or both?¹⁵ In many people requests for euthanasia are not sustained, raising questions of the problem of validating requests¹⁶. Patients' perceptions of their doctors in the context of seeking euthanasia are that they lack of confidence in their doctors' ability and knowledge, feeling they have been inadequately investigated, and have poor symptom control¹⁷. There is evidence that many people who seek euthanasia are depressed, demoralised and often both^{18, 19}. Cognitive behaviours in those making requests for euthanasia show a high incidence of hopelessness and being depressed, irrespective of prognosis²⁰.

Involvement in euthanasia also has an impact on the professionals involved. Feelings of 'discomfort' (burdensome, emotional, a heavy responsibility) were experienced by 75% involved in euthanasia and 5% had doubts or regrets^{21, 22}.

Those seeking euthanasia had particular concerns relating to their future. These were with physical symptoms, psychological suffering, being a burden or that their care needs will not be met. Compared with those not requesting euthanasia they were more demoralised, had more pointers to depression, had less confidence that they would have good symptom control, had fewer social supports and overall expressed less satisfaction with life experiences. No study has looked at the style and content of communication with those requesting euthanasia compared to others, although

evidence from the Northern Territories in Australia would suggest this is a very important influence²³. So many questions are raised. Did the physician make the patient feel more hopeless and demoralised than they already were? Was care adequate? Did the patient have messages communicated, however subtly, that he or she is a burden to those around or to society, or that in the future he or she would become a potential burden? And did that generate a feeling in the patient of a duty to die and that others would be spared by their death?

DNAR orders

Decisions over future cardiopulmonary resuscitation in the event of cardiac arrest are now a routine part of inpatient decision making in hospitals up and down the UK. But what does such discussions or the lack of them imply. Are we saying that the life is worthless? Are we classifying people into those who should or should not live, on basis of real or imagined preferences? Any treatment offered must be appropriate to the situation²⁴. The proposed treatment that will benefit the patient sufficiently to justify the burdens it involves. Thus cardiopulmonary resuscitation should perhaps not even be raised for discussion with those who are so ill that evidence to dates shows they will never return home after a cardiac arrest, even if a cardiac output is restored temporarily. Whatever the theoretical ethic behind the situation, the importance of sensitive communication to the patient and the family cannot be overstated.

Withdrawing treatment

Decisions about treatment withdrawal are now being examined in the context of the Mental Incapacity Bill and also in the Patient Protection Bill²⁵ that has passed through the House of Lords but is unlikely to pass through the House of Commons due to lack of Parliamentary time.

Refusing treatment or requesting that treatment ceases is a decision of the same magnitude as consent to treatment; indeed at times it may have greater implications if the condition of the patient is life-threatening already. But it is fundamentally different from requesting a lethal injection, when a barbiturate with or without a curare-like drug is given with the express intent to induce death within a few minutes. For patients to take such decisions, the communication with them must again be of the highest calibre.

Such decisions are not 'passive euthanasia'. That is a misnomer that misleads the observer and the decision-makers. The decision to withhold a treatment that is likely to do more harm than good or to withdraw a futile treatment may be linked to the patient's death. But it may turn out to be a decision of great respect for the personhood of the individual, provided it is also what the patient really wants. Value judgements by others over a person's life are dangerous, utilitarian and can lead all down a nihilistic road.

Teaching communication skills to improve quality of life

As outlined already, communication with patients is at the heart of effective care. Difficult decisions can only be taken if the information communicated has been

understood, is framed in the patient's concepts and is within a context that the patient feels safe to question and to explore options.

Since 1989, University of Wales College of Medicine has run the Diploma in Palliative Medicine aimed at experience doctors who wish to expand their knowledge and competencies in clinical palliative care. The course requires satisfactory performance in a communications skills exercise, in which actor patients role play a simulated consultation and the student is assessed by peers as well as by an examiner. Recently the concept of mapping the consultation has been developed to look at the styles of these post-graduate mature students and their ability to pick up cues from the actor-patient.

Interestingly, the initial pilots reveal that those who score highly on the conventional assessment are the doctors who respond rapidly to key signals in the consultation. They also allow the majority of the consultation to be taken with the patient speaking, and use fewer words than those who have attained lower marks on their conventional score. They showed an involved style of discourse, with a personal conversation, which did not use passive speech. Their reflection of the patients' phrases gave the impression they were linguistically dancing together, as if going to a for in time to the music of the orchestra of the task in hand; sometimes slowly as the gravity of the situation was addressed, more rapidly when decisions were being re-iterated and summarised.

So perhaps the good communicator will be the one who engenders hope, the patient's agenda of their remaining ambitions. Perhaps it is the good clinician who gently steers the vulnerable patient towards life-affirming decisions and to resolution of conflicts. Yet those physicians must always abide by that basic tenet of care - first do not harm.

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