## The development of palliative care nursing essay



The philosophy and principals of palliative care are well established in many countries. The author of this assignment will look at this development and critically analyse the development of the palliative care concept and examine the impact of these developments in the provision of palliative care services to patients and families in Ireland. Let us first define the term Palliative Care as per the 2002 definition from the World Health Organisation:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". This definition differs from previous ones as it makes no reference to cancer and so implies that palliative care should be accessible to all patients with life threatening illness.

The author will base the analysis of the development of Palliative Care services within Ireland on the philosophies and principals of autonomy, respect, dignity, equity and fairness. Palliative care should be based on the needs of the patient regardless of diagnosis and for the purpose of this essay the writer is going to show that this is not the case.

Death in the 19th century was caused mainly by chronic illness of longer duration in contrast to deaths from infectious diseases which were common in the 18th century and more rapid. This shift in duration and possibility of treatment led to the change in practice of people dying at home to the

development of religious institutions for the dying. It was during this period that the term Palliative care emerged in preference to terminal care as patients were being treated for their symptoms earlier in their illness (26) the early hospice movement in both England and Ireland were religious institutions whose Philosophies were based on the concept of a good death through spiritual healing and saving the soul. They were run by religious orders and therefore religion had a profound influence on the rituals and philosophies surrounding the care delivered to patients. By the late nineteenth century it was emerging that care of the body was primarily more urgent and to alleviate suffering than spiritual needs (25) As stated in Palliative Care in Ireland, the foundation of the hospice movement in Ireland began in the 1870 with the foundation of St Patricks Hospital in Cork under the guidance of the Sisters of Charity. It was mainly due to the influence of Sr Mary Aikenhead that the Irish Sisters of Charity grew and evolved the concept of hospice care in Ireland. They were responsible for the foundation of not only the first hospice in St Patricks, Cork but also the convent where Mary Aikenhead spent her final years which opened as Our Ladys Hospice for the Dying in Harold's Cross in 1879. 3

Elizabeth Cooper Ross during the 1960's was one of the early pioneers in reaching the whole concept of death and dying. It was her writings and well documented philosophy on the stages of dying that set the seeds of development for the early hospice movement. (31) According to David Clark, Palliative care in Western Europe made rapid progress from the early 1980s, It began with the foundation of St. Christopher's in England in 1967 by Dr. Cicely Saunders, but it was ten years until the first services began to appear

elsewhere in Sweden (1977), Italy(1980), Germany(1983), Spain (1984), Belgium(1985), France(1986) and the Netherlands(1991). 2Up to this time the main focus was on treatment and cure, with the dying patient receiving very little input and viewed as a medical failure. These concepts of dying were further built upon by the extensive work and writings of Cicely Saunders whose message was " you matter because you are you and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully but also to live until you die"(19)This concept of the " whole person" incorporating physical social and spiritual care was now part of the philosophy of the hospice movement. By the mid 20th century the medical neglect of the dying and the development of the concepts of personal dignity, autonomy and respect had emerged. This holistic approach is further extended by the WHO definition of Palliative care 2005(1) which also incorporates the care of the family, the right to early detection assessment and treatment and the provision of palliative care to all people regardless of diagnosis. It is in light of the developments of these concepts that we will examine how Palliative care has progressed in Ireland.

## Irish Experience

Although we have achieved a great deal since the recognition of palliative care as a speciality in Ireland in 1995 there are great variances in the services provided in different health board areas throughout the country. It wasn't until 1995 that Palliative care became a speciality in Ireland, at that time there were only two palliative care consultants in the country , only three hospices and a few hospice home care teams. (13)According to the Palliative Care Study in the European Union in 2008 Ireland ranked second in https://assignbuster.com/the-development-of-palliative-care-nursing-essay/

2006 in a European study of Palliative Care services . It states that in 2008 there were are 147 palliative care beds for a population of 4. 2million and 8 hospice teams , 28 home care teams with 22 hospital support teams , 5 day centres and 1Paediatric hospital support team.(31)So while these figures demonstrate a very positive review on the development of services in the country as a whole , there is still much to be achieved in the principal of equity and fairness in palliative care for all life limiting illnesses.

The National Advisory Committee on Palliative care in 2001 chaired by Tony O'Brien issued a report on palliative care services in Ireland and set out recommendations for the development of services to be implemented over the following 5 -7 years. This report subsequently became government policy. As specified in this report all patients should have access to specialist palliative care services when and where these are required (16) In the 2008/09 report on End of Life Care it was found that cancer patients in the assessment of nurses had better End of Life care in hospital settings than those with circulatory disease, respiratory disease and with the worst care end of life care being attributed to patients suffering from dementia. This outcome was thought to be mainly due to the fact that Cancer admissions were usually planned admissions, with single room accommodation if possible. There is usually multidisciplinary team involvement and better communication with greater family participation and family presence at time of death. This in contrast to dementia end of life experience which scored the lowest are more likely to be nursed in multi - occupancy rooms with less family involvement and presence at time of death 5(3. 5. 1 Cancer Deaths p. 91). It is as a result of these recognised deficiencies that the concept of"

Palliative care for All" becomes an essential part of the future development of services. The Irish Hospice Foundation has also sought to address this inequality issue of availability and access to palliative care services for all patients faced with life limiting disease by the publication of the Palliative Care for All report in 2008. The term "palliative care for all" is based on the expectation that Palliative care should be based on "need and need alone", it should be individualised, flexible, responsive, and accessible where and whenever necessary. This report concentrated on patients suffering from chronic obstructive airways disease, dementia and heart failure. In 2006 circulatory disease accounted for 48% of deaths (29% were cancer related) Three action research projects in the areas of dementia, heart failure and advanced respiratory disease were implemented to establish a framework for palliative development. 6The future developments of palliative health care should focus on professionals striving to implement the same standard of end of life care to all patients as those with a cancer diagnosis. The services provided to children in Ireland are also very inadequate with most children suffering from life limiting illnesses dying in hospital due to the lack of specialist palliative services in this area in the community (32) This issue is being addressed by the Irish Hospice Foundation with the establishment of a five year program to develop a hospice home care service for children. (33)Staff with experience in Palliative care should advocate and show leadership in expanding their role to include all patients regardless of diagnosis The author will now examine the gap in this concept between aspiration and reality in her local health board region

Autonomy for the patient is recognised as being paramount in achieving" a good death" (21). Patients should have choices in where they receive care and treatment in the last phase of their life. Respect for the patients individuality and the provision of an environment which facilitates the highest standard of care, affording the patient and family privacy, rest and space for communication throughout this difficult period. This requires regular discussions between the health care professional and the patient(20)and is dependent on the provisions of suitable facilities. The author will now examine the gap in this concept between aspiration and reality in her local health board region.

The recommended number of specialist palliative care beds in the south is 108, at the moment there are only 26 specialist beds , 24 in St Patricks Marymount and 2 in Waterford Regional Hospital (22)Specialist beds are dependent on the level of training and skill of the staff in these units and the involvement of a multi disciplinary team(23). In areas where there are no access to inpatient palliative care units, services are often provided in care settings for older people with the clinical guidance of a community based Palliative Care Clinical Nurse Specialist .(17) An area consultative committee in the HSE south was formed in 2006 chaired by Fionnula O'Sullivan and given the task of assessing the current provision of intermediate palliative care beds in community and district hospitals. It was also to examine the potential of providing palliative care services as laid out in the NACPC report 2001. A sub committee was formed in 2007 to carry out this work. The results showed 42 intermediate care beds in the HSE south, 30 located in the HSE south west and only 12 in the HSE south east. This survey included

residential care settings similar to the author's work place and the report identified these buildings of which 35% were over one hundred years old as being one of the biggest challenges to giving appropriate care to the palliative care patient. This is due to the environmental structure of these buildings with poor facilities and accommodation only available in multibedded wards. (14)

How can we claim to offer dignity and respect to the palliative care patient whose only access to an acute hospital bed is through A&E and has to endure the inhumane long admission procedure on a hospital trolley? . A moving account of such a case was experienced by Kay Coburn who accompanied her sister Mary, one month before her death through the A&E in Galway University Hospital bed in a medical ward. (24). In an audit carried out in 2008/09 it was found that hospital admissions through A&E had a negative effect on patients care at the end of life(34)

The whole concept of Autonomy which can be defined as a state of self governing has its foundations in the patients right to choose. This is the right to accept or refuse treatment, which may be curative or palliative.

(27)Truth telling is paramount to the patients right to make an informed decision and this right, so often denied to the patient in the past is now an accepted "centre of excellence for Palliative care". It took 25 hours of waiting for Mary to gain admittance to a

principal of palliative care in Ireland. The extent of information given to any patient is a matter of careful analysis by the clinicians involved and an essential component in advance care planning. (28)Randell and Downie

while accepting the patients right to choose argue that this right should be limited by the medical judgement of the physician and the ethical decisions resulting from resource constraints(29) It is necessary also to mention the development of" Not For Resuscitation" decisions between patient, family and physician. This development within the Irish health system has afforded dignity to the dying process and is dependent also on the informed consent of patient and family. In light of these positive conceptual developments of autonomy, dignity and respect it must be remembered that the debate is ongoing in Ireland on the right to assisted suicide or euthanisa but this is not acceptable practice within the Palliative care philosophy in Ireland.

## Conclusion:

As expressed by Robert G Twycross in his journal of Pain and Palliative Care, the idea of palliative care for all is possibly a utopian idealism as cancer worldwide already accounts for 6 million deaths. He does suggest that it will only be by the inclusion and education of all health care professionals in providing palliative care and their acceptance of death as an integral part of health care that this idealism can become a reality. (7)There are 56million deaths approximately worldwide each year and it is estimated that 60% of these deaths would benefit from palliative care (12). These figures put into context the aspirations of the World Health Organisations definition. The concept of palliative care is difficult to promote as Cure and to preserve life is the primary objective of good health care and death is often seen as failure by health professionals.

The way forward in Palliative care will be mainly built around improvements in assessment tools to standardise identification of patients on needs basis and to give access to these patients to the right care, at the right time by the right people. (18) Because of resource implications into the future and the provision of specialist palliative personnel, one must review the delivery of this service in order to extend its role. Specialist Palliative Care has developed with the perception that it requires specialist ideas and expertise. But as discussed by Randell and Downie this perhaps should not be the case and the future of Palliative care lies in its strength to educate all health care professionals in the skills and treatments necessary to extend the concepts of palliative care to all.(30)They agrue that the whole concept of palliative care arose out of the fact that the dying process was to technical busy and medically involved and now that ethos is slowly creeping back into this speciality. There in lies the need to step back simplify and see the future in providing a palliative whole person concept by all health care professionals to all patients in who need it