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The evolution of palliative care

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Abstract

An encounter with one patient in 1948 was the catalyst for the Hospice Movement. The challenge to undertake appropriate pain and symptom control together with experience in further listening to patients in the small number of homes especially planned for dying people, finally came together during the 1960s as the impetus for the first modern hospice which opened in 1967. Since then, palliative care has been developing worldwide and has shown that the basic principles demonstrated in those early years can be interpreted in various cultures and with different levels of resources. Symptom control by a multi-professional team backed by research and education of both professionals and public has spread both into home care and into general hospitals. The family is seen as the unit of care as it finds its own potential, searches for meaning and makes the achievements possible at the end of life. © 2000 Elsevier Science Ireland Ltd. All rights reserved.

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1. Introduction

No presentation of history can be totally bias free and this talk on the evolution of palliative care comes very much from my own experience of the beginning and the ongoing development of the Movement. What began as a response to one patient, gathered input from history, from many articles and anecdotes, as well as from patients, families, professionals and volunteers from around the world. The process may be compared to the assembling of a kaleidoscope, the putting together of a number of demands which were not previously related, giving a shake and finding that they came down in a new pattern or synthesis. So St. Christopher's Hospice was put together over years of intensive thought and

experience and from its opening in 1967 integrated into a community of 1.5 million in the outer London Boroughs. Subsequent teams have copied and modified this pattern as they have grown out of their different circumstances and cultures. Those who travel and attend national and international congresses find that they all reflect a recognizable specialty or movement, wherever that may be.

2. Small beginnings

The beginning of it all came from a patient, a Polish Jew from Warsaw, who died of cancer of the rectum in 1948 aged 40. He was in a big London teaching hospital and during many visits we discussed somewhere which would help people in his predicament; somewhere more suited to the need for

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symptom control and, above all, where there was a chance to come to terms with the situation more easily than in a busy surgical ward.

Two phrases he used in our long talks formed for me the challenge I came to believe I had to respond to. Referring to a small legacy of £500 he said, 'I will be a window in your Home'. And again, 'I want what is in your mind and in your heart'. The first phrase gave us all a commitment to openness — openness to and from the world, to all who would come and to all future challenges. From the second, although at the time it was a very personal exchange, came the commitment to everything of the mind; research, learning, full scientific rigour, always matched with the friendship of the heart, the vulnerability of one person before another. After he died, having made a private peace with the God of his fathers, I had the assurance that he had made his journey with his own quiet dignity in the freedom of the spirit. So openness, mind together with heart and the freedom of the spirit are the three founding principles, not only of St. Christopher's Hospice, but of a now worldwide movement. David Tasma, the Polish Jew who thought he had made no impact on the world by his life, started a movement founded on the Judean-Christian ethic, which has shown it can flourish in different cultures, each initiative with its own characteristics, but with the common aim that people should be helped not only to die peacefully, but to live until they die with their needs and their potential met as fully as possible.

From extensive reading, which coincided with volunteering in an early home of 48 beds for patients dying of cancer, together with a medical training and 7 years of clinical care and research at St. Joseph's Hospice in East London, I learned something of the early hospices and their values. In the late 4th Century of the Common Era Fabiola, a Roman matron, opened her home to pilgrims, the sick and the destitute as a Christian commitment. At that time, she chose the word 'hospice' which referred to guests or strangers, their hosts and the relationship that developed between them as true hospitality. That personal emphasis remains central to our work today alongside all the expertise that has developed. From this small beginning and the work in the Eastern Mediterranean countries that had inspired her, the Christian Church attempted to carry the burden of

the sick, poor and countless pilgrims and crusaders throughout the Middle Ages.

In England and in much of Northern Europe, this came to an abrupt end with the Reformation and the dissolution of many monasteries. None of these early hospices set out specifically to care for the dying but they welcomed people with material and spiritual help which must often have included care until they died. The early hospitals which then grew up were frequently unwilling to admit those they considered incurable. This echoes the Hippocratic tradition which apparently considered medical treatment in such circumstances as 'against the will of the gods' [1].

The first institution founded especially for such care seems to have been in France. It was founded by Mme. Jeanne Garnier, who after first visiting people dying in the back streets of Lyon, opened what she called both a hospice and a calvaire. Her Paris establishment opened its beautiful new building in January 1996. Calvary Hospital in New York owes its foundation to that inspiration.

The first use once again of the word 'hospice' in the UK was by the Irish Sisters of Charity at St. Joseph's Hospice in Hackney, East London, which opened in 1905 following the opening of their founding hospice outside Dublin in 1879. There was no connection with Mme. Garnier's seven homes. Other homes without such a link — Catholic, Protestant and Jewish — were founded in the United Kingdom, the United States and Australia around the turn of the century. There were doubtless other similar institutions in Europe, such as Kaiserswerth in Germany which opened in 1836.

Of them all, much is owed to St. Luke's Home for the Dying Poor, which was opened in 1893 by Dr. Howard Barrett. It would seem that it was the most similar to today's foundations. Dr. Barrett, in his many years of writing reports, does not write of 'the poor' or 'the dying' but of each individual patient and the desolate family left at home with no welfare state help. Witnessed here from 1948 was the effective regular 4-hourly giving of oral morphine, balanced to each individual patient's need. They could trace this back to 1935 soon after the introduction of the Brompton Cocktail, devised by the chest hospital of that name for patients dying of tuberculosis as well as cancer. It included morphine or diamorphine,

cocaine, gin and honey. St. Luke's omitted the gin and honey so far as I can remember.

After 3 years the surgeon I was working for finally said, 'Go and read medicine, it's the doctors who desert the dying. There's so much more to be learned about pain and you'll only be frustrated if you don't do it properly — and they won't listen to you'. With his help and my father's support I enrolled as a first year medical student at the age of 33. I continued as a volunteer at St. Luke's for a further 4 years and then, after qualifying and some hospital experience, a clinical research fellowship enabled me to introduce regular giving of analgesia and monitor pain and symptom control at that other early hospice, St. Joseph's — at that time virtually untouched by medical advance. The 7 years work there enabled me to lay the foundations of palliative care and raise the money to build St. Christopher's Hospice, the first modern research and teaching hospice.

Seven years of listening to patients, 1100 analysed cases and endless networking, finally enabled the home to be built round the window; 19 years in all of learning what dying people are asking of us and can teach us in their turn. A whole body of research has grown from that early work both in our hospice and in many other centres.

3. Total pain

Tape recorded conversations and the descriptive studies of the hundreds of patients showed that the two myths so aptly described recently by Professor Patrick Wall in an editorial in the journal *Pain* could be disproved: 'The valiant development of palliative care has succeeded in the face of two common myths which were shared in common by patients and doctors... the myths were swept aside by precise and convincing observations. One myth was that narcotic medication inevitably replaced the misery of pain with the misery of an insatiable yearning for narcotics. The other myth was that effective repeated doses of narcotics so rapidly escalated that the drugs were only of use for brief emergency periods' [2].

If the 'total pain' experience is analysed it can be seen to include several elements. That concept of 'total pain' was spelled out in an answer given to me by one patient in 1963 when I asked her to describe

her pain. She said, without further prompting, 'Well doctor, it began in my back but now it seems that all of me is wrong'. She spoke of several other symptoms and went on — 'I could have cried for the pills and the injections but I knew that I mustn't. Nobody seemed to understand how I felt and it was if the world was against me. My husband and son were marvellous, but they were having to stay off work and lose their money. But it's wonderful to begin to feel safe again'. Physical, emotional and social pain and the spiritual need for security, meaning and self-worth, all in one answer. Such a holistic approach will enable the dose of opioid to remain between each patient's own effective and sedative levels while regular giving enables constant control of the almost invariably constant pain.

It took 19 years to build St. Christopher's Hospice around David Tasma's window. Evaluative research began before the first patient was admitted. The psychiatrist Dr. Colin Murray Parkes began his detailed study of the memories of the carers of dying patients in our locality as we opened and as our patients began to enter his cohort of more than 270 carers. He found much unrelieved pain, whether the patient died in a hospital or at home. As our patients came into the study he was able to show that people with serious pain problems were referred from the start to the hospice and were largely relieved [3]. Further studies have compared a number of issues within hospital and hospice care three times in our 30 years of existence. Although pain and symptom control has improved in hospital since the first study, these showed that psycho-social need and continuity of care continue to be better approached in the hospice.

4. Controlled studies

Twycross compared morphine and diamorphine (heroin) in a double blind within patient cross-over study in St. Christopher's in the 1970s and found no clinically observable difference between the two drugs. He also reported the absence of tolerance and drug dependence [4]. Clinical and evaluative studies have continued, always balanced with the development of patient care. As Peabody wrote, 'The treatment of a disease may be entirely impersonal;

the care of a patient must be completely personal' [5]. As other units and teams sprang up from the early 1970s onwards some of them also took up the challenge to evaluate and to teach from researched as well as observed practice.

One early patient, having been a hostess at Caesar's Palace in Las Vegas, USA, took a particular pleasure in talking to students of her need to understand what was happening 'to my own body'. She removed a cross which at that time, though not now, had a place in a niche in her single room. She replaced it with a little red devil. Like many hospice teams we had a spiritual, indeed a Christian, foundation but it has always been left freely to patients whether they wished to draw on this philosophy. As it happened, this patient never mentioned the subject until her last night when she suddenly asked the night nurse what she herself believed. The nurse was able to say something very simple and the patient replied, 'I can't say that I believe now, not like that. Would it be all right if I just said I hoped?'

Hospice teams meet many very individual hopes and continually see that trust and faith in the present and the carers around can develop into trust that can be held to in the mystery of death. If they are given the control still possible at the end of their lives, they remain open to new discoveries.

Home care was planned before St. Christopher's opened and was supported by our Department of Health as a research and development project. After nearly 2 years of establishing the in-patient base, a nurse and doctor experienced in community care set out to discuss and offer a complementary service to the local Primary Health Care teams.

Our new comprehensive system of bereavement follow-up began in 1971, ably led by Dr. Colin Murray-Parkes who, as previously mentioned, had joined the planning team before the hospice opened. Such help must be especially aware of cultural differences. He also found that effective, compassionate care of the last stages of life can bring lasting comfort to survivors even though nothing can take away the loss itself.

By 1969 a stream of professionals had begun to arrive on sabbatical leave for varying periods of experience. The first were from the USA and Canada and led to three different patterns of developing palliative care. That title was first chosen in 1975 by

Dr. (now Professor) Balfour Mount in Montreal, where he set up the first unit within a teaching hospital, consulting among his colleagues and in patients' homes. Already, by 1974, Hospice Inc. in New Haven, Connecticut had begun caring for patients in their own homes with no back up beds of their own, and soon only had to admit 30% of their patients to local hospitals. Their building followed eight years later. At the same time, a peripatetic team with no designated beds had begun work around the wards of St. Luke's Hospital, New York under the chairmanship of their senior Chaplain. It can also be claimed that our NHS was being influenced, though the first hospital team did not start work until 1977 in St. Thomas' Hospital, London. Since then variations on these established patterns have spread worldwide, integrating into local health systems as appropriate.

5. Basic principles

These may be defined as follows. *Symptom control* comes first even though it should not stand alone if we are to meet the whole needs of a patient and family. A postcard of a many headed dragon in a medieval tapestry was presented by a patient with motor neurone disease who said, 'That's what my illness feels like to me'. We need to analyse and address all these many heads as far as we can.

This can be converted to a second dragon picture drawn by a patient with cancer about 10 days before her death. This too represented her illness. The picture shows that although the dragon is so much bigger than herself, she is no longer afraid. And we can recall, as Dr. Michael Kearney has reminded us, that in the fairy stories the dragon also guards a treasure [6].

The care for such a whole and, sometimes, overwhelming experience, should be by a *multi-professional team*, often enhanced by experienced and supported volunteers. Such teams may operate in hospice, hospital, or day centre or at home.

Hospice Home Care has spread widely and in many countries is the only possibility. For example, there is now a team in Brasov, Romania. Begun initially as an extension of an English Home Care programme, it is now staffed locally and works extensively with patients in their own homes.

A survey carried out over 3 months of all telephone calls received to St. Christopher's Hospice Home Care department during the 17:00–09:00 h period of its 24-h service, showed that with a caseload of around 290 patients at any one time, 641 calls were received, 29% for a new or worsening symptom, 21% for advice on medication and 19% for family anxiety. Other problems varied. Most calls could be dealt with by telephone or by referral to local night nursing services (where they existed). Fifty-three home visits were made by the palliative care team [7].

Peripatetic hospital palliative care teams are also spreading around the world. One of the early teams in St. Bartholomew's Hospital, London has recently published the second edition describing this important and demanding interface [8].

Maximising the potential the patient and family still have for activity, relationship and reconciliation. This will be a unique experience which may reveal hidden strengths, often to the surprise of both patient and family.

The patient and family must be the *unit of care*. This includes the children who must never be left out if they are to come safely through their loss of parent or grandparent, sibling or friend. A *Bereavement Service* must include them too.

Much *research* now underpins our practice and is a worldwide concern.

Education has grown in scope and depth over the past 30 years. Seven Professional Chairs are now spread around the United Kingdom and others are developing around the world.

Each team forms a *community* of its own for learning and support.

Every Palliative Care Team has to assess both its own *administration* and its relationship with their local Health Care System.

Spiritual needs may be paramount with some patients and are far more prevalent than is commonly recognized or addressed. Each patient attempts to sing his own song in their own space. An illustration from a German team shows how a many-headed dragon overshadowed the patients efforts but the team enabled him to find his own voice, his own search for meaning. Some people need the support of familiar words or rituals, others search through metaphor or oblique comments or even silence to

make their own journey, as did our first and founding patient. A Japanese Hospice garden visited showed the comfort of a still beauty but the doctor of the hospice believed that true spiritual help arises from relationships [9].

There, as in many parts of the world, the question of the active taking of life or euthanasia or physician assisted suicide is much debated. A regional survey undertaken in the United Kingdom is a unique study of many facets of the last years of life of 3696 people. Among the reports from this work, one paper is concerned with the patients' view on euthanasia. The patients' carers were asked 'Looking back now and taking the deceased's illness into account, do you think she or he died at the best time — or would it have been better if she or he had died earlier? What about the deceased? Did she or he ever say they wanted to die sooner? And (if yes) did she or he ever say they wanted euthanasia?'

A total of 28% of the respondents, with a bias towards the younger carers, and 24% of the deceased expressed the view that earlier death would be, or would have been, preferable. However, only 3.6% were said to have asked for euthanasia at some point during their last year [10]. This figure is very unlike those quoted in national opinion polls where figures of 70–80% are given. The regional study illustrates what people who are facing the end of life are actually saying from the memories of their carers.

It is interesting that the House of Lords of England Select Committee on Medical Ethics [11], the New York Task Force [12] and the Canadian Senate Committee on Euthanasia and Assisted Suicide [13], all recommended the spread of palliative care rather than any change in the law. The House of Lords Committee was much influenced by a visit to the Netherlands. Kathleen Foley of Memorial Sloan-Kettering Cancer centre, New York recently published an important article 'Competent Care for the Dying instead of Physician Assisted Suicide' in the New England Journal of Medicine [14].

We have a strong call for appropriate treatment from one of our most renowned Judges, Judge Devlin, who addressed the jury at a much publicised trial thus [15]:

If the first purpose of medicine, the restoration of health, can no longer be achieved, there is still

much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measure he takes may incidentally shorten life. This is not because there is a special defence for medical men but because no act is murder which does not cause death. We are not dealing here with the philosophical or technical cause, but with the common sense cause. The cause of death is the illness or the injury, and the proper medical treatment that is administered and that has an incidental effect on determining the exact moment of death is not the cause of death in any sensible use of the term.

Some hospices have chosen a free flying bird as the symbol of the quality of life remaining.

A memorial pillar with three birds at the top recalls the men, women and children who died in Majdenak Concentration Camp during World War II. Their feet are imprisoned by walls and barbed wire but their wings are free. We too must work to free the wings of the life and spirit of the patients who come to us for palliative care in the hope that they will find a truth strong enough to hold to in death.

Over the past decades these principles have shown themselves to be transferable to very different cultures, to countries with a great variety of traditions and resources. The growth of international conferences has gradually brought more and more practitioners together to learn from each other. A variety of journals have been generated as research has developed; the World Health Organisation added palliative care to its cancer centre and drew up its definition [16]:

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families.

The WHO booklet on Cancer Pain Relief first published in 1986 [17] and since translated into many languages and into a second edition, has been instrumental in making opioid drugs more widely available. However, there is still far to go before all

patients in need have access to them. Both politicians and medical and nursing professionals have often withheld relief and many rural and city populations fail to receive what should be standard treatment. Millions still suffer needlessly.

As palliative care workers have met and shared experience, national and international associations have grown up and research and education have been stimulated. Clinical, psycho-social and ethical issues are debated. No one need or should work in isolation.

6. Conclusion

Further evolution depends not only on the dynamism of early pioneers but on the ability of palliative care to hold its position between specialist teams with continually developing expertise and the general challenge to all that patients should have skilled attention to the end of their lives, whatever their disease or disability. The focus on cancer and a few other diagnoses, notably motor neurone disease and HIV/AIDS, enabled much of the early research to be carried out and published. These patients continue to present their challenges but the Regional Survey of the last year of 3960 patients who died in the UK showed that 16% of people with other diagnoses suffered many of the same symptoms, often for longer periods [18]. Those of us who have developed the specialty have learned from all the other disciplines whose workers will always meet most dying people. By our efforts, we have developed much to share with them but we have no monopoly of caring. The multi-disciplinary teams and units which have spread around the world during the past 30 years, together with some of the early workers have still an important role to play, especially with particularly difficult clinical and family problems. St. Christopher's watchwords, since taken up widely, states 'you matter because you are you and you matter to 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]. The evolution of palliative care, by whoever it is practised, should not cease till each dying patient hears this in a way suited to his own situation and personal needs. They in their turn have much to teach us. A lecture in London's Royal

College of Surgeons in 1966 ended ‘What we will learn here comes through the patients themselves. When we look back we remember not what death has done to them but what they have done to our thoughts about it’ [20].

I believe we need our personal meetings with dying people if we are to remain human and true to the original commitments to openness to people and ever new challenges, to the balance of the scientific rigour of the mind with the sensitivity of the heart, and to the freedom of the spirit which is fundamental to us all.

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