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Terminology: the historical perspective, evolution and current usage – room for confusion?

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ABSTRACT

Modern palliative care started with St Christopher's Hospice in 1967 and was initially regarded as 'terminal care'. This served as a template for a developing model of multidisciplinary clinical care, teaching and research. A decade later, several hospital Palliative Care Teams were established and different terms were used to describe them. An evidence base developed slowly and a medical subspecialty was established, known as Palliative Medicine. Over the last two decades we have seen an expansion in non-hospice palliative care. The terms used to describe this care have been variable and inconsistent.

Our challenges in progress involve establishing clear terminology and an evolving improved evidence base, along with a realisation that there are large gaps in patient care.

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1. Historical perspective

The first use of the word 'palliative' (pallium is the Greek for cloak) was in 1890 by Dr Herbert Snow, a Surgeon, in what is now known as the Royal Marsden Hospital, London. His book, 'The Palliative Treatment of Incurable Cancer' had an Appendix on the use of the Opium Pipe^{1,2} However, the concept of modern Palliative Care is recognised as starting with St Christopher's Hospice in London (1967). The main components behind this driving force were the presence of an individual and a group of colleagues with pioneer attitudes, along with the realisation that care of the dying was suboptimal on hospital wards.³ Dame Cicely Saunders, the central pioneer to the foundation of St Christopher's Hospice felt a new philosophy of care of the dying could only be introduced if a different model of care were developed independently from the UK National Health Service. The intention was always to transfer the philosophy of modern Palliative Care, or more precisely at

that point, Care of the Dying, back into the acute sector. St Christopher's Hospice served as a template for a developing model of multidisciplinary clinical care, teaching and research (See Fig. 1).

The philosophy of 'whole person care', combined with a practical, multidisciplinary approach and a greater understanding of physical symptomatology was gradually developed.⁴ Other modern hospices soon followed. Through the initial years of modern hospice care, the term palliative care evolved but was understood clearly at this point to mean 'end-of-life' or 'terminal care' (See Fig. 2).

In 1974–5 the first hospital Palliative Care Teams were created and this was the beginning of the introduction of some aspects of the philosophy of palliative care into the acute sector, along with expertise and basic evidence in symptom control, such as the use of regular oral morphine. By the 1980's the medical component of Palliative Care became a formal medical subspecialty in the UK and is known as Palliative

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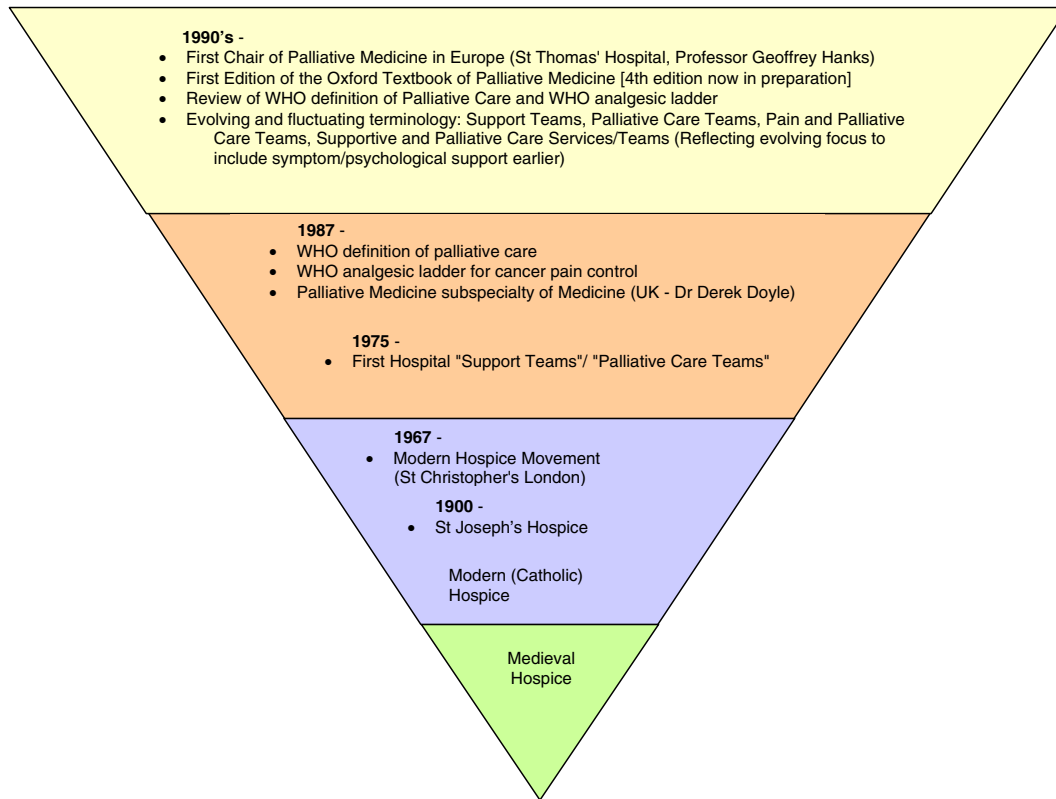


Fig. 1 – Evolution of palliative medicine.

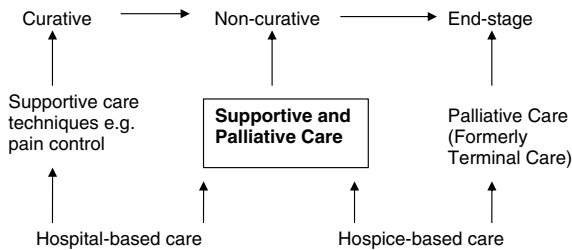


Fig. 2 – In reality the stages are a continuum.

Medicine. A research journal followed, along with the first academic department and the Oxford Textbook of Palliative Medicine in the early 1990's. With the development of this nascent speciality came a further evolution of the multidisciplinary care offered.⁵⁻⁷

2. Terminology

It is clear that the evolving nature of who is receiving palliative care and what is being offered by Palliative Care Specialists has led to a shift in terminology.

The issue of terminology is important. It gives some explanation of what is being referred to, for both professionals and patients. While Palliative Medicine has on the one hand remained a constant and accepted term to describe the medical speciality, the attempts at terms to describe the evolving

focus of multidisciplinary palliative care have not always been consistent and have often met with resistance.

The term 'hospice care' is generally understood by patients as terminal care although hospices now provide a much wider spectrum of care in many countries.

On the other hand, 'Supportive Care', 'Support Team', 'Supportive and Palliative Care Team' and 'Pain and Palliative Care Team' can be presented and interpreted in different ways. An increasingly used term in the UK to describe relevant research is 'Supportive and Palliative Care' (SuPaC) and this is also used in some clinical services. This term tries to convey the idea of the spectrum of care, physical and non-physical, and the fact that such input can be at any stage in the cancer illness, not simply when tumoricidal options have been exhausted. While we refer to the integration of such care into Oncology Services we are not referring to 'Integrative Oncology'. The latter term can mean integration of complementary and alternative medicine into Oncology Services. It is, however, usually accepted that complementary medicine can be a small part of the supportive and palliative care armamentarium.

In practice, the non-curative care provided in the hospital setting, especially in Oncology Centres, is Supportive and Palliative Care. The supportive end traditionally has been provided by Oncologists, however both clinical care provision and research at this end of the spectrum have increasingly come under the remit of the palliative care end of the spectrum in many centres. This is seen as positive from both clinical and research perspectives.

3. Future development

The equipoise in the development of Palliative Care or SuPaC services is the available evidence base. It is clear that traditional hospices provide a special philosophy of care, in a particular environment, and local communities usually feel passionate about their support and existence. Most Oncologists, along with those caring for patients with advanced non-malignant incurable disease, who have access to hospice care would also support very strongly the continued need. On the other hand, the continuation and further development of hospital Palliative Care Teams or SuPaC Teams, will be influenced by a number of factors:

- Perceived impact on patient care
- Development of an improved evidence base
- Local and national direction in patient care

It is clear that our over-burdened state health care systems could not, for example, support consultant salaries simply to recycle best practice guidelines.⁸ We are at another crossroads in the development of non-hospice palliative care services but it is clear that an improved evidence base for care and continuing individual patient contact will remain core elements.

An agreed common language for non-hospice services seems fundamental to the argument regarding progress. The final paper in this Special Edition addresses the future direction of research and therefore, indirectly, clinical progress. We believe that the papers which follow exemplify progress to date and define our gaps in knowledge.

4. Gaps in care

A particular issue occurs with the support and palliation of survivors and possible survivors of cancer treatment.⁹ Symptomatology in this area can often be severe, very debilitating and associated with significant family and socioeconomic problems. The care of such patients can be ill-defined with no clear pathway to appropriate care. This is exacerbated by a lack of research to help direct appropriate management. Certainly some of the evidence relating to symptom control

can be extrapolated from other situations, however there are huge gaps in both evidence base for management of a variety of problems and specialist opinion when necessary.

A particularly difficult gap in care exists for those patients who may be cured but have difficult symptoms, either physical, psychological or, more commonly, a combination of both. Such situations can be very challenging and informed multi-disciplinary care is crucial. We need to develop a particular supportive care model for sick patients and traditional palliative care expertise should feed into this model. Life and illness are a continuum and our patients do not always fit into well-defined boxes. As specialists our challenge is to accommodate this continuum rather than restrict it.

Conflict of interest statement

None declared.

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