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The Hospice Movement

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ABSTRACT: The Hospice Movement had its beginning in the U.K. some three decades ago and has now spread to over 70 countries throughout the world. It is rooted in the Christian ethos of profound respect of the human person and of human life threatened by inexorable and progressive disease. It has given rise to the new medical specialty of Palliative Medicine which embraces the most recent advances in scientific medicine and psycho-social science in its daily practice of succour and relief of the suffering of patients and their families. The Hospice idea came to Malta ten years ago. It is now well established as a voluntary organisation providing services to sufferers from advanced cancer and motor neurone disease.

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Introduction

The Hospice Movement, or as it is sometimes called, the Modern Hospice Movement, has now spread throughout the world. Like other global "Movements", such as the Trade Union Movement, it embodies a philosophy of thought and action that affects the lives of very many of us. However, although it is described as 'Modern' by historical standards, the fundamental concepts on which it stands are as old as Christianity itself. What is remarkable, is the mix of circumstances and personalities that led to its emergence and diffusion throughout the developed and developing world.

The early hospices

The provision of some kind of organised care for the indigent, incurable and dying person can be seen in the Christian states in Europe from as early as the fourth century after Christ. Julian, nephew of Constantine the Great, and his successor as Byzantine Emperor enjoins his priests[1] "to establish hospices in every city and thereby not to permit others to excel us in good deeds". Julian the Apostate might have been referring to Christian groups whose actions in this regard made some impression on him, a serious minded and ascetic emperor.

The word hospice derives from the Latin word hospitium meaning guest-house. The earliest hospices were generally to be found within the precincts of religious houses and were intended to take in and look after weary pilgrims journeying to the Holy Land or to some Christian shrine. The essential quality of these hospices or guest-houses was that the care and hospitality they offered was open to anyone and was free of charge. It was offered out of love and respect for the traveller as exemplified in the parable of the good Samaritan, and Christ's answer to the question posed by the expert in the law, "Who is my neighbour?" The number of these hospices became greatly reduced with the coming of the Reformation, being replaced in some measure by Poor Law Institutions in the U.K. In our own context one finds the establishment of "L'Ospizio" [2] by Grand Master de Rohan in 1785. This institution took in the aged and infirm, the young incurables and, over the years, also offered refuge to sick and destitute prostitutes. It lasted for one hundred years.

The swelling of its inmate population without the necessary increase in its financial resources reduced it to "an insanitary and wretched hole and a scandal to the age in which we live". This was the considered opinion of the Governor of Malta at the time, Sir J.A. Lintorn Simmons who visited the Ospizio in 1885. It ran counter to another opinion expressed by an expert [3] sent from London, Sir P.G. Julyan who, in his "Report on the Civil Establishments of Malta", London 1880, stated that "the Ospizio, not being a curative institution, should not be made in any way attractive, for fear of encouraging the people to be improvident". Lintorn Simmons' view prevailed. The Ospizio was closed and a new institution named after St. Vincent de Paul was opened in 1892. The word "Ospizio", however, continued to conjure in people's minds a public place where the most wretched conditions awaited the weakest members of society, the poor and the dying.

Hospices in the 19th century

With the social upheaval brought about by the Industrial Revolution and the increasing urbanisation of large populations, the lot of the indigent and incurably sick and dying became even worse. Towards the middle and latter half of the 19th century the first responses to this disquieting situation began to appear, firstly in Europe and closely followed in the United States and Australia.

In 1842 the French widow Mme. Jeanne Garnier opened her first Home for the Dying or Calvaire in Lyn. Others, with no strict connection but often by Christian

religious organizations both Catholic and Protestant, followed. The Irish Sisters of Charity opened Our Lady's Hospice for the Dying in Dublin in 1875. The same Catholic Order set up the St. Joseph's Hospice in Hackney, East London in 1905.

Protestant hospices that opened in London about that time were the Hostel of God, later the Trinity Hospice, in 1891 and St. Luke's Home for the Dying Poor in 1893. In the U.S.A. the Calvary Hospital opened in New York in 1899. All these hospices laid emphasis on the compassionate care they gave their patients and clearly drew their inspiration and motivation from the teachings of Christ. In most of these homes the word "Hospice" was retained and today it is still regarded as a useful 'umbrella word' covering palliative care across the whole ecumenical spectrum, although difficulties have been raised by some religious leaders. Lord Jacobwitz [4] has expressed the view that "neither hospice (a word that has Christian connotations in Jewish minds) nor any other term suggestive of a fatal prognosis should be used in the Jewish context ..." and Dunstan and others speak of the "religious neutrality of hospice care for each patient in his individuality having sound theological justification being not merely a necessary accomodation to life in a secular society".

Birth and spread of the modern hospice

The development of hospice care took another crucial turn with the far reaching advances in scientific medicine and medical technology that occurred after the end of World War II. These remarkable advances have proved to be of immense benefit to large numbers of people throughout the world.

The common infections were controlled by specific antibiotic therapy; new techniques in mechanical cardio-respiratory support paved the way for opening new horizons in surgery particularly that of cardiac surgery; other forms of organ support like dialysis gave new hope to sufferers from end stage renal disease; organ transplantation became a more widely practised life saving procedure.

This efflorescence of medical technology, however, may have contributed to the general attitude of the medical profession in being more interested in high-tech curative procedures and therapies than in persons suffering from incurable and progressive disease approaching the end of their lives. The charge raised by the lay public that doctors, particularly in the case of patients suffering from advanced cancer, often lost interest saying nothing more can be done, appears now to have had some substance.

It certainly had a profound effect on the pioneers of the Modern Hospice Movement and especially on Dr. Cicely Saunders. Dame Cicely Saunders O.M. [5] occupies a unique position in the making and leadership of the Modern Hospice Movement. She is recognised worldwide as the Dean and guiding light of the Movement.

Dr. Saunders was brought up in an affluent agnostic London household and had finished her time at the Roedean Boarding School for girls when World War II broke out in 1939. She chose to train as a Nightingale Nurse and worked in the wards at St. Thomas' Hospital in London. Her nursing career was cut short by a health problem (a lumbar discopathy) for which she was to have surgery later. Her time in the surgical wards was long enough, however, to leave her with the feeling that the suffering of patients dying of cancer was seriously under-estimated and not adequately addressed.

There followed a period of training as an Almoner at Oxford where she came under the influence of Dr. William Temple, a former Archbishop of Canterbury and of C. S. Lewis, an Oxford don with a deep interest in religious questions. At about this time, the break up of her parents' marriage came to a head. It was a difficult and soul searching time for her. She went on holiday to Cornwall with three of her University friends, all convinced Christians and while there went through a deep and disturbing spiritual experience which led to her being received into the Evangelical Anglican Church. From then on, her religious conviction played a determinate role in the development of her ideas on Hospice Care and Philosophy. Her religious orientation, however, remained widely ecumenical, embracing all faiths and excluding nobody.

Eager to further the quality and impact of her work with the mortally sick, she went on to become a medical student at St. Thomas' Hospital at great personal sacrifice and after qualification at a mature age, sought and obtained a scholarship to research into the treatment of persons with advanced cancer. She chose to go to the renowned Catholic Hospice, St. Joseph's in Hackney, East London. There she spent an extended period of seven years, doctoring and researching. She confirmed the validity of basic and important new modes of therapy such as the scheduled, round the clock prescribing of analgesics and the matching of the right kind of analgesic in the right dose to the precise nature and severity of the pain, the so-called "Analgesic Ladder". The new advances in clinical pharmacology such as the phenothiazines, the anti-depressants and anxiolytics, the synthetic steroids and anti-inflammatory drugs were all incorporated into a revised and updated Hospice Formulary.

With the better understanding of family dynamics and bereavement emanating from studies undertaken at the Tavistock Centre for Human Relations in the late '50s, the importance of psycho-social factors came to the fore as matters bearing on the overall suffering of the patient and his or her family. The concept of total pain was evolved and developed to become one of the preoccupations of the hospice approach. It necessarily meant that the manifold needs of a gravely ill person and his family could not be met simply by the attentions of a doctor and a nurse. The team required to be widened to include a clinical psychologist and counsellor, a social worker and a spiritual advisor. The multi-dimensional nature of the suffering could only be adequately addressed by a multi-disciplinary team approach. And the above disciplines were not necessarily the only ones that could lighten the burden of dying and bereavement. The essential multi-disciplinarity of the care required to help relieve the suffering of the dying was pressed home in the 1960s by the work of two physicians, Elizabeth Kubler-Ross and Colin Murray Parkes.

Dr. Kubler-Ross interviewed some 600 grievously ill patients in a large Chicago general hospital and set out her results in a book entitled "On Death and Dying" published in Toronto in 1960. The book had a profound

effect on health workers caring for persons with advanced cancer and greatly promoted the growth of hospice services in the United States, particularly that of Home Care.

In the United Kingdom, Dr. Colin Murray Parkes' work influenced Dr. Saunders in the latter part of her nineteen year period of preparation and planning for setting up a modern hospice run along lines she had painstakingly worked out over a long time. The long gestation culminated in the opening of St. Christopher's Hospice, in Sydenham, South London in 1967. The Modern Hospice Movement was born and St. Christopher's became the Mecca of the Movement attracting doctors, nurses and other health workers from all parts of the globe eager to learn the modern, humane hospice approach in the care of the dying, preached and now practised by Dr. Saunders in her own hospice.

Malta Hospice Nurse with Dame Cicely Saunders at St. Christopher's Hospice.

Notable among them was a doctor from Canada, Dr. Balfour Mount who spent sabbatical years at St. Christopher's. After returning to Canada, he opened the first Palliative Care Service at the Royal Victoria Hospital in Montreal in 1975. It was Dr. Balfour Mount who first used the term "Palliative Care", finding the word "Hospice" inappropriate in Canada, as it meant custodial care. This also applies to the term "Ospizju" in the Maltese context.

The spread of modern hospices and hospice services to other countries gathered momentum in the 1970's. From the U.K. to North America to Europe to Australia to India and S.E. Asia to Africa, the message of the Modern Hospice Movement spread and took root. Palliative Medicine became the newest specialty in Medicine recognised by the august Royal College of Physicians of London in 1989. Professorial Chairs in the new specialty were set up in Britain and N. America. To date, there are seven such Chairs in medical schools throughout the U.K. Public Health Services in various countries included Palliative Medicine and Palliative Care as one of their important concerns and set up Palliative Care Units within their Health Service structure.

In advanced Western states in Europe and N. America, governments work hand in hand with voluntary organisations in this field providing material and moral support and demonstrating how the mutual support of state and private organisations work to their mutual advantage. The burden of cost to the State is lessened while the quality of care services that are offered are given a more humane and personal face. Moreover, these services are of great significance to the weakest and most vulnerable members of society, the less well-off and the dying.

Hospice today in Malta and elsewhere

Within our own shores the idea of setting up a hospice service was first mentioned by a doctor at a Meeting called by the Director of the Cana Movement to discuss "Bereavement Therapy" in 1987. A Steering Committee was formed to prepare for the founding of a voluntary society which was to be called the Hospice Movement in Malta, the object of which was to organise hospice type services for persons suffering from an advanced stage of cancer and motor neurone disease. These services were to be free of charge, and modelled on those provided in Modern Voluntary Hospices in the U.K. and N. America. By 1988, a draft statute was prepared. It was adopted and signed by ten founder members in January 1989.

In October 1988, a highly successful three-day seminar was held at the Holiday Inn in Tigne to introduce the idea of Modern Hospice or Palliative Care to Health Care Professionals in Malta. A team of five British experts were invited to lead it, including Mr. Derek P. Spooner, a Hospice Planning Consultant, Mrs. Anne Brown, a Macmillan Nurse and Consultant on Cancer Relief, and Dr. R. Corcoran, Medical Director of Hayward House, a Continuing Care Unit within the N.H.S., with whom we developed a special relationship of co-operation and friendship.

It became evident at this stage that the operation of the Hospice Movement in Malta would have to be based on providing day care and home care services. The availability of back-up beds in a voluntary in-patient unit could only be a long term aspiration.

With the shorter term goals in mind, suitable premises to house the Movement's day centre were searched for and found with the help of the Church Authorities in part of the Cini complex at Santa Venera. After the necessary refurbishment at the Movement's expense, the day centre was officially opened in May 1990.

There followed a period of development of day care and home care services by recruitment of the required professional staff, mostly nursing and administrative, plus a very essential corps of motivated and disciplined volunteers. All of this was, of course, underpinned by the excellent performance of the Movement's Fund Raising Sub-Committee, active among whom were a number of generous minded British residents.

As the Hospice Services developed and became more widely known, there was a significant increase in the number of families seeking help and support from the Hospice. The number of deaths from cancer in our Islands had reached 700 per year, reflecting the underlying significant demographic ageing of our population [6].

The inadequacy of the Hospice Centre at Cini Annex

became more evident and acute with this expansion. The time had come to embark on a more ambitious set-up and it happily coincided with the inclusion of new entrepreneurial blood within the Council of Management. New schemes were devised with the help of organisations like the G.W.U. to raise considerable sums of money. More spacious and suitable premises were found in Balzan and specifically furbished to be the new home of the Hospice Movement in Malta. The new home was officially opened by the President of Malta, Dr. Ugo Mifsud Bonnici on 18th October 1996. The modern and better appointed premises provide a base and a home for Day Care for three days a week, a Home Care Service, a Loan Service for medical aids and equipment like patient lifters, syringe drivers, etc., a Bereavement Service to help families through difficult times of loss, a Night Nurse Service for patients dying at home and other services. A cursory look at what is happening around us in Europe is enough to show that Malta has a long way to go in the provision of modern palliative care services to a growing number of persons dying of cancer and motor neurone disease.

Prof. J.A. Muscat with guest visitor from Brussels.

The Malta Hospice Movement, in the first decade of its existence has pressed home the value of this kind of "Hospice" care and the services it offers to the community. The Health Authorities are now also sufficiently aware of the existence and validity of Voluntary Palliative Care organisations as to "want to facilitate access" to their Services. However, our Health Department has gone no further than this in its National Health Policy Consultative Document - Health Vision 2000 published in February 1996.

There are indications that the present Administration has the will to go beyond these tentative statements, to begin seriously considering the establishment of a Palliative Care Unit within the Oncology Centre at Boffa Hospital. One of the chief mid-term objectives of the Hospice Movement is to work closely with the Health Department in the planning and realisation of this project within the foreseeable future. The Hospice Movement in Malta has been engaged in the teaching of Palliative Medicine to medical students and to trainee nurses for some time and is presently aiming to have this subject formally included in their respective curricula. Professional staff specially trained and experienced in Palliative Medicine is a necessary requirement for any future Palliative Care Unit. The steady increase in the demand for hospice services has led to an increase in hospice professional salaried staff entailing an added and considerable financial burden. Government subvention to date contributes only some 12% of the current annual budget. The rest is made up by voluntary contributions, fund raising activities, membership subscriptions (Lm2 per member), etc.

The care of the dying on hospice model is particularly suited to the nature of a voluntary organisation. Widespread and continuing support from the community and from non-Statal Institutions like the Church, are essential for the Malta Hospice Movement to carry on in its mission of modern compassionate care guided by Christian teaching.

Conclusion

Palliative Medicine as a new medical specialty has evolved from the Modern Hospice Movement which is, itself, a re-discovery of the Christian approach to suffering and death on which has been grafted the applicable modern advances in scientific medicine. It is a well established specialty in the U.K. providing more than 3,000 special beds accomodated in special Units within the N.H.S. and in voluntary free standing hospices.

The Public Health Service in Malta is moving towards recognising the status of Palliative Medicine and its potential for nation-wide benefit. Together with the Faculty of Medicine and the Institute of Health Care, the Department of Health is presently working closely with the Hospice Movement in Malta to bring the comfort of Hospice Care within easy reach of everyone in Malta and Gozo who may come to need it.

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