

Palliative Care, Hospices and Home Care

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Introduction

There are few things in our life which are certain. One of them is the certainty that we shall all die at some point and that we shall not be able to enjoy our wealth any more and our earned assets we need to leave will not make us immortal. This fact is so obvious and so depressing to most of us, that we spend significant parts of our earnings on denying, hiding or romanticizing death.

People are much more rich than ever before, they want to be treated for all kinds of diseases, their lives prolonged even at the price of severe side effects, permanent mutilation or chronic pain. Science and industry produce still more and more expensive medicines and 'high-tech' smart treatments. Most of these new methods, although based on sound evidence make a multitude of promises but they still can not cure. Doctors are willing to prescribe these medicines and new therapies; they want to try. Partly, because there is a continuing demand. A perfect business circle, where billions and billions are pumped around. And what are the societal results of this "perfect business circle"?

People certainly live longer than half a century ago. Many diseases, if noticed early, can be effectively treated and cured. However, most fatal diseases are still diagnosed quite late in their advanced stage. There are still more and more diseases which are due to excessive food intake, excessive smoking or alcohol consumption. The type of cancers that can be cured have not changed for nearly three decades. Yes, some fatal diseases have become chronic. Patients are not imminently dying of these diseases, but they can not get rid of them either. And also, thanks to modern technologies they can effectively hide them, still able to pretend they are healthy and may be that they will live for ever. The wealth is crating an illusion of eternal life which is gradually replacing belief in hereafter so characteristic for many religions. While the diseases are slowly progressing people are more and more afraid that their expectations will not be met in the future. Sometimes they try even harder to grasp the chance of cure against still increasing risks. The health costs of the last years of are a significant post of the health care budgets.¹ Part of these costs are

due to increased disability, but part is due to trying still more and more aggressive therapy to prolong life.

From ethical point of view all these new and high tech therapies are not obligatory; they are “optional” and/or “extraordinary” means while the basic care remains the “ordinary” mean and should be seen as the basic human right. In fact we spend so much money on “optional” treatment that we do not have enough (or better to say: do not want to spend enough) for the basic care of the same people. Even in the richest of countries, long term care is often of a poor quality with issues around inappropriate environments and inadequately qualified staff. Staying at home, when you are chronically or terminally ill is affordable only to some. Sometimes a wide network of family and friends can help, but families and networks have become smaller over recent years. Broken families, children living overseas and a small number of children per family are all reasons why terminally ill people frequently cannot stay at home and need to be admitted to institutions. Sometimes people outlive their peers and find themselves alone. Doctors know very well how to prescribe a one shot injection worth thousands of pounds but are not well trained in the care of the terminally ill person with, for example, complex physical and psychosocial needs.

This “consumption” model combined with rapidly progressing secularisation can not last forever. The concept of a self chosen death appears to emerge to people across the globe who may or may not be depressed, when they realise that their affluence cannot make them immortal, their doctors cannot offer any hope and they feel that their life is no longer worth living.^{2,3}

In a secularised world suffering lost its meaning. Psychiatrist Victor Frankl, a survivor of a Nazi concentration camp wrote “Man is not destroyed by suffering, he is destroyed by suffering without meaning”.⁴ In our wealth we are loosing the meaning of suffering. We simply forgot that suffering is inherent to our existence and in the commotion of disease and our searches for cure, we forgot to reflect on our life and on our suffering and we forgot that we may discover that there are many other people around us who suffer too and need our help and example. Suffering is not a goodness which should be aimed at, but it is an inevitable part of our human

existence which can be accommodated and accepted. It may break you but it may also make you strong. We should fight suffering to allow people to live and to adapt to the inevitable, but not to fight suffering just to add to unrealistic hopes and expectations.

And there is not much difference any more between the people who have a religious faith and those who do not. In that sense medicine has become for many their New Religion and doctors are their priests. God and Jesus Christ are still seen by some as saviours at a time of desperation who may help in the miracle of cure and denial of death.⁵ If you only pray hard enough!

Hospices

Hospices emerged against these developments. Hospice (*Hospitium*) in the Middle Ages were shelters for pilgrims travelling from the north of Europe to Rome or Jerusalem. Early hospices were staffed by monks, Hospitaliers, who cared for the exhausted, sick and dying pilgrims. Modern hospices date from the end of the nineteenth century.⁶ Although the first hospices originated and have been established in Ireland for decades, credit for the first modern hospice is always given to the late Dame Cicely Saunders who found inspiration in one of her patients who was a Jewish Warsaw Ghetto survivor.⁶ This charismatic woman founded St Christopher's Hospice in London in 1967. The legendary St Christopher was for her somebody who helped Christ cross the river and when trouble came, did not let him down. Our patients, she said, are like travellers, crossing the river, passing from one life to another. Dame Cicely's wish was to assist the dying, whether rich or poor (mostly with cancer), who needed experienced doctors, nurses and social workers who understood their needs. People who would be there to care for them and who would 'not let them down in difficult times' and who would also preserve their dignity up to the moment of their death and thereafter. The Hospice concept is deeply rooted in Christian spirituality and is embraced by many Christian Churches in Europe and outside it. However, because of its Christian character, even in secularised countries, hospices are not frequented, for example, by people of the Muslim faith. So, hospices by their concept may isolate some groups of dying people

who are uneasy with this. In Dame Cicely's vision, hospices are places providing "Safety & Peace of Mind". However, her main achievement is the integration of physical (medical) care with the psychological, social and spiritual needs of patients and the so called concept of holistic care. Traditionally doctors are trained in the physical aspects of the disease, leaving psycho-social and spiritual aspects to other professionals. Cicely taught us how to grow and become excellent in the whole of the care, which language to use and how to understand people "between the lines".

Hospices, developed in the UK in the seventies and eighties but it has taken 30 years before the concept crossed the Channel and spread throughout continental Europe. Hospice was seen as an answer to many problems in dehumanised modern medicine. Everywhere, where health care started to struggle with resources, hospices emerged. Most of them were developed from the bottom up, with the initiative of volunteers, families of deceased patients and local charismatic leaders. It was only later that they were, although not without some reluctance, accepted by official health insurance schemes and health care systems.

Palliative Care

Hospices started to grow as a separate, "ideal" world. Not integrating but irritating the "systems" which were unable to cope with reforms and changes. There was a dramatic need for better integration of the hospice concept with main stream medicine. In the early eighties St Christopher's Hospice was visited by a surgeon, Professor Balfour Mount from Montreal, Canada, who first coined the name of palliative care and palliative medicine as a more secularised concept that was likely to be more acceptable to mainstream medicine. Palliative care is holistic (holism from Gr.: *holos*: complete) in the sense of all including care provided together by different people from different professions. Palliative medicine is a small part of it which can be done only by doctors in cooperation with nurses like prescribing drugs, diagnosing symptoms, taking decisions about therapy etc.

The inspiration for the term palliative medicine, and a story which I personally find inspiring, can be found in the legend of St. Martin who met a sick and dying beggar at the gates of Amiens. When he saw the beggar, St. Martin took off his cloak (Lat: *Pallium*) and with a sword divided it and gave half of the cloak to the beggar. Apparently he said: "I can not cure you, but you do not need to suffer cold my friend". There are so many people around us whom we can not cure any more, but they do not need to suffer cold, pain, nausea and negligence. We can help them by sharing what we have. During the night Christ appeared in St. Martin's dream dressed in the cloak he had shared with the beggar.... The most appealing to me in this legend was the element of sharing.

Palliative Care is now a rapidly developing speciality among nurses as well as doctors. It is still not very well integrated in main stream medicine but at least it is not ignored any more. There are good training and research programmes attracting many young and older doctors and nurses who want to work not with their hands alone, but with their hearts and minds as well. The job satisfaction, not surprisingly, is so high, that the numbers of staff who are reported to be 'burnt-out' are the lowest in the whole of medicine.

Up until now only 3 countries in Europe have officially accepted palliative medicine as a medical speciality (UK, Ireland and more recently, Poland). There is still a great deal to be done. Even in the UK, the cradle of palliative care and palliative medicine, the concept is not yet well integrated with other specialties and is frequently seen as a Cinderella specialty. The dilemma of course is on the one side to integrate into main stream medicine, but on the other side, not to lose the unique character of the specialty. Some people are dreading the possibility of becoming "symptomalogists" instead of palliative care doctors or nurses.

Diversity of services

Hospices in different countries are not uniform - they differ from one another as local needs differ everywhere. In countries like Holland, where there is a strong network of nursing homes, the concept of a hospice was not accepted for many years.⁷

Absence of hospices have led to the idea that euthanasia may be the only viable alternative to unrelieved suffering. They emerged there only when the permissive euthanasia law became operational and some people who could not accept euthanasia as an ethical choice went to search for alternatives. Hospices of all kinds emerged as a response to the pressure of euthanasia. Some of the secularised Dutch hospices initially accepted euthanasia as a possibility, but reversed this policy later as it did not fit the atmosphere and the spirituality of the hospice. Doctors who volunteered as second opinion consultants in cases where euthanasia was being considered, discovered that before that step was taken, a lot of others things could be done which usually made euthanasia unnecessary.

Palliative care is not only perpetrated in hospices. Most of it is done in the community by general practitioners and district nurses, sometimes assisted and advised by the more specialised services like (in the UK) Macmillan nurses or hospices-at-home organisations. Most palliative care needs will be met by first line generalists who practice a “palliative care approach”. Only some patients need the care of specialists. Besides hospices there are a multitude of other institutions like hospital based palliative care units, palliative care support teams, palliative care help-desks, nursing homes etc providing palliative care and fulfilling both local and national needs.

Patients usually come (or it would be better to say: should come) in contact with palliative care services in the early stages of their disease, or at least in the first stage of terminal illness. At this stage they still have a potential to improve and remain at home and enjoy being there, autonomous, surrounded by their family and loved ones. But in the changing world it is still more and more difficult to discharge patients home. Facilities provided at home are scarce. There are not enough good quality nursing homes worldwide for an aging society. Palliative Care facilities are in danger of being blocked by patients who cannot go home, and in that way some hospices may become institutions with beds for the incurably ill who are needing long term care, rather than hospices providing palliative care in its dynamic form. It is in the hospices’ own interest to help maintain good standards of care for patients in the community and in nursing homes so that the discharge of patients and communication between different institutions can be easy and supple. Patients may

be readmitted to hospices in the later stage of their disease when again, an expert environment is necessary for their care.

Only Cancer?

Early hospices mainly admitted patients with cancer and especially those with solid tumours. The hospice concept struggled for decades with opening its doors to non-cancer patients such as those with chronic lung, heart and kidney diseases, mainly because the processes during these diseases are much longer and less predictable. One of my patients said “you are very good in sprinting but much less so in marathon running”. Dependent on local needs many hospices are devoted to the treatment of patients with AIDS, very much like the leper hospitals of the Old World. Hospices tend to serve the poorer parts of society as the richer people can afford care at home. Most married men usually die at home, cared for by their spouses. Widowed women, tend to choose hospices if they develop cancer, where they can be cared for not only by competent staff and volunteers, but also by their families. Increasingly, many patients who require hospice care come from problematic, complicated and broken backgrounds - the so called “patch-work” families and relationships. Such patients require far more resources and expertise in these areas, not only from the doctors and nurses but especially from the social workers.

Younger patients with terminal illnesses also come to hospices in search of specialist treatment and expertise usually lacking in hospitals and at home.⁸ Patients with malignant blood diseases rarely come to hospices as they tend to be treated till the end in ‘high-tech’ environments in hospitals. In that way the technology frequently denies them the rest of the terminal phase.

Beside hospices for adults, there are numerous hospices for children and adolescents only. They differ from adult hospices as they specialise in providing respite care for young patients and their families. Children who are dying at home are usually cared for by their parents, assisted by expert hospice-at-home teams. The latter organisations bring their expert knowledge to the home to support and complement, but they do not replace existing structures.

Finally, hospices should not only be seen as bedded units. Most of them also have day care units where people who are still at home can come for one day a week for example, for psychological, social, spiritual, nursing and medical support. These services are among the most powerful elements of institutions providing palliative care.^{9, 10}

Multidisciplinary team

The most powerful aspect of palliative care is the concept of integration of many disciplines together.¹¹ Not working alongside each other or after each other, but with each other. Understanding and being interested in what the others are saying and giving them the space and opportunity to work. The boundaries between the specialties and expertises are blurred. The doctor in palliative care should be ready to help the nurse but also to understand the spiritual needs expressed by the patient. The chaplains should also understand that the patients may sometimes get very agitated and irritated because they are constipated or in pain.

The relationships within the team are not hierarchic but are more like the pieces that fit together to make up one pie. They do exist alone, but they work at best when they are together. Together they are able to crack even the most difficult problems. In palliative care the distance between the carer and the cared for is diminished but in order to do this, the carer needs to feel the support of the whole team behind him so that he does not need to 'retreat' from the patient or become emotionally 'burnt out'.

Parts of the multidisciplinary team work with the bereaved. This includes the patients and their relatives. It is an integral part of the concept of palliative care. Half of what we are doing in palliative care we are doing for the patients but another half is done for those who need to carry on later with the burden of loss.

The multidisciplinary team would not be complete if it did not include the expertise of the patient himself and his family. In that way the doctor and the nurses are the

experts in the diagnosis and treatment of the disease and the objective part of it, while the patient is the expert in the illness and the more subjective aspects of it. Palliative care gives the opportunity for experts of both kinds to meet. They need to respect each other and work together.

Concept of dignity

One of the most important issues in palliative care is to preserve patients' dignity at the end of their lives. Not to reduce them to objects of care who may be perceived as nothing more than corpses being artificially fed, hydrated, ventilated and drained with catheters. Palliative care allows people to be cared for as human beings who are able to feel and sense, but also inherent to this, able to suffer as well. The suffering may be minimised but can not be taken away from the aware and conscious human being. If we are able to take away the suffering caused by pain, we hardly can touch the suffering of transition. Suffering can also have different faces, sometimes it can be bearable, sometimes not. Harvey Chochinov did a lot of research about this.¹² Dignity has been defined by him in terms of being worthy of honour, respect, or esteem. In his study 15% of patients indicated loss of dignity. Patients with intact dignity were less likely to indicate a desire for death, or loss of will to live. Appearance and body image emerged as the strongest predictor of dignity in the researched group, followed by "burden to others", requiring assistance with bathing, uncontrolled pain, and location of care. All of the patients declaring loss of dignity were still in hospital unable to go home. Loss of dignity was something they experienced most of the time, and was associated with a feeling of being degraded, ashamed, or embarrassed. Women who cared for their husbands, children and family for the whole of their life and who may have done the dirtiest and most 'undignified' jobs one can imagine, are likely to feel a loss of dignity when somebody needs to help them on the commode or wipe their bottom. In that sense loss of dignity is equal to the loss of their important role in life of others. A loss which can hardly be compensated by anything.

The natural Process of dying

Terminally ill patients enter the terminal phase of their life when their disease does not respond to the treatment, or such treatment brings more harm than good and they together with their doctors decide to stop it.

In the first stage most people may suffer from unrelieved symptoms and anxiety, they are frustrated by the failure of treatment, their hope is gone and they feel despair at facing progressive losses. This is a time of instability and a loss of confidence. In this stage many patients are depressed and may even consider suicide or euthanasia.¹³ A shelter, expert support and symptom control, warmth and friendship are in many cases able to create a new stability and a new balance where the pain and other symptoms are adequately controlled, without inducing cognitive failure.(stage 2) In that way there may be a new space created, a spiritual space where there is enough time and opportunity for “unfinished business” and to live until death. The quality of life at this stage is measured by the qualities of relationships patients have and can maintain. Many patients are able, at this stage, to accept their nearing death and be of great support to others. The thought of eternal life may become important and comforting at that moment. This acceptance should not be seen as giving-up life, but losing the fear for what will happen next.

Here Figure 1.

These situations are of great reward, privilege and inspiration to all of us working in palliative care worldwide. Interestingly, patients who in the first stage were contemplating suicide or euthanasia, usually withdraw their request, change their mind and are happy with new hope and “new life”. There is a change in the target of their hope, from the irrational hope to be cured (sometimes in a miraculous way) to the more realistic hope of a peaceful death, hope that their spouses and children will survive the loss and will build a new life without them. All that we try to do in palliative care is to create this spiritual space and facilitate the process of adaptation, allowing the patient their own will on how this space should be filled. Dying oncologist Dan Frimmer said to a journalist from Time: “You can not die cured but you can die healed”.¹⁴ This period of balance and stability may last for one day or many weeks or months.

The third stage is heralded by the appearance of new problems and complications with rapid progression of symptom severity. Drugs which worked effectively for weeks or months apparently do not work any longer. The pain may surge up and high doses of drugs may be needed. The pain may be so severe and need so many pain killing drugs that the doctor and the patient need to accept that the patient may lose the ability to communicate with their surroundings and may even fall unconscious. Here emerges the concept of terminal sedation which is widely practised in hospices worldwide. This concept embraces the idea of the administration of sedatives as the last resort in the care of patients with refractory symptoms which are causing enormous stress to the patient and their family. It is based on the doctrine of a double effect where the bad effect of decreased consciousness and potential speeding up the patient's death is necessary for the good effect to relieve the suffering.¹⁵ This concept is distinguishable from euthanasia where the relief of suffering is attempted by explicitly ending the life of the patient.¹⁶ However, there is a lot of anxiety and uncertainty in the world around terminal sedation and this anxiety may increase the suffering of many millions of dying patients. Although it has its origins in the Catholic Church and Rome terminal sedation is not widely accepted by some Church communities who sometimes think that suffering similar to the suffering of Christ is needed for redemption. Even allusion to this makes many secularised people furious and very sad.

Moral issues in Palliative Care

There are many moral issues in end-of-life care. First of all is the balance between meaningful life prolongation and acceptance of the inevitable. By the use of many drugs and treatment methods virtually nothing is "natural" and this is seen as "normal".¹⁷ The doctor together with the patient and his/her family may agree to discontinue futile treatment like dialysis which may result in rapid deterioration and death.^{18, 19} Doctors, sometimes unwillingly, may institute treatment with antibiotics or other drugs that may change the course of dying for weeks or months; these situations which are not always welcome can be very confusing.²⁰ The family may be unprepared and unable to accept that their loved one is dying and may insist on the use of 'high-tech' approaches to keep their life going even at the high price of

suffering. The imminently dying person may be in so much pain and they may suffer so much from other symptoms including agitation and confusion, that terminal sedation may seem the only comforting measure.^{13, 21} Others will say that there is no moral difference between terminal sedation and euthanasia as both end in the patient's death by the use of medical technology.²² People working in palliative care believe that both these things are close to each other, but at the same time, are very well distinguishable from each other.²³ Turning their back on people in need, pretending that things are too close to euthanasia and thus are dangerous or forbidden, is as wrong as performing the act of euthanasia itself. Doctors should learn how to deal with patients who consider euthanasia to comfort them, and relieve their anxiety without needing to do things which they do not wish to do.²⁴

Doctors and nurses working in palliative care may feel sometimes squeezed between Christian ethical norms and values and what is expected from them by the patients and their families. At least part of this can be solved by better education in medical ethics.²⁵ Most doctors believe that they may refuse treatments and procedures requested by patients and their families which do not accord with their beliefs and their conscience.²⁶

In conclusion

Palliative care and hospice care will never become a fashionable specialty. It will always attract good and kind people willing to help others. It will probably always be under-resourced as palliative care has no, or only few connections with new drug developments and industry. However, it should maintain the shelter function envisaged by Dame Cicely for the weak and frail, for those without hope who are suffering and for those who are troubled. The concept is now "secularised" but it is still deeply rooted in the Christian faith and spirituality. Struggle as they do, hospices do not always provide what people want. On the other hand, hospices frequently have a monopoly on the care of the terminally ill, so patients have little choice. Hospices and workers in palliative care should never become arrogant and dismissive of others. Hospices struggle with many ethical issues such as discontinuing futile treatments, postponing of hydration at the end of life and terminal

sedation. In many countries the law states what is right and what is wrong, not the conscience of the doctors, nurses and social workers involved in care. These people deserve more moral support and understanding from the Church authorities who should also endeavour to better understand the people on the ground, their struggles, doubts and sometimes impossible choices.

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