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The development of palliative care in national government policy in England, 1986–2000

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Palliative care is an established and expanding speciality, important in many areas of service delivery within health and social services and the voluntary sector. Traditionally, palliative care is viewed as most closely linked to cancer services. National government policy has an inevitable impact on the organization and provision of such services. As part of a wider project, an investigation of the content and development of English government policy relating to palliative care was carried out. The development of policy follows a cycle that has no closure; it takes place within changing contexts, between multiple organizations and across sectors. Data collection involved the collation and close examination of policy documents and other documents that demonstrably influenced policy. This was in order to identify a national view of policy intentions for palliative care. In total, 53 policy documents were examined. The analysis revealed a number of pertinent issues relating to shifts in funding policies and an evolving definition of palliative care. There is an increasing recognition in the policy documents of the need for palliative care to extend beyond the traditional focus on cancer services and terminal illness. In tandem, is an increasing recognition of the need for partnership between sectors, reflected in more recent health and social services legislation. *Palliative Medicine* 2003; **17:** 270–282

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Introduction

In the UK, policy makers concerned with palliative care need to take account of a highly mixed economy of care. The three major service sectors (National Health Service (NHS), social care and charitable sector) that each have a potential and actual contribution to make to palliative care provision, are also qualitatively different in terms of funding, organization and the way they operate. This paper reports an analysis of policy documents carried out to inform the first stages of a research project about interprofessional working in palliative care, that would draw data from each of these three sectors.

One aim of the wider study was to look at how the intentions and plans formulated at a national level were played out across the sectors and in different service configurations locally, in each of four separate case sites. A standard literature review was carried out at the start of the overall research project.[1] This identified sources of professional expertise, evidence and respected opinions that could be fed into the analysis of what constituted good quality in interprofessional working in palliative care. However, the literature review proved unhelpful in identifying the diversity of sources and influences in national government policy. Most formal policy documents fall into the body of information known as 'grey literature', so are not accessible through a search of electronic databases. A different approach was needed, therefore, to ensure that relevant documents were collected and analysed to identify a national view of policy intentions for palliative care. One of the first tasks for the research team was to understand the formal basis from which each of the three selected data sources (specialist palliative care, primary care (district nursing) and social services) operated. This is outlined before moving on to explain the policy cycle and methods used to collect and analyse the documents.

Palliative care services

A fundamental tenet of the British National Health Service (NHS) is that it should be available to all residents on the basis of clinical need and free at the point of delivery. This founding principle has been reiterated in the English NHS plan,[2] a government statement of purpose that also announced the establish-

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ment of 'care trusts'. These will bring certain social and health services under the umbrella of a single organization in primary care, responsible for both the provision and commissioning of a wide range of services. A key issue in this change concerns the two different funding systems. The NHS is wholly funded from taxes levied by central government; in respect of palliative care, this includes hospital provision as well as the community outreach, district nursing and primary care services that were one focus in the wider study from which this paper was derived. Whilst social services, a second key area in the wider study, receive some central funding, much of their income is derived from locally levied council taxes and users may be charged for services, on a means tested basis.

As well as providing a universal, clinical service, the NHS is charged with an overall responsibility for improving health and healthcare through the development of collaborative, multisector Health Improvement Programmes (HImPs).[2] Commissioners of health care are not, therefore, expected to limit their expenditure to provision of NHS services alone, but to fund other service providers where this can be shown to improve service provision. In particular, this is encouraged if a joint strategy can be forged across a local area, or if a named person's clinical needs cannot be met through mainstream health services.

The term 'palliative care' may be less familiar to those working in social care although the need to provide support to people with complex needs at any point in their lives is well established. In practice, both the needs and the kinds of services required to meet them may be very similar for vulnerable individuals nearing the end of their lives, whether these are regarded as 'palliative care' or 'complex packages of care'. Since the NHS and Community Care Act 1990,[5] much of the responsibility for providing care for vulnerable older people has shifted from health to social services.[4] As a result of this expanding responsibility, local authorities that provide home care support and social services to older people at the end of their lives are increasingly likely to be engaged, as well, in provision for those designated as needing palliative care.

The charitable sector is both influential and active in the provision of palliative care, being intertwined in a variety ways with the publicly funded health and social services. It encompasses a range of different activities concerned with palliative care, including funding the provision of services. The terms 'charitable sector' and 'voluntary sector' tend to be used interchangeably, reflecting the diversity of a sector that is growing in size and influence. Sometimes described as the 'modern hospice and palliative care movement,' it is often traced to the establishment, in 1967, of St Christopher's Hospice in South London, but there were many preceding influences before and after the NHS was established.[5] This sector encompasses many organizations that are large or small employers, like local hospices and some of the support, information or advocacy groups. Some significant cancer charities (notably Macmillan Cancer Relief and Marie Curie Cancer Care) are major players and some of the greatest strides in specialist palliative care have been developed in and through services provided in the charitable sector.

Collectively, the charitable sector not only plays an active role in funding services in the form of specialist nurses, palliative care teams and hospices, but has carved out a key place for itself as expert adviser and role model. However, it is not synonymous with specialist palliative care because of the crossover in funding. The NHS funds a small part of hospice provision and the major charities, in turn, fund some services that are wholly based within the NHS. Furthermore, there are specialist palliative care services that lie entirely outside the charitable sector. Indeed, Bosanquet identifies what he considers to be a new phase in the development of palliative care, as specialist knowledge, initially developed in the charitable sector, is increasingly made available through a wide range of services across all the sectors.[6] The inclusion of social services in the delivery of palliative care is a natural sequel of this expansion, which recognizes that people who require palliative care may be in their last phase of life but, increasingly, that phase lasts for longer, bringing more and broader challenges for services. Oliviere *et al.*[7] highlight the current challenge within palliative care, of redefining its role within health care provision as a whole. A developing model of health care aims to improve quality of life alongside increasing patient autonomy within a partnership between professionals and patients.[6]While individual service providers have a key role to play in ensuring the quality of care in their own particular team or unit, major changes need a national perspective to ensure that policy operates as an enabling force, rather than as a barrier to development.

Given the complexity of these three different sectors, research about the impact of different service configurations on the quality and adequacy of palliative care and multiprofessional collaboration seemed timely.[8] This paper stemmed from one aspect of that wider study: identifying the 'starting point' of what expectations and meanings were embedded within the policy in relation to palliative care.

The policy cycle

Policy may be thought of as a set of instructions from policy makers to policy implementers that spell out goals and, at times, the means for achieving those goals. Policy making is developmental in nature and incorporates the notion of a continuing process without closure. This policy cycle occurs in three phases:[9]

- Policy formation: how policy is constructed, by whom and with what agenda.
- Policy implementation: where initiatives are transmitted into programmes, guidance and directives.
- Policy accountability: where policy is mature and the question of evaluation and outcomes are considered.

In preparation for the wider study, which incorporated policy intentions into the analytic framework, a review of policy relating to palliative care was needed. A set of aims was formulated to guide data collection and analysis for this part of the study, which were:

1) To identify sources of national guidance about palliative care and how it has developed in policy by
    - identifying the form and content of the guidance;
    - identifying trends, consensus and diversity within policy;
2) To investigate different meanings and definitions associated with the phrase ‘palliative care’ in policy, concentrating on points of consensus, agreement and diversity within policy.
3) To determine a prevailing view of how palliative care should be commissioned, organized and delivered.

Methods

Documentary analysis

Research by documentary analysis is unobtrusive, as the documents themselves are unaffected by the data collection process and the analysis.[10] Documents are secondary research data, in that they are produced for purposes other than the research itself, so each document has to be processed, first by selection and then interpretation. Constraints of the method include the practicalities of access to the documents and the time involved.[11] Further limitations relate to the fact that documents are produced as a result of human activity and are therefore bounded by the particular social, historical or administrative conditions in which they were produced. Policy documents, in particular, are open to stressing one aspect more than another, depending on the political climate, the author’s agenda and unconscious decisions at the production stage.[11] Questions about how the sources came into being can yield valuable information, forming part of the analysis and interpretation of the selected documents.

Data collection

The three sectors identified for the wider study (specialist palliative care, social services, primary care) provided a natural platform on which to base data collection. The search was designed with the aim of accessing the most relevant sources of information across the three sectors of health, social and voluntary-funded services.

The search technique developed as an evolutionary process, following methods that would be more familiar to qualitative researchers doing fieldwork than to researchers undertaking a systematic review of the experimental literature. To begin with, the research team had a basic knowledge of many of the relevant documents. This knowledge was increased after carrying out the initial literature review.[1] The search strategy began with a broad sweep of the relevant sources based on communication with experts, some of whom were identified through the literature review and others participating in the research advisory group for the wider study, and the team’s personal knowledge. As one relevant document led to another, a process of snowball sampling and systematic funnelling approach was adopted to focus and narrow the search.[12,13]

Obtaining information about palliative care policy from social services and local authority sources proved problematic because of the differing concepts and terminology used in documents. Social workers may be more likely to discuss an individual as being ‘at risk’, ‘vulnerable’ or with ‘complex needs’ than having ‘palliative care needs’. The Department of Health is the national government body responsible for social care provision, so they issue parallel guidance to both health and social services. It was therefore easier to access information via the health sector, but a concern remained that some documents relating to this sector remained unidentified. The Department of Health communications to local authorities identified in the database relate to interprofessional working and issues such as continuing care, within which palliative care is highlighted.

Documents were included when it was noted that they were relevant to the aims and objectives of the data collection. Inevitably, some of these were discarded from the database as they were found not to be relevant or, for example, they have been superceded by another document. Some pragmatic decisions were made along the way, but where there was doubt about whether to include or discard, decisions were made by discussion with the research team and, at times, discussions with the advisory group. In one example, the research team suggested that the various clinical outcome guidance papers (referenced below) may have been too disease specific to be of relevance across palliative care. The advice of those working in the field was that they were influential in decisions about service provision and commissioning, so they were retained in the database. In another example, the major research charities, particularly Macmillan Cancer Relief and Marie Curie Cancer Care were extremely helpful when contacted, but directed the team to the policy documents produced as a joint endeavour under the auspices of their umbrella organization, the

National Council for Hospices and Specialist Palliative Care Services (NCHSPCS).

Most of the documents were collated in 1999, which was a time of significant change in legislation. In 1997, a Labour government came to power for the first time in 18 years, and set about introducing policy changes with a reforming zeal. Papers dealing specifically with these reforms inevitably influence policy relating to palliative care, so are included in the database. Data collection was stopped when 'data adequacy'[14] was recognized, because the same documents from the list as a whole were coming up time and again. No documents were collected beyond the start of the year 2000, as that was when data collection for the wider study was complete.

Data analysis

A content analysis of textual data involves the systematic and objective identification, linking and counting of specified characteristics.[15] Three basic criteria for carrying out a content analysis on documents are authorship, body (form on which data are found) and function.[16] These serve as a useful basis in establishing an initial database, which was then extended to identify key points reflecting the aims and objectives of the data collection. Each document was read carefully and a database sheet completed to facilitate decisions on and extract specific pieces of information from the documents. As with the collection of data, the analytical process involved the systematic funnelling of data into the database categories in order to obtain the information required to meet the research objectives.

Results

In all, 53 documents were identified on the basis that they were either policy, or related to policy within palliative care or interprofessional working and palliative care. The documents came from a variety of sources, and were initially categorized into three main groups with their own subgroups, listed in Table 1.

Health sector documentation

The documents on this group were further subdivided into five subgroups. The Calman-Hine Report[17] was written in response to concerns about variations in the outcomes of treatment for cancer across the country. This report and the subsequent Clinical Outcomes Guidance[18–23] were all specifically concerned with cancer, but they provided reviews of both palliative care research and recommendations for multiprofessional working. A key policy document in palliative care (EL(96)85 – A Policy Framework for Commissioning Cancer Services: Palliative Care Services)[41] arose from the Calman-Hine Report.[17] In due course, this would also inform the important NHS Cancer Plan,[35] which was published just as this policy analysis drew to a close.

Documents in the next two subgroups report the plans of the new government to replace the former, competitively based internal market with what they considered a more modern system;[24–27] later documents developed this theme.[2] Various executive letters, health service circulars and guidance[33–42] were identified from the Department of Health. These provide definitive policy guidance to health authorities, NHS providers and local authorities, mainly focusing on service organization and commissioning. Some set out specific funding guidance. These documents clarify responsibilities, often aiming to facilitate the provision of a comprehensive and equitable service. Parallel guidance from the Department of Health, including specific issues engaging the local authority social services, were identified in local authority circulars listed in the fourth subgroup.[29–32] Finally, 12

Table 1 Source and form of policy documents

Sector	Documents	References
Department of Health and NHS	1. Report by the Expert Advisory Group on Cancer-Calman-Hine Report and subsequent NHS Executive Clinical Outcomes Guidelines = seven documents.	17–22
Total = 31 documents in five subgroups	2. White Papers on NHS and social services reforms = five documents.	2,24–27,72
	3. Health service circulars/executive letters relating directly to NHS reforms = two documents.	44,45
	4. Local authority circulars = five documents.	28–32
	5. Health service circulars/executive letters relating directly to palliative care = 12 documents.	33–42,70,71
Voluntary sector	1. NCHSPCS publications = 16 documents.	47–62
Total = 17 documents in two subgroups	2. Continuing Care at Home: report on disability, dependency, palliative care = one document.	63
Professional/expert opinion	1. World Health Organization = one document.	64
Total = five separate documents	2. Chapter on epidemiologically based needs assessment and palliative care = one document.	65
	3. Royal College of Nursing = one document.	66
	4. House of Commons Health Select Committee report = one document.	43
	5. Standing Medical Advisory and Standing Nursing and Midwifery Advisory Committees, Report to the Minister on palliative care service provision = one document.	47

documents specifically about palliative care were identified.[33–42,70,71]

Voluntary sector

The majority of the documents from the voluntary sector came from the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS).[47–62] The NCHSPCS acts as a co-ordinating and representative organization for hospices and palliative care services in England, Wales and all of Ireland. The Council includes representatives from statutory, voluntary and professional organizations with an interest in palliative care and elected members from England, Northern Ireland, the Republic of Ireland and Wales. It presents the views and interests of palliative care services to central government, the media and so on. Bearing in mind that the major cancer charities had indicated that their views were represented by the NCHSPCS, the only other relevant expert report identified from this sector was from the charity concerned with Continuing Care at Home (CONCAH) for people with incurable neurological disorders.

Government policy documents frequently refer to the Council's work. One health service circular[42] came with three attached NCHSPCS occasional papers[49,60,61]. These were published by the Council and recommended by the Department of Health for distribution to all levels of planning and service provision. The NCHSPCS documents provide a source of expert opinion on a variety of issues relating to palliative care and thus would appear to have a direct influence on policy. Expert opinion includes specific clinical guidelines, advice on commissioning and service organization, joint working and measuring outcomes. The Council is concerned with providing a comprehensive, high quality, and equitable service to all those in need of palliative care.

Two common threads running through the documents were recognition of the need to provide a service integral to all areas of clinical practice and to work in partnership with the wide variety of organizations involved.

Other professional influences

The aim of this documentary analysis was to identify the official intentions of policy that might have an influence on service provision or practice. In view of this, no attempt was made to identify particular authors whose work may or may not have influenced the development of those policies. Instead, it is acknowledged that a number of palliative care experts, specialists and the organizations that are members of the NCHSPCS are, themselves, repeatedly cited in that Council's reports. Documents published by NCHSPCS vary in their authorship, presumably reflecting their different status (official Council policy, discussion paper or policy briefing for members, for example) within the organization. However, documents published by the NCHSPCS were collated together as regardless of authorship.

Personal communication with NCHSPCS, other expert organizations in the field, e.g., Marie Curie Cancer Care, Macmillan Cancer Relief (formerly Cancer Relief Macmillan Fund) and professional bodies such as the Royal College of Nursing Palliative Care Forum and the Association of Palliative Care Social Workers led to a small number of key documents like a book chapter on 'Needs Assessment in Palliative and Terminal Care'.[65] This promoted the idea that service provision should be planned according the needs of the local population and gives guidance to those involved in planning and commissioning palliative care services. It was included in the database as a 'policy document' because it was distributed by the Department of Health to all Health Authorities in England and Wales, having initially been flagged up in an executive letter.[42]

Form and content of policy documents

Table 2 summarizes the form and content of the documents identified in the analysis, indicating where the different issues arose and how they were represented. It is evident that there is a great deal of cross-referencing between the different sources, reinforcing both the cyclical and iterative nature of policy formation. The joint influence of specialist experts and policy makers were becoming apparent during the late 1980s,[72–74] leading to an advisory document from SMAC/SNMAC in 1992.[46] At the same time as these were being cited in formal policy in the form of the Calman-Hine report[17] and subsequent Clinical Outcomes Guidance,[18–23] the NCHSPCS were developing further expert advice about the scope, definition, organization and funding of palliative care.[47–54] The continuing nature of the cycle is illustrated by the various NCHSPCS discussion documents[55–57] and more recent government guidance about cancer and palliative care,[35,70,71] which also feature mutual cross-referencing between documents.

Unsurprisingly, no single event or author could be traced as leading to a specific change in policy, but the collective influence of expert and specialist sources is apparent. These were mainly collated through the NCHSPCS, which helped to make the influence apparent, but other professional sources, such as the World Health Organization (WHO)[64,73] and Royal College of Physicians[72] were also widely cited.

Trends, meanings and definitions

The evolutionary nature of policy development was particularly clear in respect of definitions of terminal and palliative care. Not all documents in the database attempted to define palliative care especially (unsurprisingly) where they were about health and social care

Table 2 Form and content of the policy documents

Documents	Year	Refer to
Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee[46]	1992	Department of Health and Social Security and National association of Health Authorities: proceedings of a conference on care for the dying, 3 December 1985;[73] World Health Organization Palliative Cancer Care Policy Statement 1989;[74] Palliative care report of the of the Royal College of Physicians.
Calman-Hine Report[17] and Clinical Outcomes Guidance[18–23]	1995, 1996 1997	Recommend adoption of NCHSPCS guidelines on palliative care. Refer to the work of national cancer charities, e.g., Cancer Relief Macmillan Fund and Marie Curie Cancer Care. Recommend the work of 'leading palliative care centres'.
Government White Papers on current NHS reforms[24–27,3]	1997, 1998, 2000	Emphasize partnership between health, local and voluntary sectors. Initially highlight Calman-Hine Report[17] as part of National Strategic Framework for Service Delivery, moving on to flag up the forthcoming Cancer Plan.[35]
Local authority circulars[29–32]	1991, 1995, 1998	Concerned with previous and current NHS reforms (White Papers cited above) and the role of Social Services within this. Palliative care is mentioned only as part of continuing care legislation.[30]
Health service circulars/executive letters directly related to palliative care[33–42]	1987–2000	1994 – began to emphasize the importance of the work of the NCHSPCS.[39] 1996 – emphasized the importance of the forthcoming work on needs assessment in palliative care by Higginson.[65] 1996 – also highlight Calman-Hine Report[17] and the subsequent accompanying executive letter.[41] 1998 – NHS Exec. Document[42] reaffirms the role of the NCHSPCS (recommending three of their occasional papers) and NHS reforms (White Papers cited above). Cancer Plan[35] has a chapter specifically about palliative care. Letters and circulars generally copied to local authorities for information.
House of Commons Health Committee report[43]	1998	Widespread reporting to the Committee from health social and voluntary sector.
Health service circulars/executive letters relating to NHS reforms[44,45]	1998	Working in partnership with local authorities an expectation. Mentions Calman-Hine[17] as part of emphasis on cancer services. Mentions importance of integrating care with voluntary sector.
NCHSPCS documents[47–62]	1995–1999	Written by working parties composing of representatives from health, social and voluntary sectors. Aimed at Commissioners and providers of palliative care in the statutory and voluntary sector. Refers to the importance of the Calman-Hine report[17] and the subsequent executive letter.[41] Refers to the importance of the work of Higginson[65] on needs assessment in palliative care.
CONCAH[63] (Report of a conference proceeding on issues pertaining to disability and palliative care)	1995	Reporting to conference from health, social and voluntary sector.
Higginson[65] (Book chapter on needs assessment and palliative care)	1997	Refers to the work of the NCHSPCS Emphasizes the importance of mechanisms to co-ordinate care between health, social and voluntary sector. Copy of this chapter on needs assessment in palliative and terminal care was sent to each health authority.
World Health Organization[64]	1990	Definition of palliative care quoted throughout documentation.
Royal College of Nursing[66]	1996	Refers to Calman-Hine Report.[17]

Table 3 Changing definitions of palliative care

Document by group	Year	Definitions and descriptions of palliative care	Source
Health sector			
DHSS[33]	1987	'Terminal care is the provision of skills and services to meet the special needs of these patients and their family/close friends, whether in hospital, at home or in a specialized terminal care unit. The objectives are to control pain and other symptoms; to maintain independence as long as possible; to alleviate isolation, an, anxiety and fear; to make possible a comfortable, dignified end and to provide support for the patients, family/close friends both before and after bereavement'.	No source cited.
DoH[34]	1990	Refers to 'terminally ill' – does not define.	No source cited.
WHO[64]	1990	'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 quality of life for patients and their families'.	1989 Policy statement based on the recommendations of a WHO consultation.
NHS Executive[36]	1991	'Terminally ill are those with an active and progressive disease for which curative treatment is not possible or not appropriate and for whose death can be reasonably expected within 12 months'. Annex describes it as broader than cancer and HIV and 'cuts across every clinical speciality and care centre . . . '.	
NHS Executive[37]	1992	Definition used the same as in 1991 paper.[36]	No source cited.
Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee[46]	1992	'Active total care offered to a patient with a progressive illness and their family when it is recognized that the illness is no longer curable in order to concentrate on the quality of life and the alleviation of distressing symptoms within the framework of a coordinated service'.	1986 DHSS/NAHA consensus conference 1989 WHO 1991 Royal College of Physicians.
NHS Executive[38]	1993	'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 quality of life for patients and their families' This document differentiates between 'palliative' and 'terminal' care (terminal care as defined in 1991 and 1992).	Palliative Care – WHO (1990)[64]Terminal Care – NHS Executive 1991, 1992.[36,37]
NHS Executive[41]	1996	Palliative care encompasses the spectrum of care, ranging from the palliative ***approach to care which aims to promote both physical and psycho-social well being,*** and should be practised in all disciplines and regardless of whether or not death is expected, through to specialist palliative care.	No source cited.
Calman-Hine Report (Expert Advisory group on Cancer)[17]	1995	1995 Makes a distinction between 'palliative' and 'terminal' care but does not define. Mentions the importance of a 'palliative care approach' from diagnosis but does not specify a definition.	No source cited.
Clinical Outcomes Guidance, NHS Executive[18–23]	1996 1997 1998	No specific definition given in any of the documents in this group.	No source cited.
Government proposals for NHS DoH[24–27]	1997 1998	No definition of palliative care in any of the documents in this group.	N/A.

Local authority circulars[29–32]	1991 1995 1998	No definition of palliative care given in any of the documents in this group.	N/A.
NHS Executive[42]	1998	Same definition as 1996.	NHS Executive 1996.[41]
House of Commons Health Committee report[43]	1998	No definition.	N/A.
NHS Executive relating to NHS reforms[44,45]	1998	No definition.	N/A.
NHS Cancer Plan[35]	2000	Para. 7.2 'the principles of palliative care: holistic, patient-centred care, apply across all conditions and in all settings'.	No source cited.
Voluntary sector			
NCHSPCS[47] Statement of Definitions	1995	Palliative care is 'the active total care of patients and their families by a multiprofessional team when patients disease is no longer responsive to curative treatment . . . '. The document gives this definition and then goes on to describe palliative care as encompassing the palliative care approach, palliative medicine, specialist palliative care and terminal care. It defines terminal care as above in NHS Executive 1991.[36]	1995[47] Source Palliative Care, WHO[64] Terminal Care, NHS Executive[36] 1995.[48]
NCHSPCS[48]	1995	As above,[47] with specific reference to Black and ethnic minority communities.	NCHSPCS.[47]
NCHSPCS, Working Party on Clinical Guidelines in Palliative Care[58,59]	1995	Appendix of definitions – WHO definition and also 'palliative care is care for the dying by providing active, total care at a time when 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 care for the dying is the highest possible quality of life for the patient and family'.	Source – WHO[64] and Eurpoean Association for Palliative Medicine.
NCHSPCS[49]	1996	WHO definition. Promotes palliative care approach.	Source – WHO.[64]
NCHSPCS[50]	1997	Describes palliative care approach and specialist palliative care.	Source – NCHSPCS 1995.[47]
NCHSPCS[51,52]	1997	No definition explicit.	N/A.
Doyle 1997[55](NCHSPCS)	1997	WHO, 1990[64] and promotes the definitions of the palliative care approach and specialist palliative care.	1997 WHO, 1990[64] and NCHSPCS, 1995.[47]
NCHSPCS[60,61]	1997	No specific definitions given.	N/A.
NCHSPCS[62]	1997	No definition explicit.	N/A.
NCHSPCS[53,54]	1998	Palliative care approach.	Source – NCHSPCS.[47]
Tebbit[56] (NCHSPCS)	1998	No definition explicit.	N/A.
Tebbit[57] (NCHSPCS)	1999	Palliative care approach Also highlights two principles: (1) the right of every individual 'with a life-threatening illness to receive appropriate palliative care wherever they are' and (2) the responsibility of every health care professional to adopt the palliative care approach and to call in specialists when the need arises no matter what the illness or its stage.	Source – NCHSPCS. 1995.[47]
CONCAH[63]	1996	1995[63] No definition given.	N/A.
Other expert opinion			
Royal College of Nursing[66]	1996	1996[66] Quotes the NCHSPCS Statement of Definitions, 1995.[47]	NCHSPCS, 1995.[47]
Higginson[65]	1997	1997[65] States that the most straightforward definition is from the NCHSPCS, 1995[47] and is based on the WHO[64] one described above. Feels the most comprehensive is the 'active total care offered to a patient with a progressive illness and their family when it is recognized that the illness is no longer curable in order to concentrate on the quality of life and the alleviation of distressing symptoms within the framework of a coordinated service'.	WHO, 1990[64] NCHSPCS, 1995,[47] SMAC/SNMAC, 1992.[42]

organizational issues as a whole, rather than specifically about the delivery of palliative care services.

However, the shift in terminology can be seen clearly in Table 3, which traces definitions and descriptions of palliative care over the last 10–15 years. Initially, in 1987, the term ‘terminal care’ was used, being associated with an expectation of a limited prognosis – ‘from which death can be reasonably expected within 12 months’.[33] This offered firm guidance for welfare benefits and income support.[65] The WHO[64] defined palliative care in a broader sense, with less emphasis on the prognosis of the disease and more emphasis on the philosophy of care, with a focus on a whole person approach and quality of life. This definition appears to have had a major influence on subsequent definitions, having been taken up, clarified and extended by the other sources.[38,43,47–49,55,58,59]

It is apparent from Table 3 that government documents (such as Calman-Hine and the Clinical Outcomes Guidance[17–23]) use specific definitions far more sparingly than the NCHSPCS, whose work seems to have become a driving force in the policy cycle. Their Statement of Definitions[47] emphasized the importance of the WHO definition of palliative care[64] but extended this to develop the term ‘palliative approach to care’. This concept and its encompassing definitions have subsequently appeared in government documents about palliative care, such as an executive letter about commissioning.[41] Issued in 1996, this seems to be the first government document to adopt the term ‘palliative approach to care’, suggesting that this should be practised in all disciplines, regardless of whether or not death is expected. Use of the term in formal policy guidance indicates broad acceptance of the extended meaning stressed by WHO and NCHSPCS and marks a distinct change from the emphasis, 10 years earlier, on a clear prognosis and on terminal care. As shown in Table 4, the term ‘palliative care’ now seems to be used as an umbrella term encompassing a range of more specific meanings, that all extend its scope and purpose whilst retaining a distinction for specialist palliative care services and palliative medicine.

Whilst analysing the documents for definitions and coherence in relation to palliative care, a parallel search was carried out in relation to interprofessional and interagency working in the field. No parallel coherence was discovered about the understanding and meanings attached to these terms. Instead, a huge range of terms were used with neither definitions nor explanation of how these were to happen in practice. The one exception was the SMAC/SNMAC report,[46] which stated: ‘Multidisciplinary care is the team approach to palliative care which recognizes that many health care workers have roles to play. Leadership of the team may vary according to particular problems of the patient and local factors’ (p5). However, most of the documents extolled the virtues and importance of shared care and partnership working, emphasizing how important they were in the delivery of comprehensive palliative care services.

Table 4 Meanings associated with palliative care

Palliative care as an umbrella term	*Terms related to palliative care*
Palliative care approach ● The palliative approach to care aims to promote both physical and psychological well-being and should be an ‘integral part of all clinical practice’.[41]	**Palliative interventions are** ● Noncurative treatments such as palliative radiotherapy or chemotherapy, anaesthetic interventions or surgical procedures aimed at improving quality of life.[57]
Palliative care services encompass ● A broad range of services in both community and inpatient settings. ● Funded and/or organized through either voluntary or statutory sources. ● Multiprofessional or uniprofessional services. ● Specialist training in palliative care and or wide experience in the area.[47]	**Palliative Medicine is** ● The medical speciality which concerns itself with the appropriate medical care of patients with progressive disease.
Specialist palliative care is provided ● Where an individual has progressive, advanced disease with a limited prognosis. ● Where individuals have complex or acute needs and require the care of a multiprofessional team with a broad mix of skills such as medical, nursing, social, pastoral or therapy services.[57]	**Terminal care is** ● Is viewed as an important part of palliative care. Normally it refers to the care of an individual in the last few days, weeks or months of life.
Specialist palliative care services are ● ‘those services which have specialist palliative care as their core speciality and provide services directly to patients or indirectly through advice to a patient’s existing professional carers’.[47]	

Organization and delivery of palliative care services

Tebbit[57] highlights the two principles underlying the challenge of palliative care provision. They are

1) the right of every individual with a life-threatening illness to receive appropriate palliative care wherever they are; and
2) the responsibility of every health care professional to adopt the palliative care approach and to call in specialists when the need arises no matter what the illness or its stage.

As highlighted in Tables 3 and 4, the official government policy documents appear to adopt this extended version of the meaning of palliative care. Paradoxically, however, the documents themselves also link palliative care firmly to the provision of specialist palliative care services that are, themselves, mainly concerned with cancer. The position and responsibilities of primary care and social services in the provision of palliative care is rarely mentioned or addressed in the policy documents.

The NHS Cancer Plan[35] signals a possible departure from this trend, by highlighting district nurses as central to the delivery of palliative care in the home; £2 million has been ring-fenced to support educational initiatives for this source. It may be seen as significant that 'palliative care' remains inextricably linked with cancer services in the current modernization programme, with developments in palliative care being within the NHS Cancer Plan.[35] It is, however, acknowledged that the educational initiatives within community nursing will benefit the quality of care for individuals suffering from incurable illnesses other than cancer. Indeed, both the National Service Frameworks for Older People[67] and for Coronary Heart Disease[68] recognise the need for palliative care and access to specialist services, although the emphasis is far lower than in the Cancer Plan.

A prevailing view of the requirements and guidance for commissioning palliative care services was sought in the documents. The NCHSPCS document 'Palliative Care 2000: Commissioning Through Partnership'[57] provides one acknowledged expert view. Many of the papers relevant to this part of the analysis were concerned with funding arrangements in general, rather than about palliative care in particular.[2,24–27] The documents reflected the shifts in funding mechanisms and expectations as the internal market was first introduced then changed as the NHS and Community Care Act 1990[5] was superceded by the Health Act 1999.[69]

However, there were some significant decisions about commissioning arrangements in palliative care, that illustrate changing government positions. The first government circular on 'terminal care'[33] required district health authorities to take the lead on planning these services, expecting them to be comprehensive and integrated with the voluntary sector and local authorities. In the wake of the NHS and Community Care Act 1990,[5] the Government ring-fenced money to enable health authorities to contribute to the funding of hospices and similar organizations.[36] The aim, as a national target, was to match the funding contributed by the voluntary sector with government funding. By 1995, ring-fenced funding ceased and commissioners were expected to fund services based on needs assessment from their baseline budgets.[40] The use of three-year rolling contracts with providers was highlighted and intended to contribute to stability of service provision. Later guidance[41] withdrew the aim of matching funds from the Government with the voluntary sector, stating it was 'no longer appropriate'. Instead, it placed emphasis on contracts based on the assessed needs of the resident population and funding likely to be available from other sources.

The Calman-Hine Report[17] was cited as influential in this decision, as was Higginson's chapter[65] on needs assessment and palliative care, which was circulated with the executive letter.[41] Needs assessments were expected to consider local priorities, resources and services available, although new developments should not divert resources from established palliative care units that are delivering high quality care. However, a political dimension was revealed with a change of government between two significant papers: the funding guidance given in EL(96)85[41] was superseded by arrangements set out in the NHS Cancer Plan.[35] This restored the expectation of matched funding to the voluntary sector and an assertion that core services should be agreed in conjunction with voluntary sector. The Cancer Plan[35] heralds what the government describes as a 'ten year programme of change', reflecting a commitment to longer-term service agreements.

Peer review[70] and the development of performance indicators will form part of these service developments. A survey of palliative care services carried out in 1999[71] demonstrated provision of palliative care services on a regional basis. This survey will form the basis of a checklist to facilitate peer review.[70] Again, the checklist focused on delivery of palliative care within cancer services; for example, one indicator cites mortality data related to deaths from cancer.[71] Within this, the crucial role of primary care and the need for investment in building good communication networks is reiterated.[35] It has long been recognized that if care is not co-ordinated across sectors, access to services becomes inequitable.[28] In particular, this is problematic where individuals have complex needs, as is often the case in palliative care. The Cancer Plan[35] demonstrates some political will to address these issues, even if the focus continues to be mainly on palliative care within the context of cancer services.

Conclusion

Cross-referencing the material and tracing the shifts in both definition and funding arrangements highlighted some of the key points in policy about palliative care. It is clear that a classic policy cycle has operated to influence changes in both policy and practice, with expert opinions being taken on board by policy makers, and with experts responding to changes in the overall policy dimension. This influence is made clearer by the aggregation of a range of expert views under a single umbrella organization, the NCHSPCS.

The NHS Cancer Plan recognizes that palliative care has not, in the past, been given the priority it deserves, with only one third of health authorities having a strategy for specialist services and inequitable access to services.[35] Traditionally, palliative care has been seen as synonymous with the care of individuals with a cancer diagnosis. This clarity of focus has, in all likelihood, contributed to the development of the skills needed in this complex field. However, it may also have contributed to the access difficulties experienced by patients with palliative care needs arising from other diseases. The change in terminology indicates something of a shift at policy level, with increasing recognition of the importance of addressing the needs of those with degenerative, nonmalignant conditions. This change in meaning is not yet complete, with a policy still focusing on palliative care in services that prioritize cancer care.

Nevertheless, the principles of the palliative approach to care, with its whole person emphasis on quality of life, is now seen as a required focus of all clinical specialities. There can be little doubt that this position reflects the needs of patients with advanced, untreatable disease; however, applying the term as an 'umbrella approach' to extend the scope and purpose of palliative care may also lead to confusion. It is very broad and, by attempting to encompass so much, the specialism may lose the very specificity and focus that enabled 'palliative care' to develop significant expertise in the first place. The response, which links specialist palliative care to 'progressive, advanced disease with a limited prognosis'[57] may be a way of retaining some focus, but might also effectively remove from their remit many patients with nonmalignant diseases. Furthermore, the lack of clarity about the meaning attached to interdisciplinary and interagency working, which are of central importance in attaining these broader ideals, is likely to serve as a barrier.

Notwithstanding this, the clear reciprocity and consensus between policy development and specialist expertise demonstrated in this analysis, gives cause for optimism that any difficulties arising from the extending focus will be identified as they emerge. There is always likely to be a time delay between the acknowledgement of policy ideals and their implementation into practice. However, collaborative policy development should help to extend the skills and philosophy of the palliative approach to a wider section of the population in need, without losing the clarity that formerly came from focusing mainly on cancer.

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