Practical aspects of palliative care

Dr Jürgen ABELA

Palliative Care is a relatively young medical specialty. In fact, it was only in 1987 that it was recognised as such in UK. The aim of this contribution is to highlight some important but practical points in the practice of palliative care, especially with respect to the ethical aspects of palliative care.

GETTING DEFINITIONS RIGHT: WHAT IS PALLIATIVE CARE?

In a nutshell, it is an approach in which the focus of care is to improve the quality of life of the patient and family, through a holistic approach, due to the fact that the disease per se has a limited prognosis. Such approach involves addressing the physical, psychosocial and spiritual aspects of the patient. In addition, an important aspect of palliative care is the provision of bereavement support for the family (Charlton, 2002).

Palliative care is usually delivered by a team, comprising a variety of professionals. Conceptually, there is a lot of overlap between the specialties of palliative care and general practice – both of them look at the patient from a holistic perspective, and both of them are specialties not defined by diseases of a particular organ system, as opposed to say cardiology (heart), neurology (nerves), haematology (blood), etc.

As highlighted above, Palliative Care is provided for a variety of conditions; many times, it is associated with advanced cancer, but other (incurable) conditions are usually included like motor neurone disease and end stage respiratory failure amongst others. The prevalence of disorders also affects the development of palliative care services e.g. in the African continent, the majority of patients receiving palliative care suffer from HIV/AIDS.

At times, palliative care is considered to be equivalent to terminal care. However, put simply, terminal care *is part of* palliative care, whereas the latter comprises a wider part of the disease process, where the functional status of the patient is much better.

TACKLING SYMPTOM CONTROL

Symptom control is certainly a hallmark of good palliative care. However, at times, this aspect of care is particularly challenging, especially in certain situations e.g. young patients or because of certain myths e.g. morphine accelerates the death process. Good symptom control entails first of all a thorough understanding of the symptoms the patient complains of; the concerns such symptoms raise; the effect these have on the family; and also what has been attempted so far to control such symptoms. It is only by going through such steps in a meticulous manner that symptom control can be addressed in a systematic and consistent manner. And it is only like that, that an agreed management plan can be drafted which suits patients and doctor alike.

BASICS OF PSYCHOSOCIAL CARE

It is not uncommon that psychosocial issues arise in the palliative care setting. After all, they are one of the pillars of palliative care. What is commonly difficult is to dissect the past from the present – in the sense that many times, people exhibit a variety of responses to the disease and the situations arising from it, and deciding if they are the cause of the response (premorbid personality/disorder) or a consequence of the disease can be challenging at times.

Depression is fairly prevalent in this setting but diagnosing depression in the palliative care setting is immensely challenging, since many biological symptoms of depression would be more or less present. In addition, being appropriately sad is quite common ('normal') in such setting, contrary to most other areas of medical practice where such sadness would raise alarm bells on depression. Finally, from a social perspective, it is important to consider that in addition to the strictly administrative aspects e.g. sickness benefits etc, one needs to keep in mind the changing role of the patient both with respect to his family (moving from possibly being a carer to being cared for) and also with respect to the society, where many times, due to illness, people lose their role.

TAKING DECISIONS AT THE END OF LIFE: HOW, WHO, WHEN AND WHERE?

For many people, palliative care is synonymous with end of life decisions such as artificial hydration and nutrition and the doctrine of double effect. However, it would be useful to consider a wider perspective. Indeed there are a variety of issues which come up and need to be tackled. Amongst these, for example, one finds the need to adequately inform patients about their diagnosis (and possibly their prognosis) and also the need to discuss the preferred place of care of people. The latter is quite novel for Malta; however, on mainland Europe it is gaining more and more recognition as an important topic for discussion.

It is difficult to adequately address the end of life decisions that are common place in palliative care in such a short space. However, prior to discussing some issue, it is important to draw a distinction between the setting in palliative care and the setting in other commonly cited difficult ethical situations such as persistent vegetative state. In the latter, the medical situation of the patient is more or less static, whereas in the palliative care context there is always an *underlying and progressive* disease process which ultimately (or possibly) will lead to the demise of the patient. Certainly, such differing clinical contexts must be considered when considering aspects of care and decision making.

Many times, the doctrine of double effect (DDE) is mentioned as a major and important ethical aspect of care. Hence, I would like to go into some detail with respect to the doctrine of double effect. In brief, this line of thought is used in situations where a possible intervention might have unwanted side effects but is seen to be beneficial for the patient. Thus this concept is used to guide the clinician so that patients are not deprived of proper symptom control.

To clarify thoughts on the DDE, below are four clauses which need to be fulfilled and summarise the DDE well:

- The *nature-of-the-act condition.* The action must be either morally good or indifferent. Taking as an example a non-medical issue, this means that one cannot invoke the doctrine of double effect to justify stealing objects, for example, since stealing is a bad action per se.
- The *means-end condition.* The bad effect must not be the means by which one achieves the good effect. This means that to alleviate the dyspnoea of a person, for example, you cannot kill him so that you end his shortness of breath. This thought is diametrically opposite to the concept of euthanasia.
- The *right-intention condition.* The intention must be the achievement of only the good effect, with the bad effect being only an unintended side effect. In this respect, and as George and Regnard (2007) point out, the most important and unique point in highlighting / supporting the intent of the doctor is the dose of drugs being prescribed.
- The *proportionality condition.* The good effect must be at least equivalent in importance to the bad effect.

The above ethical consideration with respect to the doctrine of double effect should not be limited to the clinician. Although, at present, the legislation in Malta does not provide for advance directives, discussing such issues with the patient (if possible) and also the family goes that extra way to facilitate a good outcome for care. There are a lot of myths with respect to the end of life and the effect medications have. Indeed, discussion of such issues is one step in the right direction to increase the awareness and avoid misconceptions. Unfortunately, it is still quite common to find clinicians believing that using morphine shortens life – when this has been proven untrue time and time again. (Good and Cavenagh, 2005; Sykes and Thorns, 2003). Other considerations which are common place include the issue that opioids cause addiction, which yet again, is not relevant in the palliative care setting.

Living in a closely knit community, pressure from family members not to divulge the diagnosis is immense and at times, to be able to get access to patients, such situations need to be accepted. However, every effort should be made by the clinician to (sensitively) inform patients about their condition, more so if one accepts the fact that the way forward in medicine is agreed management planning between clinicians and patients.

Another issue, which should be high on the agenda for discussion is the preferred place of care. It is indeed challenging – but necessary – to discuss such issues. In so doing, one allows appropriate planning of the final days of the patient, avoids crises as much as possible and at the same time needs to consider what is manageable at home. The latter includes also the care being provided by the informal carers/family.

In conclusion, palliative care offers a myriad opportunity to tackle and experience challenging ethical situations. This contribution will hopefully increase awareness about this topic and facilitate discussions.

Dr Jürgen ABELA MD, MMCFD, DCH(Lond.), MSc.(Warw.), FLCM, FRCGP(UK)
Medical Officer – Hospice Malta; Senior GP – Department of Primary Health Care
Email: jurgen.abela@hospicemalta.org

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