Department of Health

Spiritual Care at the End of Life:

a systematic review of the literature

Review and this report completed by Universities of Hull, Staffordshire and Aberdeen to support implementation of the End of Life Care Strategy

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Spiritual Care at the End of Life: a systematic review of the literature

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This review was commissioned to support implementation of the End of Life Care Strategy, published in 2009, which is available from the DH website at www.dh.gov.uk

The National End of Life Care Programme works with health and social care services in England to improve end of life care for adults, and helps services respond to the issues and challenges highlighted in the Strategy. Further information is available from the programme's website at www.endoflifecareforadults.nhs.uk

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Executive Summary

Purpose of the review

This literature review was commissioned to support the implementation of the End of Life Care Strategy in respect of the provision of spiritual care. It aimed to gather systematic evidence of the knowledge and tools available to promote and support the delivery of high quality spiritual care appropriate to the diverse contexts of end of life care in the UK, as well as to identify gaps in knowledge and skills and practice issues.

Scope of the review

The review covered the English-language literature from 2000 to 2010 which dealt with spiritual care in end of life care settings and which included spiritual assessment tools and ongoing intervention models found in the published literature. A total of 248 sources was identified, classified and critically reviewed. The documents were written by authors from 17 different countries although the UK and US accounted respectively for 41% and 35%. There were seven collaborative publications across two countries.

After a preliminary review of the literature, three consultation groups were convened comprising of academic, practitioner and service user and carer experts in the field in order to obtain their views on the preliminary findings.

Five overarching themes emerged in the review.

1. Disciplinary and professional contexts

The greatest number of sources from a single discipline came from nursing (25%) with interdisciplinary studies also accounting for 25%. Chaplaincy accounted for 14% and social work 10%. These were the largest contributions. The review of the material within each of these professional disciplines showed interesting but separate developments. Nursing is credited with having nurtured the emerging interest in contemporary spirituality and its implications for spiritual care, but is having to respond to criticisms of its early scholarship including conceptual confusion and lack of evidence for some of its claims. Chaplaincy has responded to increasingly secular work environments by broadening its remit to address spiritual need as perceived in humanistic definitions, thus raising questions about what is unique about what they do. Social work remains cautious about its engagement with spirituality and is concerned to distinguish psychosocial from spiritual care, but has particularly addressed cultural issues and differing perspectives.

2. Concepts and definitions

Considerable energy and debate continues to be devoted to defining and exploring the concept of spirituality and its relationship to religion. Over the period of this review the concept of well-being has assumed some prominence and a considerable body of research has sought to describe and quantify well-being, to link it with spiritual and religious variables and to evidence the associated health outcomes. Most of this research comes from the US where ‘spiritual’ is commonly equated with factors which in the UK are more likely to be termed ‘religious’. Evidencing health outcomes

from the broader understandings of spirituality commonly employed in the UK is a complex exercise and more sophisticated empirical studies are required.

3. Spiritual assessment

By far the largest body of material in the review was concerned with discerning and assessing spiritual need including spiritual distress. There is a plethora of tools designed to measure spirituality and rate its significance for the individual. However there is considerable scepticism in the UK literature about the value of this approach and doubts are expressed from practitioners about its efficacy and appropriateness for spiritual care. There is general agreement that identifying and responding to spiritual need is the responsibility of every worker, though there is growing support for competency models which differentiate levels of engagement. Generic questions are favoured and narrative or 'story-telling' approaches are emerging.

4. Spiritual interventions

There is rather less material on interventions designed to develop, promote and support the provision of spiritual care, except insofar as spiritual assessment is itself treated as an intervention. Interventions are viewed at service level as well as individual direct practice and a number of models were found. Broadly these belong to integrated models for end of life care which include spiritual care as an embedded aspect, or spiritual care models which take the provision of spiritual care as their starting point. There is a paucity of evaluative studies on the operation of these models in practice.

5. Education and training

The review did not reveal many studies which focused on education and training of the workforce. Some professional practice guidance is available, particularly for chaplaincy, which variously deals with skills required, training requirements and standards for practice. However, there was rather more evidence of a widespread *need for* training in all aspects of spiritual care.

6. Overview and conclusions

Although the review found a substantial literature base relevant for spiritual care at the end of life, there was considerably less material which dealt specifically with spiritual care in the context of end of life care. The report makes 10 recommendations, highlighting the need to strengthen the evidence base, including evaluation of practice models, and improve education and training with a particular focus on translating academic concepts and theoretical models into accessible practice understandings and viable interventions.

1 Introduction

Spiritual care is increasingly identified as an integral part of health care systems across the world. This is particularly so in palliative and end of life care where a holistic approach is established as both philosophy and model of care. Spiritual care has risen in visibility in health services over the last two decades, from a position where it was equated with religious care and regarded as the sole province of chaplains to one where a broad concept of spirituality is employed and spiritual care is recognised as having relevance for all sectors and to lie potentially within the remit of all health and social care workers. However, this perceptual shift has not necessarily occurred at the level of practice and there is anecdotal and other evidence of continuing uncertainty and ambiguity over how, when and where spiritual need should be addressed.

In July 2008 the UK Government launched its End of Life Care Strategy for England and Wales [1] aimed at achieving a comprehensive transformation of the care given to people approaching the end of life, their families and their carers. Amongst the tools supporting this programme, the Liverpool Care Pathway [133] includes standards for spiritual assessment and care. The First Annual Report of the End of Life Care Strategy [54] identified that there was still significant work to do on meeting these spiritual needs. This review was commissioned to address two problems in particular which were thought to currently inhibit the development of spiritual care in the NHS and other palliative and end of life care providers:

- A lack of systematic evidence concerning the spiritual care tools available and the knowledge and skills of the UK work-force, to equip them to offer high quality spiritual care;
- Concerns that many of the available tools have been developed in the US, generally regarded as a more religious environment than the UK, and may not transfer well to the UK.

Terms of the review

We undertook to provide a review of the English-language literature from 2000 to 2010 which dealt with spiritual care in end of life care settings and which included spiritual assessment tools and ongoing intervention models found in the published (including 'grey') literature. The review sought to clarify the concepts of spirituality and spiritual care currently in use and trace developments and progress in the provision of spiritual care as well as identifying barriers and inhibiting factors.

Structure of the report

Section 1 sets out the background, terms and questions for the review. Section 2 provides a detailed account of the way in which the review was conducted. Section 3 contextualises the review in relation to the disciplinary backgrounds of the authors, and also provides a perspective on the issues and developments in each of these separate fields. It is recognized that other disciplines – in particular palliative medicine – have also made significant contributions to the overall field but the volume of literature uncovered during the period of the review was not large and, furthermore, the research team does not possess the in-depth knowledge to undertake this disciplinary review

[1] Department of Health (2008) *End of Life Care Strategy - promoting high quality care for all adults at the end of life*, Crown, London

outside of their own fields. Sections 4, 5, 6 and 7 form the substantive sections of the review, treated thematically across all disciplinary contributions and types of source. Section 8 provides a summary overview, identifying gaps in the evidence and makes recommendations.

The review is supplemented by Appendix A List of Sources reviewed , numbered and organized in alphabetical order and identified in the text [*number*]; Appendix B Classification of Sources; Appendix C Consultation Groups – combined summary of meeting notes and case studies used; Appendix D Tools and Models identified in the review.

2 Method

Search Strategy

Inclusion/exclusion criteria

The aim was a systematic review of the English language literature in the fields of hospice, palliative care, end of life care and the caring professions concerning spiritual care at the end of life. In pursuit of this aim we looked for available knowledge from varied sources – research literature, 'grey' literature such as policy and professional practice guidance, professional training standards and pedagogy. We found that there was a vast amount of documentation relating to spirituality, spiritual care and to end of life care. We have, however, focused on literature which combines these elements. Thus, we have included in our review documents which specifically discussed spiritual issues in end of life. We have also included material which focused on end of life care but made some mention of spirituality as an element in this care and sources which considered spiritual care in general but referred to care in terminal illness or of dying people. We have not included literature which did not mention at all these criteria together. We have not reviewed the literature on spirituality and spiritual care in bereavement, although we have included references to the spiritual needs of families of the dying person.

We have considered systematically only literature from the year 2000 onwards. Although we are aware that seminal research was conducted before that date, the research team has lengthy experience in the field and has therefore additionally been able to draw on earlier writings in providing background context. Similarly, we did not systematically review books published in this field although considerable material is available in book form. Books are included by each reviewer as appropriate to their field of expertise and, occasionally, when following up a reference from a journal article.

Search terms

Our plan was to start with the search terms of 'spirituality', 'spiritual assessment', 'spiritual need', 'spiritual pain/distress', and 'spiritual care', and then broaden using terms such as 'religion', 'existential despair', 'meaning' and also refine (e.g. using terms such as 'spiritual identifiers', 'spiritual interventions' and combined searches such as 'spirituality + culture'). In fact it was found more helpful to initially search academic databases on the broad terms 'spirituality' and 'spiritual' in all content and select appropriate literature from that which was generated by consideration of the

title, followed by reading of the abstract. Searches of academic bases also used the words ‘religion’, religiosity’, and ‘meaning’. Searches were refined using the terms ‘end of life’, ‘dying’, ‘death’, ‘terminal’, ‘hospice’ and ‘palliative care’. Similar terms were used in searches of individual journals.

In searching the wider internet for ‘grey’ literature the starting point was ‘end of life’, ‘hospice’ or ‘palliative care’. Websites and documents generated were then searched for the words ‘spiritual’ and ‘spirituality’.

We also incorporated material resulting from hand searches at the writing up stage.

Bibliographic databases/indexes

The following databases were searched:

ATLA
Cinahl
Medline
Psychinfo
Academic Elite
IBSS

Journals

Some journals for which the facility was available were searched online or where a search was not possible, browsed on line or as paper copies. These included:

Scottish Journal of Healthcare Chaplaincy
Contact Practical Theology
Journal of Healthcare Chaplaincy
British Journal of Social Work
Practice

International Social Work

Journal of Social Work
Health and Social Work
Social Work
Palliative Medicine
British Journal of Nursing
Mortality

Specific websites

National End of Life Care Programme
Marie Curie
SWAP
SCIE
NICE Guidance
Royal College of Psychiatrists Special Interest Group on Spirituality
Dignity and Care Campaign

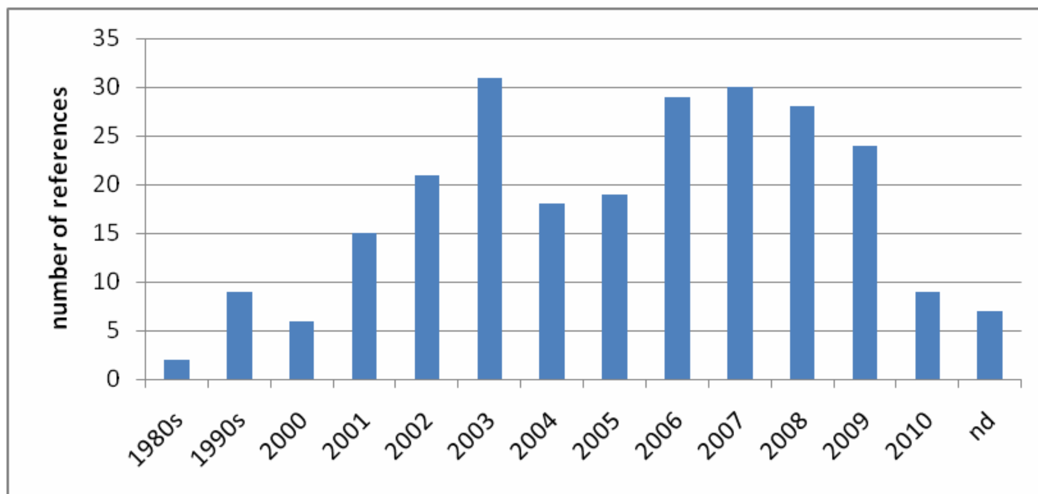
Search results

Sources found – classification and listing

The 248 sources identified are listed in full at Appendix A. At Appendix B the sources are classified by date, author's country of origin, author's discipline/s, type of document (e.g. empirical study, policy document, commentary, case study), the context of the research/discussion, the research design (where applicable), whether a model of assessment or spiritual care is described and the overall focus of the document.

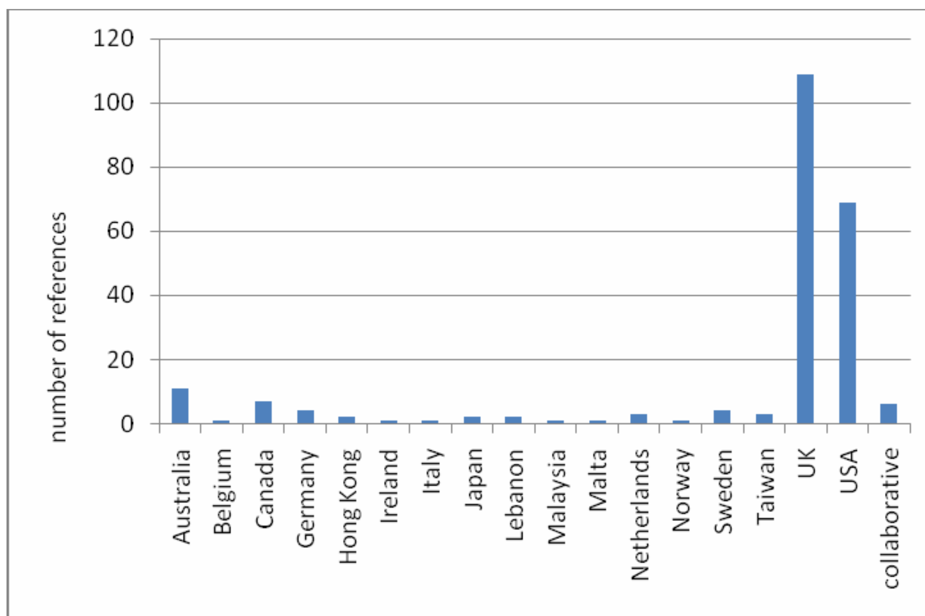
Analysis of the sources found shows that although the period covered by the searches was from 2000 to 2010 and few documents were included before 2000, there was limited literature in the earliest part of the period. There were 120 documents published between 2006 and 2010 compared with 110 between 2000 and 2005. There were 7 with no date, mostly web pages and practice guides.

Figure 1. Date of sources



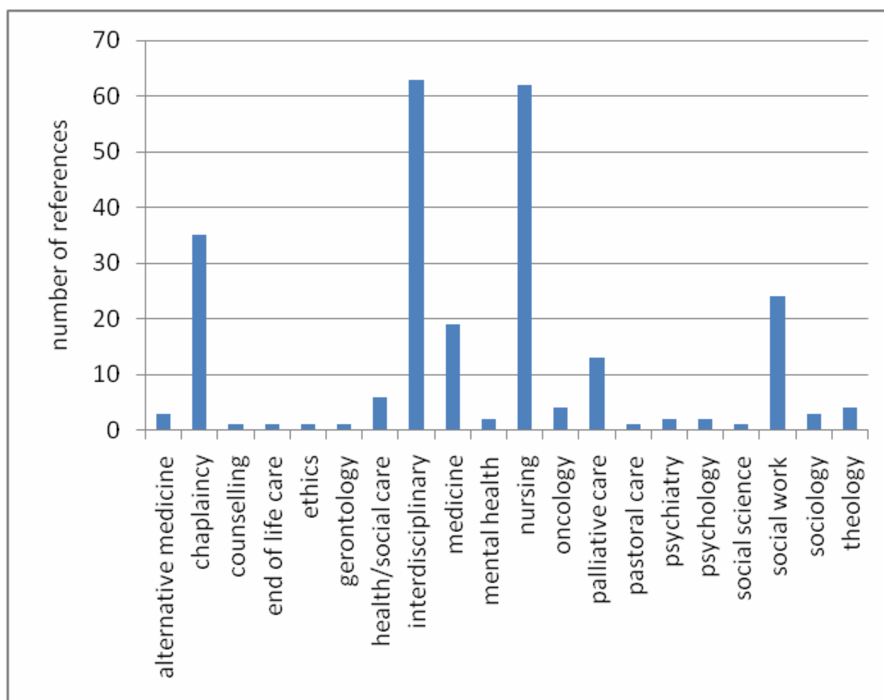
The documents were written by authors from 17 different countries although the UK and USA accounted respectively for 41% and 35%. There were seven collaborative publications across two countries.

Figure 2 Country of origin of author/s



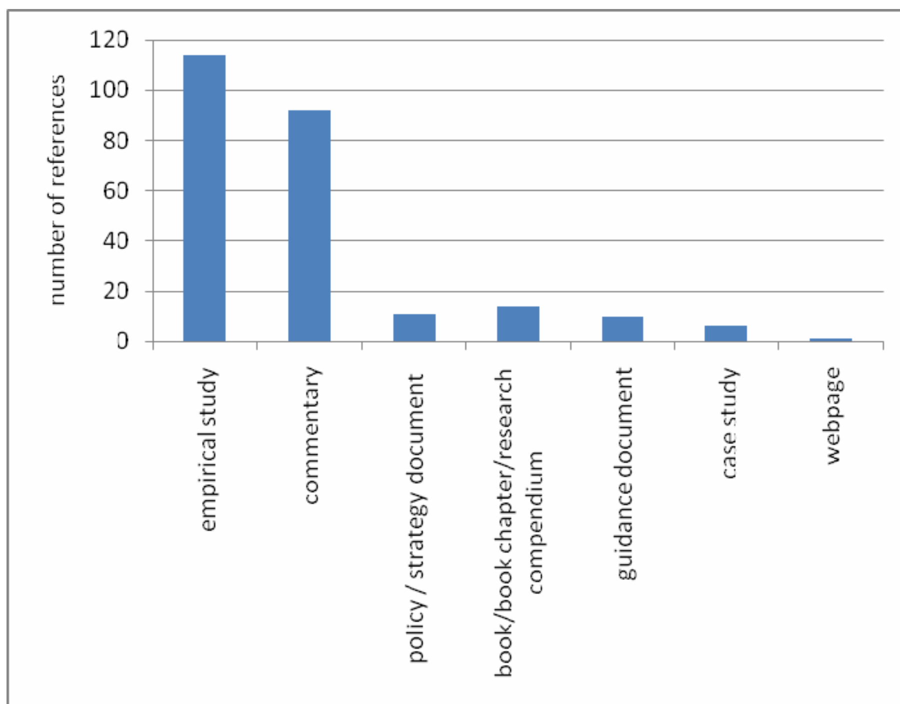
The documents examined were from a wide range of disciplines. The largest proportion of documents were interdisciplinary and nursing backgrounds, both 25%. The other disciplines represented in the research team account for 14% (chaplaincy) and 10% (social work).

Figure 3 Author/s' discipline



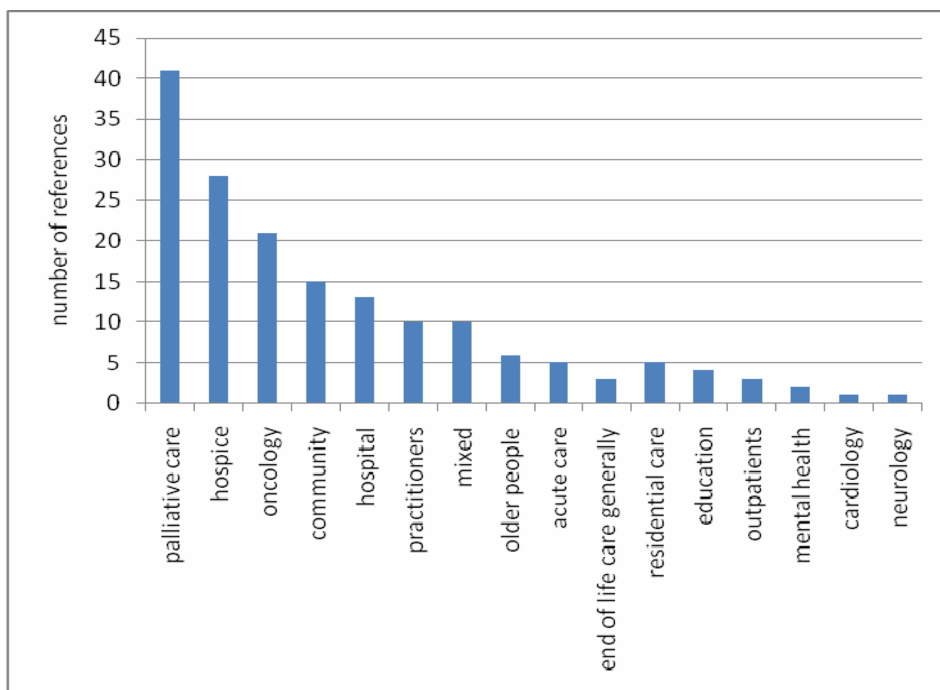
Most of the documents reviewed were empirical studies (46%) or commentaries (37%). Eleven policy/strategy and ten guidance documents were included.

Figure 4 Type of document



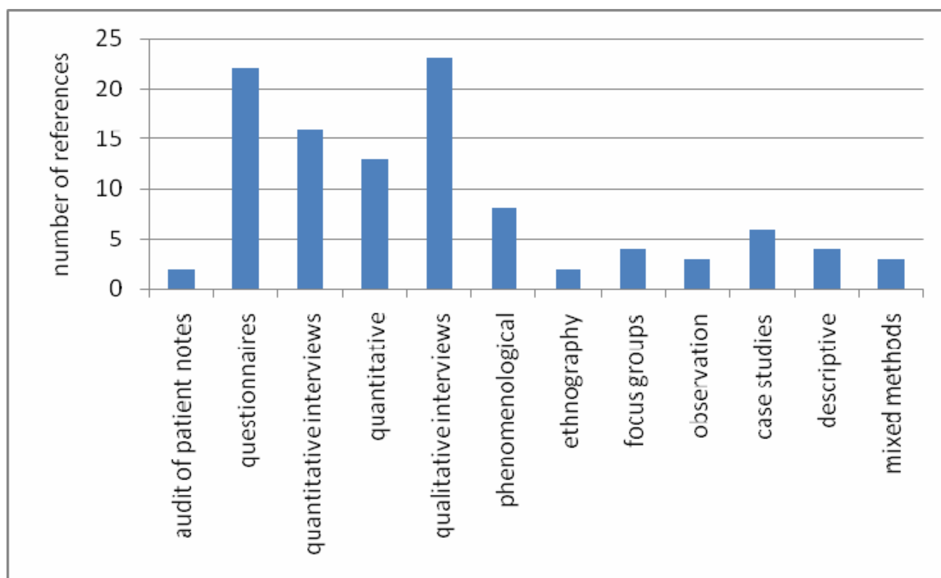
Among those documents which described empirical research or commented upon spirituality in end of life care in a particular setting, the largest numbers were written against a background of palliative care generally (24%) or hospice care specifically (17%). For 13% the focus was oncology and 9% end of life care in the community. 6% considered specifically the professionals practising in varied fields.

Figure 5 Context of writing



Of the 113 empirical studies, almost equal numbers took qualitative and quantitative approaches with three using mixed methods.

Figure 6 Methodological approach



Coding

The content of all relevant sources was coded using the NVivo software package. NVivo is a tool used in qualitative data analysis which permits a sophisticated categorisation, ordering and integration of all forms of data and has been found to greatly enhance the process and production of a comprehensive literature review (Richards, 1999; Johnston, 2006). The process of using Nvivo followed was that suggested by Di Gregorio (2000), although using a more recent version of Nvivo. For each document an 'external' or proxy document was created in Nvivo, the externals being arranged in four folders, thus providing an initial categorisation. One folder was used for each of the principal disciplines of the three research team members i.e. nursing, chaplaincy and social work. This arrangement was intended to facilitate an initial review by the research team members of material in their own disciplines. A fourth folder included literature from other backgrounds such as medicine or theology and interdisciplinary research. In addition, relevant sections of four policy/guidance documents were imported directly into Nvivo as 'documents'.

The external included the author, document title, journal title and issue, publisher and date as applicable. The external also indicated the number of pages and the verbatim abstract if present. In addition the researcher added from the main text of the document, referenced to the page number, extracts relevant to the subject of the review. In particular the researcher noted any models of spiritual assessment or spiritual care described. In some cases the researcher made critical comments in relation to the findings or methodology.

The next step was to identify themes in the externals and documents. This was accomplished by using Nvivo's word search facility and searching across all the folders. The results of the searches were coded as Nvivo nodes, in each case the entire external being coded against the node and the nodes being across disciplines. The nodes identified were:

- Assessment
- Communication
- Community
- Evaluation
- Integrated care model
- Interventions
- Spiritual care model
- Spiritual pain/distress
- Training

The research team members received initially the externals relevant to their main disciplinary background exported into Word and then the node content also exported into Word. The research team members used this material, along with their own knowledge of the field, to assess the literature. Paper copies of all the documents were retained, organised in disciplines, for detailed referral as required.

Consultation groups

After preliminary analysis of the material, consultation groups of experts were set up in Hull, Stafford and Aberdeen. The purpose of this was to draw on the implicit knowledge and practice wisdom of all stakeholders.

The composition of the groups varied between the locations but together provided input from a number of different viewpoints. The groups were led by Professsor John Swinton in Aberdeen, Professor Margaret Holloway in Hull and Professor Wilf McSherry in Stafford. In Aberdeen ten representatives from a variety of disciplines took part. These included academics in the fields of nursing and palliative care, a MacMillan nurse and MacMillan psychologist, nurses from a specialist palliative care unit and chaplains. In Hull there were 24 participants including social work academics/ practitioners/practice teachers, chaplains, hospice professionals from disciplines including physiotherapy and music therapy, clergy serving in the community from several different Christian denominations, a representative from the British Humanist Association, hospice volunteers and representatives from a service user/carer advisory group (which includes members associated with the local hospice). In Stafford three academic representatives with knowledge and experience of palliative care, dignity and care, and values education took part.

The research team recognized the sensitivity of the subject under discussion and introduced ground rules for the conduct of the groups. These were:

- each person to respond including according to their own belief or non-belief position;
- Any position is relevant;
- Individual belief positions are to be accepted and respected.

At each group the leader explained the purpose, remit and process of the review. The leader then summarized the main themes identified in the research so far, using a Powerpoint presentation agreed by all research team members. The consultation groups were then asked to consider three case studies relating to end of life care situations (Appendix C). The vignette approach has been proved an appropriate method for tackling sensitive topics which might be avoided if direct questioning of personal experience were used (Seymour et al, 2002 and 2007). The case studies were considered in the light of the findings in the presentation but focusing on the questions:

- Should spiritual needs be considered routinely?
- Who should assess these?
- How?
- Who should offer spiritual care?
- How?

At the Hull group, the meeting split into small groups to facilitate discussion which then fed back to the meeting in general while the smaller meetings at Aberdeen and Stafford discussed the issues as a single group. The meetings finished with consideration of a number of models of spiritual assessment and spiritual care. After the meetings notes concerning the points emerging from the discussion were circulated to the research team and to the participants, some of whom have since provided additional feedback. Additional references suggested at the groups were followed up and incorporated in the Nvivo database if they met the terms of the review. They were also circulated to team members.

The points raised at the consultation meetings are summarised at Appendix C.

3 Disciplinary and professional contexts

History and developments in chaplaincy

It will be helpful to begin by clarifying exactly what is meant when the review talks about chaplaincy. Historically, a chaplain, ordained or otherwise, was seen to be the representative of a particular faith community who was sent to work within a specific setting. Traditionally the word 'chaplain',

> refers to a clergyperson who has been commissioned by a faith group or an organisation to provide pastoral service in an institution, organisation, or governmental entity. Chaplaincy refers to the general activity performed by a chaplain, which may include crisis ministry, counselling, sacraments, worship, education, help in ethical decision-making, staff support, clergy contact and community or church co-ordination [103 p. 136].

In the past a healthcare chaplain has been someone whom the church (or other religious authority) has appointed as their representative within the hospital, to authentically embody the faith community's desire to minister to those suffering from illness, and to bridge the gap between hospital, community and church. However, more recently the shape and focus of chaplaincy has changed in line with the movement towards secularisation, particularly within the United Kingdom [155] and the resulting changes in the definition of spirituality. Chaplains are no longer perceived as representing any particular faith or religious tradition. Rather they are seen as being responsible for the spiritual care of people who belong to all faiths and none [175; 156]. That being so, most of the literature around chaplaincy focuses on a generic form of spirituality that sits well within a health service that seeks to offer care to a broad range of people with diverse beliefs [211; 175]. That is not to say that specific theological perspectives have no place within chaplaincy. Some of the literature draws specifically on religious traditions to show the role of the chaplain [59; 61]. Nor is to say that specifically religious needs are not addressed by chaplains [100; 131]. It is, however, to state that the model of spirituality commonly drawn on by chaplains in the UK and in the USA is broad, generic and inclusive.

The core tasks of chaplaincy

The core task of chaplaincy is to respond to the spiritual needs of patients and staff by accompanying them on their spiritual journey [155]. Precisely what spirituality is and what spiritual needs are, is open to debate, and a variety of models and perspectives have been developed [213; 175]. Spirituality is perceived as a generic characteristic of human beings that reveals itself in the search for meaning, relationships, purpose and hope [8]. Spiritual care is conceived as,

> that care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires [175].

Within this understanding of spirituality and spiritual care, chaplaincy is seen to have moved significantly from its historical roots and now inhabits a space within the National Health Service wherein it retains some responsibility for religious needs, (i.e. needs that pertain to a person's

formal religious affiliation if they have one), but which primarily focuses on the wider spiritual needs of patients which may include but is not defined by religion.

Professionalisation

In line with this is the current movement towards professionalisation, that is, the development of chaplaincy as a healthcare discipline on a par with other healthcare disciplines such as nursing and medicine [217]. This in turn has moved chaplaincy to begin to reflect on what an appropriate evidence base might look like to support the profession of healthcare chaplaincy [177; 245] and precisely what competencies such a discipline might require to find a firm and credible space within today's NHS [211; 7; 149].

It is thus clear that chaplaincy is going through a time of transition; moving away from a definitively religious identity to an identity within which spiritual care in all of its variant dimensions is the definitive aspect of the profession of chaplaincy. The lack of clarity as to precisely what spirituality is, the broadness of the definition of spiritual care along with the suggestion that it is the responsibility of *all* healthcare professionals makes the identity and role of chaplaincy rather opaque at times. If spiritual care is the responsibility of all people then why do we need chaplains? Our review indicated that one way of addressing this question might be to conceive of spiritual needs as arising on a continuum that requires different levels of competence – generalist spiritual care providers (all health care professionals) and specialists (chaplains; religious leaders and other professional practitioners such as counsellors). This would sit well with the observation that chaplains do not have any skills that are original. Rather it is the unique configuration of attributes - listening, talking, story-construction, perceiving the spiritual, counselling and so forth - that gives them their unique place within healthcare practice [155]. Despite the controversies, it is clear that chaplaincy within a hospital context is a major provider of spiritual care that has significant implications for end of life care.

History and Developments in Nursing

If one traces the antecedence of nursing it is evident that the profession has a long association with spiritually and religious belief and practice. Often referred to as its spiritual heritage, caring and nursing were provided by religious communities [18; 161; 116] whose primary responsibility was tending to the temporal and spiritual needs of the sick, dying and destitute. This religious and spiritual heritage was allegedly eroded with the inception of the National Health Service (NHS) and welfare state when the state took over the responsibility for providing the majority of health services. Remnants of the spiritual heritage persisted and survived in an increasingly secular and materialist society in the context of charitable-run hospices which strived to provide holistic care and services. Cobb [41 p2] describes a contradiction - 'the familiarly unknown fourth side of the palliative care quadrilateral which is a way both of understanding and of responding to the spiritual dimension of being human' - implying that while the spiritual dimension had been preserved and was still enshrined within the philosophy of palliative and end of life care, it had become a forgotten and largely neglected aspect of general health care practice.

The international nursing community across a range of clinical and specialist settings has been instrumental in raising awareness of the importance of the spiritual dimension for health and well-being. Nursing has been the catalyst for debate and reconnecting with the spiritual dimension of

care for many healthcare professions. However, the quality and rigour of the early empirical study and the limitations of the debate and scholarship have recently been criticised [218; 38; 179; 180]. Early work undertaken by nurses in the UK had focused primarily upon the concept of spirituality. For example it sought to clarifying nurses' and to a lesser degree patients' perceptions of spirituality and spiritual care [205; 239; 142]. The result of this research and the subsequent debate was to construct a very secular and broad existential definition of spirituality. One definition used by many nursing academics in the UK was the one offered by Murray and Zentner [158]. This definition was not developed out of any empirical or scientific study and was adopted uncritically and largely unchallenged by nurses throughout the late 1980's and 1990's. This definition was perpetuated and regurgitated in the nursing literature almost as an authoritative, definitive and operational definition of spirituality. A further limitation of this early work was the lack of engagement with other academic disciplines, for example, within the fields of theology, philosophy and religious studies. The work lacked external scrutiny and review by colleagues outside of nursing. Some of the conceptual and theoretical claims made about the nature of spirituality were largely unsubstantiated by reason, argument or evidence [180]. When one reviews these early published empirical studies they were primarily quantitative, taking the form of surveys and questionnaires. There was no in-depth qualitative enquiry into the nature and perception and lived experience of spirituality and spiritual care. Further, most of the pioneering research undertaken by nurse researchers was conducted in North America with Judeo-Christian study populations where spiritual care seemed to be closely aligned to maintaining religious belief and practice. This limited the transferability and generalisability of findings.

Despite these criticisms it is important to acknowledge the innovative and ground- breaking work that nurses, primarily in the US and UK, were undertaking into this relatively uncharted dimension of humanity and nursing practice. Within nursing there was a desire to treat the person holistically at a time when the spiritual dimension appeared largely neglected in increasingly technological and scientifically- driven health care systems. Their model for holistic practice was derived from the hospice movement, including its affirmation of the importance of attending to the religious and spiritual needs of patients. Thus, although much of the work on spirituality and spiritual care in nursing is not located in or explicitly applied to palliative care, there is an assumption of its relevance for end of life issues and practice.

Contemporary developments

Nursing has continued to build on the early conceptual and empirical foundations, but the emphasis is no longer on the development of an all- inclusive and authoritative definition of spirituality which might be universally applied. There has been a re-engagement with conceptual development as authors draw upon other academic disciplines such as practical theology, philosophy, sociology and religious studies to assist in refining and adding texture to the concepts originally articulated. Simultaneously, there is a shift from broad conceptual clarification to practical relevance. For example, there is a growing debate about the nature of spiritual assessment and the types of tools that are appropriate for practice [143]. Questions are being raised about how to distinguish spiritual from psychosocial care and other fundamental aspects of nursing care [38; 180]. An emerging area of enquiry has surrounded the teaching of spirituality to nurses, the ethical questions raised by such teaching, and pioneering work in the Netherlands [229; 230] and Malta [9] around competency models for education and practice. Methodological development is seen in a greater involvement of

patients in every stage of the research process to produce credible and reliable evidence to support earlier largely unsubstantiated claims that meeting the spiritual needs of patients has a therapeutic benefit or that it can enhance quality of life and care [45]. In addition, research into spirituality has been extended to people from diverse religious, ethnic and cultural groups [68; 11; 40; 32] and in consequence the debate is informed by more heterogeneous groups and samples.

History and Developments in social work

Social workers are established members of the multidisciplinary team in palliative care, this association going back to the team set up by Cicely Saunders at St Christopher's Hospice in London [199] and its holistic philosophy of care [96; 99; 17]. However, the volume of empirical research on the social work contribution to end of life care has been thin. Rather more has been written on the broader field of social work with people who are dying or bereaved, although most of this makes only passing reference to religious or spiritual care. The first empirical work looking at social work in dying and bereavement in the UK was published in 1997. This national study also focused on spirituality and reported social workers acknowledging existential issues as significant; 86 % said that they recognised spiritual pain in dying patients and bereaved families yet they did not identify themselves as having the skills to work with this dimension and the service users themselves reported that they were unable to discuss such issues with workers in secular organisations [126]. An important early text highlighting the social work role discusses psychosocial palliative care [202] but clearly distinguishes between this and spiritual care, which it does not see as a focus for social work intervention. UK social work literature continues to distinguish psychosocial from spiritual care, in contrast to US social work literature and an increasing tendency in health care organisations to conflate these two dimensions of need and care [184; 185; 46]. There is increasing use of the concept of 'worldview' [e.g. 99; 46] to encapsulate a psychosocial-spiritual model appropriate for social work with people who are dying or bereaved [96].

Social work studies of spirituality have been slow to emerge, particularly in the UK. The majority of the UK literature is concerned with mental health and well-being more broadly [e.g. 44] or with the inclusion of religion and spirituality in social work education and practice generally but with no specific mention of end of life care [e.g. 70; 66]. Studies of older adults (internationally) report the importance of religiosity and spirituality to mental health and well-being [182; 98] including the importance of belief for a 'good death' [25]. During the period of this review a modest increase can be seen in spirituality studies which include end of life care issues in their remit, and, similarly, a greater tendency to include spirituality routinely in studies of end of life care. We found only one empirical study which examined in detail social workers' use of 'spiritual practices' specifically in end of life care [50]; this (US) study found a range of practices such as yoga, prayer and meditation employed and those social workers with an 'eclectic orientation' to spirituality more likely to use them. One UK-wide questionnaire survey of social workers' views about their practice and training in spiritual care Furman et al [65] found end of life care and bereavement to be exceptions to the continuing caution expressed about spirituality and religion as a focus for social work assessment and intervention; doubts continued to be expressed about the appropriateness of some techniques and most respondents had received no training in spirituality or spiritual care. Holloway [97] points to the lack of progress on introducing the spiritual dimension into social work practice over more than a decade, despite continuing agreement about its relevance in end of life care and bereavement. This is borne out by the US National Association of Social Workers (NASW) report

from the Summit on End of Life and Palliative Care [2] which found 68% of social workers to be ambivalent about exploring spiritual and existential concerns with patients and their families. A UK study highlights the role social workers could play in providing spiritual support for palliative care patients in the community but found them 'conspicuous by their absence' in these patients lives [39].

Cultural context

An important theme for social work is the relationship between religion and perceptions of spirituality and culture [3]. Western narratives which distinguish religion from spirituality and develop a secular perspective on spirituality are critiqued in the context of social work practice in multi-cultural settings [99] and the exporting of western models of education and practice to postcolonial contexts [244]. The challenge for 'transcultural practice' is argued as finding the means to access and engage with the strengths and resources in the other person's spiritual tradition [95]. However, some sources identify spiritual and cultural factors as 'barriers' in end of life care [2]. A study of older African Americans highlighted spiritual resources and strength of belief as the most significant factors in end of life decisions [25]. Differing professional cultures in respect of religion and belief emerged in a study of death anxiety and medical preferences which included social work and medical student samples, and which also showed more superstitious beliefs in the community (general public) sample [33].

Relationship with chaplaincy

One developing theme compares the role of social workers with that of chaplains; this theme also occurs in the 1997 UK study discussed earlier [126] which found considerable overlap in perceptions of role and task except in the provision of spiritual care. One UK empirical study found social workers to be more concerned with personal fulfilment and well-being where chaplains focused on providing religious services and exploring psychological meanings [183]. By contrast, a US study [196] refers to blurring of roles and confusion, with chaplains and social workers playing the same role but taking different approaches and working from different theoretical bases. Social workers are often seen to take a 'problem solving' approach [97; 183; 196] where chaplains start from an acceptance of mystery and paradox [196; 96].

Competency models

Hospice and palliative care social workers in North America have developed core competencies for palliative care social work which incorporate statements about spirituality [17; 77]. The Canadian model [17] reports some dispute about whether or not spiritual care competencies should be stand-alone; the US model [77] places considerable emphasis on assessing spiritual need. Other competency/practice models focus exclusively on spiritual care [209; 93] and religion and belief [66] but provide generic statements and do not apply these to the specific context of end of life care.

4 Concepts and definitions

Spirituality, religion, well-being

A good deal of energy and discussion within the literature focuses on issues of conceptualisation and definition. For reasons highlighted previously the meaning of spirituality has shifted and changed as cultural assumptions have altered. That being so, there is a general lack of clarity with regard to the meanings of the terms ‘spirituality’, ‘religion’ and, indeed, ‘well-being’. As a general rule, the literature indicates the following understandings.

Religion or religiousness is defined as participation in the particular beliefs, rituals, and activities of traditional religion [176; 175]. Here guidelines are offered to deal with religious patients and to ensure that their specific traditions are understood and their particular needs met. Religion is respected as a mode of spirituality but is not considered to be synonymous with it. While not all writers agree on the benefits of religion within an end of life context [179; 236], there remains evidence that religious spirituality can have clear benefits in terms of coping with illness and the threat of death. [63; 235; 49; 117; 181].

Spirituality is more basic than religiousness. It is a subjective experience that exists both within and outside traditional religious systems [131]. Spirituality relates to the way in which people understand and live their lives in view of their core beliefs and values and their perception of ultimate meaning [194]. Spirituality includes the need to find satisfactory answers to ultimate questions about the meaning of life, illness and death [164; 80]. It can be seen as comprising elements of meaning, purpose, and connection to a higher power or something greater than self [201; 60]. A difficulty with the term spirituality is that it is rather diffuse and quite difficult to tie down. Some have noted this lack of clarity as a significant problem and indeed a reason for not using it within healthcare [178]. However, others indicate that the lack of definition may in fact be a strength insofar as it allows for a deep openness to the individual nuances of personal spirituality. Definitions shape the ways in which people approach patients. Broad and flexible parameters allow for person-centred care that focuses on the individual [73].

The importance of both religion and spirituality is that they provide a context in which people can make sense of their lives, explain and cope with their experiences and find and maintain a sense of hope, inner harmony and peacefulness in the midst of the existential challenges of life [31].

Well-being is also a complicated concept. At a basic level it is a subjective emotional experience that relates to the way in which a person perceives themselves to be and to feel within any given situation. Well-being is not a global concept. It is possible to have well-being in one aspect of one’s life and not to have it in another. For example, it is possible to be peaceful and hopeful when one is experiencing terminal cancer (for example due to a belief in the afterlife or that God is caring for you in the midst of your current circumstances), whilst at the same time not having well-being in other aspects of life, for example, due to experiencing pain, discomfort or anxiety. Both well-being and a lack of well-being can thus occur at the same time. This distinction becomes important, for example, within end of life care around issues of physician assisted suicide. McClain et al noted that when terminally ill patients’ existential and spiritual needs were met, requests for assisted suicide declined [136]. Thus, noting the contextual, particular and non-global nature of well-being seems important for the practice of end of life care.

The importance of religion and spirituality for healthy human development has been noted across the disciplines. There is a growing body of evidence that indicates that a focus on religion and spirituality, broadly defined, can have a positive impact on the ways in which patient's perceive and experience illness including end of life issues, and can be beneficial in terms of mental and physical health. [222; 166; 116]. However, to date much of the empirical research has emerged from the US and has focused on the impact of religion on health and well-being. The UK literature, for reasons previously referred to, has a much broader definition of the term 'spirituality.' However, because it is not tied to religion or to any particular set of practices or communities, actually measuring and assessing it is much more complicated.

In terms of understanding the general literature, by prefixing the term 'well-being' with the term 'spiritual,' researchers make a statement that they are looking at a quite specific aspect of the person's overall well-being. That being so, scales or measures which only look at one aspect of a person's life can be deceiving in terms of the actual state of a person's well-being at any particular moment in time. Consequently the meaning of the term 'spiritual well-being' is inevitably dependent on the ways in which researchers have defined the term 'spirituality.' Much of this research has emanated from the US, where the focus has been on the benefits of certain practices on health and well-being: Church attendance; religious affiliation; health enhancing behaviours; social supports; enhanced psychological states; private religious practices such as prayer and scripture reading; and sense of place, belonging and identity within a religious community.

5 Spiritual assessment

A considerable amount of the literature continues to concern itself with the assessment of spirituality and religiosity and of spiritual need, pain and distress. Indeed, the identification of spiritual need and assessment of its significance for the individual concerned is sometimes treated as a spiritual care intervention in its own right. In contrast, the ability to discern spiritual needs may not be valued as an important part of giving spiritual care by workers [42].

Categorisation of assessment approaches

Tools and models

Assessment tools and models may be divided into spiritual assessment tools which belong to research and those which have clinical applications [29]. The point is also made that in the context of a developing relationship with a researcher, people will express spiritual needs which they may be reluctant to voice to health professionals [159]. There is agreement that the challenge for practice is to turn academic models into workable and appropriate practice tools [143; 173]. Formal practice tools, it is suggested, are useful for the less experienced worker [29]. However, an audit of the Northern Ireland Hospice Chaplaincy Service against the National Standards for Hospice and Palliative Care Chaplaincy found that professional standards were useful even for chaplains in assessing and addressing spiritual needs [113].

A competency-led model which covers four levels of worker expertise is cited in several sources [131 cited in 176; 149; 172]. In this model the recognition and assessment of spiritual need belongs to each competency level, the levels relating to the category of worker as well as the skills which they may need. Despite the popularity of this model, it has been argued that it does not adequately support the setting of national professional and service standards; the weakness of the Marie Curie model lies in the lack of measurement built into its competency levels [149]. However, the pilot study designed to familiarise palliative care staff with the model [73] concluded that the lack of definition may be a strength, because it allows for unique and individual pathways and relationships, with assessments sensitive to these individual variations rather than adhering to a 'tick box model of care'.

The Trent Hospice Audit Group (THAG) defines 3 levels of assessment, and the different levels of expertise needed for each, in its work on service standards: routine, multidisciplinary and specialist [102]. It recommends routine assessment for all patients on admission but to gather only basic information. Multidisciplinary level assessment includes documentation for spiritual and religious care planning and is indicated by issues raised by patients and carers as well as observations by the multidisciplinary team. Specialist assessment is recommended to be undertaken by a chaplain where there are complex religious and/or spiritual issues which require in-depth knowledge and skills. The staff in these pilot sites raised issues about lack of clarity as to when and how to integrate specialist spiritual assessment with a holistic assessment.

Four main approaches to assessment can be identified which also form the categories under which tools and models broadly group: recognition/identification; measurement; narrative/biographical; domain [99].

Approach 1: Recognition/identification of spirituality and spiritual issues

The uniqueness of each person, the multi-faceted nature of spirituality and spiritual need and the importance of a flexible response to that need is central to these approaches to spiritual assessment [29]. Most tools advocate the use of open-ended broad questions to assess the nature and significance of the person's spirituality. For example, the Functional Assessment of Chronic Illness Therapy –Spiritual Well-being (FACIT-SP) tool [186] uses broad questions about feelings of peace, forgiveness, being thankful, feeling loved and having a sense of purpose. Another approach cited in the wider literature describes '4 strands' which inform spiritual assessment as well as intervention: identity questions; questions surrounding loss of meaning and purpose; belief questions and religious conviction; quests for new forms of spirituality [198, quoted in 213). Alongside discussion of particular spiritual assessment tools, the Report of the Consensus Conference on Spiritual Care in Palliative Care [194], an important bench-marking event held in California, recommends use of a generic screening tool aimed at assessing whether or not the patient is experiencing a serious spiritual crisis and should be referred to a chaplain. It is suggested that only brief training is required to use the screening tool appropriately. It should be followed up by the use of more structured assessment tools – for example taking a spiritual history – as appropriate and indicated by the screening.

Generic tools for assessing spirituality are also designed to identify the spiritual *resources* which the person possesses, or may be enabled to connect with. Hegarty [84] advocates use of the questions:

What nourishes you? What feeds your spirit? Where do you find strength in difficult times? If illness is an obstacle to the person getting in touch with those things that usually 'nourish the spirit', part of the assessment task is to identify alternative sources of spiritual care which meet those same needs.

Approach 2: Measurement of spirituality and religiosity

There is a considerable body of research which identifies 'spirituality' and 'religiosity' as measurable items, the focus of interest being their link with health outcomes, particularly risk of disease and length of survival (see [116] for a comprehensive review of this research, relevant for but not specific to end of life care). This evidence base is referred to in palliative care guidance although it is acknowledged that there is contradictory evidence about the strength of belief and its links with well-being, and studies suggesting that strength of spiritual and religious beliefs lead to more positive health outcomes are as yet preliminary [78]. Some evidence is emerging from US studies that addressing spiritual needs in palliative care results in less aggressive care and improves quality of life [189]. Further questions are raised about the misleading tendency to assume convergence between spirituality and positive mental health [116]. This has clear implications for understanding the spiritual distress and pain experienced by some people at the end of life.

The greatest number of tools clusters under this approach [78], although many were developed prior to the period of this review and very few have been tested in palliative care settings. It is acknowledged that it is not clear to what extent these measures can be applied across different patient populations and a further limitation is that there is considerable variation in what is measured [78; 143; 210]. The review undertaken by Gysels and Higginson [78] highlights those which measure religious coping mechanisms (for example, the RCOPE) and links with quality of life. One such tool - the Schedule for the Evaluation of Individual Quality of Life - Direct Weighting (SEIQoL - DW) - was evaluated in a mixed methods study located in a hospice in-patient unit [45]. This study found that some existential and spiritual issues which were more important to participants than physical symptoms, such as identity and faith issues, were not captured by the SEIQoL-DW but emerged in unstructured interviews.

The spiritual needs inventory (SNI) is an example of a standardised items scale developed from qualitative research [87]. Spiritual needs (defined as something required or wanted to find meaning or purpose in life) were grouped into 6 themes. The author suggests that further testing of the SNI is warranted and has combined it with another tool for rating life satisfaction – the Cantril ladder - to determine the degree to which the spiritual needs of patients in 6 hospice units were being met [88]. This study concluded that spiritual activities were important but that nevertheless a variety of patients' spiritual needs remained unmet. The study also found that patients with no connections to formal religion expressed spirituality in 'religiously connected' ways and benefited from spiritual care.

Another tool for doctors to assess the importance of spirituality in the lives of cancer patients combined a semi-structured interview (the SPIR) with post interview rating and scaling of responses [64]. This found that 25 out of 30 patients regarded themselves as spiritual or religious and 21 wanted their doctors to address spiritual and religious issues with them. Also recommended for further testing by the authors is the Palliative Care Needs Assessment tool (PC-NAT), which showed low reliability in the patient spirituality domain [234]. The Herth Hope Index, which identifies 7

hope-fostering categories and 3 hope hindering categories, has been applied to palliative care settings in England and found to have validity. Hope is defined as: 'an inner power that facilitates the transcendence of the present situation and movement towards new awareness and enrichment of being'; the authors recommend strategies to promote hope in palliative care patients [24]. An evaluation of a number of these scales [130] found high scores on hopelessness and loss of meaning or peace to correlate most closely with the desire to hasten death.

Approach 3: Narrative and biographical approaches to exploring spirituality

The earlier examples of this approach refer to spiritual history-taking and a number of intervention models incorporate a spiritual history into the initial assessment of spiritual need [215; 162]. The US Consensus Conference Report identifies a number of spiritual history tools: FICA (a tool referred to by a number of commentators) in which four core questions addressing strength of faith and belief and care preferences are derive from the mnemonic; SPIRIT, a 6-point instrument concerned with identifying spiritual beliefs, practices, and implications for medical care and 'terminal event planning'; the SBI 15R (Systems of Belief Inventory), a tool designed to address questions of meaning, relationships and their impact on the experience of dying [201; 194]. These tools are located here because they are described as spiritual history tools but they appear to the authors of this review to sit comfortably in Approach 1 because of their focus on identifying and assessing the significance of spirituality within the patient's life and care.

Working with patients' self narratives and stories is core to many approaches [29; 30; 212] A model using spiritual life maps is suggested to be useful when applied in palliative care (see Hodge, 2005, cited in 105). In similar vein, a small qualitative study of hospice patients suggested that the narrative of *how patients organised* their lives was more indicative of their spirituality than how they *described* their spiritual lives [212]. A number of current UK practice model uses core questions such as: *when life is hard how have you kept going? Is there anyone or anything that has helped you keep going? How are you coping with what's happening to you? How do you making sense of what is happening to you? What sources of strength do you look to when life is difficult?* [170;172]. A number of studies make the point that spiritual meanings and understandings may change throughout life, including through illness [31; 176; 105); hence the strength of the biographical and narrative approach.

One small scale study of hospice nurses and the extent to which they integrated the spiritual dimension into their practice also used a narrative approach to explore the nurses' own spirituality and its influence on their practice, finding that the spiritual dimension permeated all other dimensions of care [31]. This study identified that shared beliefs, narratives and familiarity with similar language and concepts facilitated the development of trust which was an essential pre-requisite for patients to share spiritual concerns.

Approach 4: The spirituality domain

A common approach to holistic assessment looks at the patient in terms of different domains in their life and also care. The domain approach may treat spirituality as a separate domain or spirituality may be considered within each assessment domain. An example of the latter applied to palliative care is 'care mapping' [148]; these authors emphasise the importance of explaining the basis of spiritual assessment questions so as to identify the patient's inner strengths and avoid giving offence

or causing confusion. However, most of these tools are not applied to end of life (for example, the Moral Authority, Vocational, Aesthetic, Social and Transcendent (Mor-VAST) model [207 quoted in 99].

Spiritual need

There is a considerable literature which explores the concept of, and engagement with, spiritual need, without this necessarily being linked to any specific assessment tool.

US studies tend to describe spiritual needs in more religious terms than those used in literature emanating from outside the US [30; 224; 67; 118]. For example, Callahan [30] lists nine, of which only three – meaning, purpose and value in life, inner peace and experience of nature - could be termed broadly spiritual. These 'religious needs' may be coupled with broader statements about spiritual assessment and care – in this study termed 'spiritually supportive generalist practice', which can be available round the clock and not just when a spiritual care provider is available.

The UK literature takes a broadly 'common humanity' approach to spiritual need. For example, a Northern Ireland study [113] in which 92% of participants self-identified a faith in God or Higher Being, highlighted their top six spiritual needs as: to have time to think; to have hope; to deal with unresolved issues; to prepare for death; to express true feelings without being judged; to speak of important relationships. The authors describe these as psychological and social in nature and also recorded that some participants were unsure whether they had any spiritual needs or indeed knew what they were. The (UK) Standards for Hospice and Palliative Care Chaplaincy [8] affirms that the assessment of spiritual and religious need should be available to all patients and carers, including those of no faith, defining spiritual needs as: exploring the individual's sense of meaning and purpose in life; exploring attitudes, beliefs, ideas, values and concerns around life and death issues; affirming life and worth by encouraging reminiscence about the past; exploring the individual's hopes and fears regarding the present and future for themselves and their families/carers; exploring the why questions in relation to life death and suffering.

A survey comparing chaplaincy services in hospices and hospitals across England and Wales [245] found patients were not concerned with issues of transcendence or forgiveness but rather the spiritual needs arising from suffering and concern for relatives; interestingly, religious needs (such as desire for communion) featured more in hospitals than in hospices. However, another study [159] found that patients and their carers sometimes expressed the need for transcendence, alongside love, meaning and purpose. This study also distinguished the separate spiritual needs of patients and carers. Specific issues identified are problems with the language of spiritual care for both patients and workers, where terms such as meaning, purpose, forgiveness, hope and compassion may more easily facilitate engagement with spiritual need [29]. Walter [236] suggests that this is a particular form of contemporary western discourse in which broadening spirituality to a 'personal and psychological' search for meaning allows all staff to engage with this dimension.

A number of commentaries focus on the person and skills of the worker as of central importance in engaging with spiritual need. For example, workers in an Irish palliative care setting were found to be resistant to the categorisation of need arguing that spiritual care was about focusing on the individual and privileging the worker-patient relationship [129]. The spiritual need (and spiritual distress) of the care-giving professionals is also highlighted, often linked to their ability to relate to

the spiritual needs of patients [131; 22; 13; 210]. A large-scale questionnaire-based study of palliative care workers in Flanders Belgium [42] advocates greater awareness and assertiveness amongst workers of their own spiritual experiences to address the 'hidden spiritual agenda' of the palliative care team as a necessary forerunner to responding to the spiritual needs of patients. Hegarty [84] likewise argues that workers need to be aware of their own vulnerabilities, describing them as 'wounded healers'. However, it is suggested [176] that health and social care professionals in the UK tend to feel awkward about discussing their own spiritual needs.

Other guidance emphasises that assessment of spiritual need should not be a one-off event as existential questions re-emerge at various points in the care pathway, particularly when new symptoms appear, treatment has distressing side-effects, and emotional and social consequences of the illness emerge. Changes in relationships with key people and feeling 'disconnected' from oneself and others may give rise to serious spiritual distress [176]. Hence spiritual care specialists should contribute to regular review of care plans. Equally, this same document points out that people may express their spiritual needs only once and therefore it is crucial that all healthcare workers are attuned to the spiritual dimension. There are calls for further research to illuminate how spiritual needs evolve over time and can best be supported [176]. The case is also made for a differential approach to spiritual need, one article based on two empirical studies suggesting that the spiritual needs of older people, and their demonstrated link with successful ageing, calls for specially trained staff - a gerontological chaplaincy [153].

Spiritual pain and distress

Spiritual distress is commonly identified in the palliative care literature, though linked to broader issues rather than specific concerns. For example, Carroll [31] found hospice nurses identified spiritual distress as arising from the loneliness of dying and Callahan [30] similarly suggests that spiritual pain arises from the dying person's struggle to accept the dying process. Musi [160] prefers the term 'spiritual suffering' arising from threat to the integrity of the self which may occur as identity and personal resources are changed or diminished through the dying process. In an article which questions whether spiritual need should be assumed in everyone and also whether all staff in palliative care should assume responsibility for spiritual care, Walter [236] suggests that spiritual pain is really biographical pain – life has not gone as the person wished and for those in palliative care it is too late to do anything about that. Hinshaw [91] agrees that threat to personal meanings and purpose creates spiritual suffering in dying, but this (US) study also identifies specific spiritual concerns identified by Americans about death: not being forgiven by God; not being reconciled with others; dying while cut off from God or some higher power; not being forgiven by others for a past offence including not having the blessing of family or clergy; concerns about after death.

The mental health literature addresses religious and cultural interpretations of illness as a potential cause of spiritual distress – for example, that the illness is caused by sin or demonic possession - and practice recommendations include creating the opportunity for patients to explore the spiritual meaning of their illness [Royal College of Psychiatrists, 2006 cited in 55]. This is not translated into the context of serious physical illness and end of life care. Specific reference is, however, made to suicide, and the implications for families bereaved through suicide and for those whose suicide attempt fails, of the condemnation of suicide by all the major religions.

Practice issues

Arguments are made that good spiritual assessment is essential to effective palliative care and that unmet spiritual needs and suffering may be under-diagnosed [193; 240; 46]. Without understanding the patient's beliefs and values the physician cannot engage in shared decision-making with the patient and family; questions about spiritual beliefs can open up conversations about other symptoms and 'spiritual conversations' may enable the patient to get in touch with fears and anxieties more broadly [193]. US studies indicate that most patients would like their spiritual needs to be addressed but for the majority they are not [192]. The US 2009 Consensus Conference produced clear recommendations for spiritual care practice in palliative care, most of which are focused on the assessment of spiritual need and distress, routinely for all patients and operationalised by all types and levels of staff at screening and referral stages, followed up by more structured and detailed assessment carried out by chaplains (who should respond within 24 hours).

UK guidance recommends that spiritual needs should be assessed on a regular basis alongside other assessment, but is less specific about process and procedure [176]. Despite the increasing emphasis on assessing spiritual needs, however, there are indications that these needs are not being met, through lack of spiritual awareness in the workforce generally, coupled with lack of confidence to broach spiritual issues, with at the same time a reluctance to refer to chaplains [176]. The 2001 survey of chaplaincy services in hospices and hospitals [245] found that nurses were involved in spiritual assessments in both settings. However, 29% of hospital respondents said they did not do spiritual assessments and of those that did, practice varied widely as to what constituted an assessment. In another hospice study [13] nurses gave the following reasons for not undertaking spiritual assessments: patient and/or family reluctance; not knowing what to ask or how to approach the subject; no available assessment tool; feeling embarrassed or awkward; feeling reluctant to bring up a personal subject; expectation that the chaplain or social worker would do it; stating that they themselves did not believe in God; the patient being unable to communicate; the patient being short-term. Other studies report nurses' concerns that raising the subject of spirituality might cause distress to patients [102] and arguments that staff lack the time to address spiritual issues [159]. An American study [80] which compared receipt of religious and spiritual care for residents of four types of long-term care facility for older people, found that pre-existing religious or spiritual practice was the strongest determinant that spiritual needs would be picked up by staff and 'traditional' residential or assisted living care facilities were significantly less likely to respond to spiritual need than nursing homes and 'new model' facilities.

Specific to the implementation of the UK End of life Care Strategy, a retrospective audit of assessment documentation completed under the Liverpool Care Pathway found that only 50% of patients (excluding those who were comatose) and 74% of relatives had their spiritual and religious needs assessed through direct contact between worker and patient/carer; 42% had a religious tradition and/or spiritual need identified and 42% were offered chaplaincy support [228]. This finding is borne out by an audit of patients' notes in one hospice [173] which revealed that very few spiritual or religious care conversations had been documented since 2005, suggesting that little assessment of spiritual need was taking place although anecdotally it was known that such discussions had taken place between patients and carers. This hospice has since introduced comprehensive assessment of spiritual and religious need into their baseline assessment and has recorded year on year increases in spiritual need assessments, with resultant improvements in

spiritual care (although the evidence for this is not documented). However, these findings about reluctance to undertake assessments need to be set alongside the view of many workers that spiritual care in the last few days of life is to do with ‘being there’ rather than formally assessing spiritual need (see below). It is suggested that such conversations should begin before the LCP is initiated, and that staff may not be comfortable with discussing religious or spiritual issues at the first meeting [228].

Much of the UK practice guidance is concerned with identifying the religious beliefs and spiritual practices of the dying patient and relatives in order that health care practice does not offend or contravene important tenets of faith or religious practice and staff are aware of the implications of specific treatments for particular religious groups. This includes actions which should be taken by healthcare staff to facilitate religious practice and create the necessary environment for a patient of a particular religious persuasion to die in the manner prescribed by their religion [55; 176; 12; 174]. The practice guidance literature does not address broader spiritual needs at the point of death other than relational needs - that is, the presence of family and friends - although the belief of many religions that dying is an opportunity for spiritual insight is highlighted [55]. A study of perceptions of culturally sensitive care held by older South Asian patients and carers emphasises that in eastern religions there is no distinction between ‘religion’ and ‘spirituality’; indeed religion is the path to spiritual salvation [40]. Elsewhere dying is described as a ‘creative act’ of the spirit [84].

In contrast to the practice guidance, a number of empirical studies and commentaries do focus on broader spiritual need and distress in suffering at the very end of life and suggest the main approaches as companionship – ‘being there’ – and helping the patient to find sources of strength and meaning, not necessarily in the suffering itself but in their life more generally [31; 129; 228]. Hegarty [84] terms this creating and holding a ‘safe nurturing space’ through ‘deep listening’. The ability to show empathy and compassion, to enter into the ‘weak places’ of the other [42] is regarded as a core component of recognising the spiritual distress of the other person [84]. Other sources refer to a ‘supportive presence’ which affords the patient a safe space to ask questions [30]; new ways of being in which spiritual care involves being rather than doing [155]; ‘sharing the journey’ of the dying person [245] and [236]; the importance of attentive listening and silence [29]; ‘focused discussion’ rather than formal assessment [109].

More detailed assessment of specific spiritual needs does not feature in these approaches. In fact, Gysels and Higginson [78] point out that there is a body of opinion which opposes the ‘medicalising’ of spiritual need through an over-emphasis on assessment through standardised scales. This is particularly a concern amongst chaplains [129]. One study in intensive and cardiac nursing suggested that available assessment models were not appropriate for this setting and a specific model should be developed [226]. Set against these concerns others suggest core transferable concepts of spiritual need, such as the search for meaning and purpose, across cultures [162] and patient groups [163; 221; 174; 170]. A case study of one palliative care patient (an African woman) suggests that it is necessary to check regularly that the patient’s spiritual needs are being met and argues that tools can be adapted to each case and lengthy questionnaires used section by section [105].

Calls for all staff to have basic training in understanding spiritual needs and assessing spiritual care as well as formal supervision which addresses the spirituality and spiritual needs of workers themselves are made in various practice guidance documents as well as research studies [176; 42; 73]. The

Flanders study discussed earlier found serious lack of understanding and communication within teams, and all professional disciplines, as well as volunteers, self-rating their spiritual distress higher than as perceived by their colleagues [42]. A study exploring the impediments experienced by hospice staff in Scotland to the delivery of spiritual care [22] found that nurses were unclear what to put in the spirituality box on their initial assessment form; they felt they did not have the knowledge or confidence to pick up spiritual issues.

6 Spiritual Interventions

We have used the term 'spiritual interventions' (as favoured in the American social work literature) to distinguish between those aspects of spiritual care which focus on assessment (as detailed in the preceding section) and those which seek to go beyond the assessment of spiritual need by responding to the spiritual issues raised and seeking to meet that need. Both are aspects of spiritual care and in reality, of course, even the simple act of acknowledging spiritual needs and the broader spiritual dimension is to respond to that need, as the literature makes clear. In addition, many of the interventions identified include assessment as an integral part of the intervention.

This section, however, presents and examines the different types of interventions advocated in the literature to promote, support and develop spiritual care practice in end of life care. We treated 'intervention' as any activity that has the potential to enhance the provision of spiritual care practice. The analysis revealed that interventions can be subdivided into *scoping* interventions and *improvement* interventions. There is considerable overlap between both types of intervention. However, to differentiate, scoping attempts to map out the territory and challenges, while improvement is about enhancing the delivery and practice of spiritual care.

Scoping interventions

Scoping interventions provide knowledge and understanding to inform and develop an evidence base for spiritual care practice. They take the form of systematic reviews, outcome measures and empirical enquiry that have been undertaken in order to gain insight into the practice of spiritual care. The aim of these interventions is the development of an evidence base to assist the development and delivery of services as well as front-line practice, concerning spiritual support for people receiving end of life care. This review identified an important review of the research evidence (up to 2003) for spiritual support in cancer services [78] which itself identified one Cochrane review of the effects of prayer. Both these reviews were more limited in scope than our review. However, Gysels and Higginson concluded that:

> There are not many studies on the effectiveness of interventions to improve spiritual support for people experiencing the effects of illness, treatment or who are approaching death. (p.174)

Our literature search revealed that in the intervening period there have been no significant changes in debates and the available evidence. The findings suggest that the evidence base is still underdeveloped especially within the UK. However, it did reveal the extent to which the provision of

spiritual care at the end of life is a multidisciplinary and interdisciplinary concern with many professions - nursing [e.g. 13], social work [e.g. 39; 50], medicine [e.g. 215; 194] and chaplaincy [e.g. 22; 149; 210] and psychology [e.g. 136] - undertaking research which points to the inclusion, educational preparedness and enhancement of spiritual care practice.

One development was the number of interdisciplinary papers that have been published [102; 92; 94]. The review indicated that there is recognition that spiritual care at the end of life is very much a multidisciplinary responsibility, with no single professional group having a monopoly over the spiritual dimension. Further, there is recognition that a coordinated approach is required [102].

Of the 25 sources included in this category only 2 (international) studies were identified that directly involved patients as research participants [136; 88]. One study [136] interviewed 160 patients in a palliative care hospital to explore the importance of spirituality in coping with a terminal illness, assessing the relation between spiritual wellbeing, depression and end of life despair. The other [88] investigated with 62 female and 38 male hospice patients to what degree the spiritual needs of patients near the end of life are met. The fact that only a small number of studies involving patients as research participants is concerning since it implies that spiritual care interventions may be being developed without the scrutiny and involvement of patients, families, carers and the general public. This may result in the development of strategies, policies, procedures and practices that make assumptions regarding perceptions and expectations with regards to spirituality and spiritual care at the end of life without being informed by primary users. It is suggested that spiritual care practices must meet the needs of diverse groups of people and therefore must start from their perspective [209].

Organisational trends

A recurrent theme evident in the review is the changing trends and perceptions regarding the philosophy and infrastructure within palliative/end of life care. There is a notable expansion of end of life care from cancer to include a broad range of conditions such as heart failure with implications across a much wider sweep of services [54]. Concerns are raised not only about the quality and consistency of end of life care in all sectors, but in respect of spiritual care, there are issues about staff training and support. Chaplains, for example, find it difficult to provide ongoing spiritual support to patients as they move around different parts of the health care system, not least because staff may not be as attuned to spiritual needs as those in specialist palliative care settings and unsure of who or when to refer at the end of life [154].

The literature review points to a realisation that there is a transition in the role of chaplains from religious provision to more secular support [78]. There is also a noticeable emphasis on the need for environmental and organisational change, for example, the shift from chapels to multi-faith rooms [149; 78]. One emerging (for the UK) area is how spiritual, religious and philosophical beliefs may impact upon health outcomes [102; 210].

Improvement Interventions

In this review these take the form of theoretical and conceptual argument, commentary and reflection from empirical studies to improve and enhance the delivery of spiritual care. We did not find any evaluation studies that sought to demonstrate specifically the impact that spiritual interventions had on end of life care. They can be categorised under three broad themes:

recognition and discerning; environment and organisational context; and workforce development. We found one other intervention categorisation [92] - of psychosocial interventions for existential suffering in palliative care – which suggested six subcategories: a supportive-expressive approach; providing comfortable environments; meaning centred approach; being; education and coping skills training; and a religious approach. These fit within our 3 categories.

Recognition and discerning

The literature affirms that there is growing recognition by a spectrum of health professions as well as patients of the important role religious and spiritual beliefs may play in adjustment to illness, death and bereavement. Spirituality is considered an essential component of holistic care and there is emphasis that discerning and assessing spiritual aspects or needs of individuals must be considered when providing end of life care [215]. Of the empirical studies included in this section the majority originate from the US. However, some of the challenges outlined are common across countries and professional groups - for example, the discomfort and unease that some health care professionals experience in engaging with patients spiritual needs [22; 13; 50].

Environmental and organisational context

Within several of the documents reviewed reference is made to the importance of the organisational and environmental setting in supporting patients, families, visitors or staff with their spiritual needs [92; 163; 88]. The Association of Hospice and Palliative Care Chaplains [8 p8] under standard 6 'resources' identifies a number of facilities or requirements necessary for the chaplain to fulfil their role: access to quiet/private areas for confidential support of patients, carers, staff and volunteers; access to a chapel/prayer room for religious observance of all faiths; access to patient information systems for recording information and interventions. While this list is directed specifically towards chaplains working in hospice and palliative care services, consideration of the spiritual needs embedded in these requirements are relevant for all end of life care. While some people receiving end of life care might not want religious support they may want private and confidential areas to be alone with family and friends [149; 92].

Workforce Development

The review revealed an increasing focus upon the development of the workforce to deal with spiritual concerns at the end of life. Several workforce development or competency frameworks were identified. The aim of these is to prepare staff and health care professionals to recognise and support individuals' spiritual needs at the end of life [131; 149; 8; 164]. These frameworks suggest that there are different levels of competency required to deal with spiritual concerns.

For example, Marie Curie Cancer Care [131 pp 3-6] outlines 4 levels of competency from Level 1 (all staff and volunteers who have casual contact with patients and their families) through to level 4 (staff or volunteers whose primary responsibility is for the spiritual and religious care of patient, visitors or staff). A person's role and responsibility with regards to the provision of religious or spiritual support will dictate the level of knowledge and expertise required. The development of these competency frameworks appears to belong to developing work on outcome measures for spiritual care, although the linking of these is as yet at a very early stage [149].

It is argued that consideration must also be given to the qualities, skills and caring attributes of staff. Self-awareness [22], attitude, disposition and sensitivity to spiritual issues [213] are regarded as fundamental to the delivery of high quality end of life care. One study [94] highlights that the nurse must acknowledge the powerlessness and fragility of the patient by using interventions such as silence and gentle touch when attending to personal needs. This requires practitioners who are confident and self-aware and able to confront their own attitudes towards spirituality and death; issues of personal and professional development are raised [73].

Integrated models of end of life care

The literature search yielded a small number of manuscripts specifically describing integrated models of end of life care [225; 52; 37; 192]. The concept of integrated care signals a move towards more consultative and co-ordinated, multi-disciplinary approaches. Integrated models are underpinned by a philosophy of care which privileges the inherent value and dignity of all people irrespective of their health status and attention to spiritual needs therefore belongs to the model, in part, also, because it is concerned with relational aspects of humanity [192].

Integrated models advocate an integrated (generic) approach to end of life care as opposed to being fragmentary - that is, seeing the individual as a set of discrete dimension for intervention [37]. They adopt an inclusive view of spirituality rather than seeing it as something separate to be included. Integrated models usually comprise of physical, psychosocial and spiritual 'primary domains'. All domains are considered equal whereas in the past less emphasis was placed on the spiritual [192]. The model of integrated care operates around the principles of communication, consultancy and skill development [52].

The models looked at in the review have been developed in a range of clinical settings providing end of life care to diverse groups, including those with chronic heart failure and people experiencing depression while receiving end of life care. One study [225] was concerned with the construction of measurement tools that could capture the patient's and family's perceptions of receiving integrated end of life care. The models imply that successful end of life care is dependent upon both a consultative approach (in which partnership with the patient and family is seen as integral to the therapeutic care) and a co-ordinated approach to care [225]. Teno et al [225] identified five functions that were indicative of high quality medical care at the end of life: promoting physical comfort; control and decision making; lessening the burden on family members; education for family members; emotional support for family members. Inter- and intra-disciplinary co-working within and across all professional groups and sectors for the co-management of care of both patients and their families is fundamental [52]. Implicit in all the models is the need for excellent communication and compassionate presence, lessening the burden of responsibility felt by families at the end of life.

Three out of the four models reviewed had been developed systematically either through empirical investigation [225; 37] or by conducting a systematic needs assessment and documentation of local resources [52]. Puchalski [192] refers to studies highlighting that the majority of patients would like their spiritual needs addressed by health care professionals but this is not happening in practice. The method of construction of such models is regarded as important if they are to meet local need.

Spiritual Care Models

Spiritual care models differ from integrated care models of end of life care which incorporate spiritual care, in that the provision of spiritual care is the starting point for the model. Their aim is to enable practitioners to interpret and apply theories and concepts concerning spirituality, spiritual need and distress in the everyday contexts of care. Spiritual care models have the specific goal of promoting awareness, development and integration of spirituality within practice, and may treat spirituality as a discrete but fundamental dimension of care. Spiritual care models may therefore sit within integrated models of end of life care or they may be used by a practitioner working in some other environment.

The review yielded 12 spiritual care models [112; 236; 233; 129; 213; 73; 208; 215; 193; 99; 175; 145]. Not all of these were developed within and specific to palliative and end of life care.

Classification of spiritual care models

Spiritual care models can be classified under the following broad approaches: conceptual; competency based; whole person-synergy; interdisciplinary; organisational. However, it should be noted that models discussed have been located according to their primary location, but may contain elements of several approaches.

Conceptual

These models provide valuable insight and understanding into the concepts of spirituality, spiritual need and the provision of spiritual care. These models use a range of strategies and methods to critique, explain and expand understanding and practice. They may explain why particular groups and people hold specific views and attitudes about religious and spiritual belief and how these may influence perceptions and practices towards end of life care [233; 129]. Conceptual models may also assist in the elucidation of key components of spiritual care around which a theory is developed. For example Kellehear [112] presents a theoretical model of sources of transcendence - situational, the moral and biographical and the religious - and explores the implications for spiritual care in palliative care. Walter [236] challenges the assumptions made in palliative care that all patients recognise a spiritual dimension and that all staff can offer spiritual care, offering a fourfold typology which may assist practitioners in differentiating between patients' needs and reduce the obligation for all staff to offer spiritual care routinely.

Competency based models

This type of model is aimed at developing the workforce to be clinically competent in the provision of spiritual care [73; 175]. These competency frameworks aim to prevent the 'tick box' mentality associated with spiritual assessment by ensuring the entire workforce is aware of the need to respond to patients' spiritual needs. There are different levels of competency; the higher the level the more in-depth spiritual support and educational expertise is required to support patients' spiritual needs. The NHS Scotland [175] generic skills and competency framework implies that all NHS staff require a general awareness and generic skills to provide routine spiritual care, with a smaller number of specialist staff (chaplain or a counsellor) with specific skills providing specialist spiritual and pastoral care.

Whole person -synergy

The whole person approach view individuals as a 'whole' person encapsulating the body, mind and spirit. Smith [208] implies that the synergy model possesses a vertical and horizontal component, the vertical relating to God or a higher power, and the horizontal relating more to people's relationships with each other and their external world. Sulmasy [215] presents 'A biopsychosocial-spiritual model' for the care of patients at the end of life. This model suggests that there are a number of variables and interactions that must be considered by health care professionals in the clinical encounter:

> …the patient comes to the clinical encounter with a spiritual history, a manner of spiritual/religious coping, a state of spiritual well-being, and concrete spiritual needs. Some of these states serve as independent variables predicting how the patient will fare spiritually in the face of illness. In addition, according to this model, this spiritual state may in turn be modulated by the biopsychosocial state of the person, and the spiritual state may also modulate the biopsychosocial state. (p 7)

Whole person approaches highlight that the delivery of end of life care is both complex and challenging because of the diverse and interacting factors that may impact upon the person and their family. This reinforces the uniqueness of each dying person's care.

Interdisciplinary models

Interdisciplinary models recognise and emphasise the need for all health care professionals to work collaboratively and collectively when dealing with patients' spiritual needs. Puchalski et al [193] assert that spiritual care must be interdisciplinary and that each member of the interdisciplinary team has a responsibility to provide spiritual care. However, there is a realisation that some members of the interdisciplinary team have specific responsibility for meeting the religious and spiritual needs of patients and staff for example chaplaincy teams. The Fellow Traveller model [99] was developed from empirical research with dying and bereaved individuals and demonstrates how different professionals may provide spiritual support (singly and/or together) at different points in the person's journey.

Organisational

Some models are designed to ensure spiritual care is addressed within and across organisations, for example by making specific reference to spiritual care within all aspects of service provision, thereby legitimising staff responsibility and accountability in this area [175]. McSherry [145] presents the principal component model for the integration of spiritual care, developed out of primary empirical research. This models draws attention to the main factors that may enhance and promote the integration of spirituality and the improvement of spiritual care within organisations, suggesting that an awareness and adherence to the principal components may aid health care professionals to overcome some of the structural, organisational, political and social factors that prevent the integration of spiritual care.

The review suggests that spiritual care models have been developed with a number of primary functions to aid the integration of spiritual care:

- to aid awareness and understanding of spirituality and spiritual care;
- to develop, critique and refine theory;
- to map the provision of spiritual care;
- to provide frameworks for the delivery of religious and spiritual support;
- to engage with spiritual needs;
- to develop knowledge, skills and competency;
- to respond to diversity of belief;
- to develop culturally sensitive practice;
- to enhance the patient experience.

7 Education and training

As has been noted, the relevance of spirituality for end of life care is generally recognised. The meeting of spiritual needs requires specific training and the development of perspectives and approaches that allow carers to recognise and deal effectively with the spiritual needs of patients. The NICE Guidelines [176] note that, 'Survey data demonstrate that although many health care professionals are extremely competent and inspire high satisfaction levels among carers, some have inadequate knowledge and feel ill-prepared to care for patients in the advanced phase of illness'. This issue is recognised as having particular relevance within the area of spiritual care. Despite the fact that spiritual care is a core component of palliative care national policies, healthcare professionals express difficulties in delivering it [248]. What literature there is highlights some key issues and offers strategies and approaches to enable healthcare providers to care effectively in this area. We might divide the literature into three categories: required skills; training requirements; standards and competencies.

Required Skills

The identified skills for spiritual care include the following:

Techniques of active and compassionate listening

Here the spiritual carer is required to learn particular listening skills which focus on hearing the spiritual dynamics within their encounters with patients. Concerns and worries about personal suffering, being a burden to others or abandoning loved ones, regrets about unfinished business and fears of dying alone are recognised and addressed [191].

Companioning

Here the carer is required to move beyond the model of expert helper to one that includes accompanying the dying person in his or her spiritual struggles [109; 99]. This of course raises the issue of professional boundaries and requires that such relationships are managed carefully and ethically. However, the evidence indicates that such a movement within professional relationships is both manageable and potentially therapeutic [188].

Non denominational spiritual practices such as prayer, contemplation and meditation

Here the carer becomes familiar with particular techniques that can enable patients to meditate and contemplate in ways which bring them peace and well-being [125].

Specialist chaplaincy skills
These would include: good communication and effective listening to stories [216]; the use of rituals [109]; being comfortable in meeting other people where they are; helping people think through the difficult questions in their search for meaning [35].

This list of skills is not exhaustive but illustrates in general terms the type of person-centred skills which the literature highlights as necessary for the application of good spiritual care.

Training requirements

In order to facilitate such skills a variety of approaches have been developed.

- Training to elicit, recognise and meet individual needs. [134]
- Opportunities for professionals to practice asking questions about spirituality and to find natural ways of engaging with patients. [248]
- Meaning centred groups to encourage and establish the significance of spirituality for carers and people nearing the end of their lives. [20]
- Mentoring schemes which explore ways in which more experienced professionals can mentor newer staff. [248]
- Education programmes and training - medical schools, university professional training programmes and staff induction programmes. [47; 127; 35]

Benefits of training

Training seems to be beneficial, not only in terms of enabling people to carry out better spiritual care, but also in terms of the spiritual wellbeing of carers. Wasner et al found that training in spiritual care led to significant and sustained improvements in 'self perceived compassion for the dying, compassion for oneself, attitude towards one's family, satisfaction with work, reduction in work related stress and attitude towards colleagues.' [237] Spiritual care training had a positive influence on the spiritual wellbeing and the attitudes of the participating palliative care professionals which was preserved over a six month period. Spiritual care training thus has significance for the well-being of both staff and patients.

Standards for professional practice

The final aspect of education and training relates to the development of competencies and standards. Such competencies and standards are designed to enable professionals to:

- recognise spirituality and spiritual need;
- understand its meaning and the possibilities for effective intervention;
- become aware of situations and perspectives around spiritual issues;
- develop particular abilities necessary for the delivery of spiritual care;

For example, the Marie Curie Spiritual & Religious Care Competencies for Specialist Palliative Care [131], inter alia, instruct carers to:

- recognise everyone has a spiritual dimension
- recognise some have religious element to their spirituality
- understand the importance of active listening skills
- understand the importance of verbal and non verbal communication
- understand the importance of confidentiality and when to disclose/document
- develop awareness of own spirituality
- develop awareness that spiritual needs require acknowledgement
- develop the ability to identify individuals who have spiritual/religious needs
- develop the ability to listen actively and demonstrate empathy

In terms of standards, the Standards for Hospice & Palliative Care [8] state that:

- national standards set service levels and audit process for units;
- professional standards focus on professional service responsible for provision of spiritual and religious care;
- competencies support and enhance spiritual care offered by individuals especially chaplains.

In this way, competencies raise the consciousness of staff to new possibilities for spiritual care and the integration of a spiritual perspective.

Within chaplaincy David Mitchell [149] has noted that a combination of National Care Guidelines, Clinical Standards, Professional Standards and a Competency Framework have come together to engender considerable discussion and an impetus for developing a framework for spiritual care, religious care and chaplaincy services and practice. His work on the development of Clinical Standards for Specialist Palliative Care presents an approach wherein there are no individual standards for spiritual care for chaplaincy. Rather spiritual care is integrated throughout the standards e.g. through the provision of a dedicated environment - quiet areas, chapel/prayer room; developing core teams which must include chaplain; providing education relating to the spiritual aspects of palliative care introducing spirituality into multi disciplinary team meetings; recording patient and family contact and developing standards for spiritual therapeutic interventions.

Gordon and Mitchell [73] state that the delivery of spiritual and religious care has received a high profile in national reports, guidelines and standards since the start of the millennium yet there is to date no recognized definition of spirituality or spiritual care nor a validated assessment tool. They suggest an alternative to the search for a definition and assessment tool and seek to set spiritual care in a practical context by offering a model for spiritual assessment and care based on the individual competence of all healthcare professionals to deliver spiritual and religious care.

8 Overview and conclusions

This review uncovered a substantial literature on spirituality and spiritual care which makes connections with end of life issues and care. There is, nevertheless, a significant gap between research which looks at spirituality and spiritual care in the broader contexts of health and well-being and health and social care services more generally, and the aspirations and standards relating to spiritual care at the end of life contained in end of life policy and practice documents. This gap is perhaps surprising given the nurturing of the vision of holistic care in the hospice and palliative care movements and highlighting of spiritual care in the early hospices. Authors of work which is primarily located within the broader field, or makes reference to dying *inter alia*, would no doubt claim generic transferability for their concepts, tools and models. There is evidence from the review of researchers applying these to studies in palliative and end of life care. However, findings from front-line practice and service delivery suggest that the particular sensitivities, ethical questions and practice skills required in work with people who are dying and their families, raise issues for spiritual care in both its conceptual underpinnings and practice delivery which are peculiar to this environment.

A number of assessment and intervention tools intended for end of life and palliative care were identified. However, we did not find one example of a validated tool or evaluated model (developed specifically for palliative and end of life care) which is in common use in clinical or other practice settings although certain generic spiritual assessment tools do seem to be in fairly common use in the US. Yet clinicians and practitioners from all professions in studies across the review identified confusion, ambiguities and uncertainties in addressing spiritual need and offering spiritual care or support, which might be assisted by a framework to guide and facilitate their individual engagement with spiritual issues as well as making optimal use of the resources of the multidisciplinary team. We did observe a gradual trend towards the development of local tools, particularly those designed for the identification and assessment of spiritual need. These share the following characteristics:

- They should be routinely applied;
- They incorporate a first level which operates as a screening mechanism;
- They progress through different levels of complexity of need;
- They also progress through different levels of skill competencies;
- They potentially involve any worker but engaging with different levels of need and employing different levels and range of knowledge and skills.
- They employ a number of open-ended questions concerned with meaning, relationships, sources of strength, personal resources, and well-being.

Interestingly (given the context) questions which address spiritual pain and distress do not appear to be included in these core questions, although they do appear in a number of research instruments. Use of such questions is, however, implied in the assessment and addressing of more complex spiritual need.

Despite the proliferation of assessment scales and schedules, those based on wholly quantitative research appear to be diminishing in popularity as research instruments and we did not find any

take-up in practice in the UK although scales and schedules show continuing popularity in the US. There is a recent tendency towards assessment tools based on mixed methods studies or validated schedules derived from qualitative interviews. However, there is a stronger leaning (in both empirical research studies and expert commentary) towards the view that spiritual care at the end of life should not concern itself with formal detailed assessment of spiritual need but rather be attuned to the nature and significance of spiritual issues for the dying person and their families and carers. The notions of spiritual care as 'being' rather than 'doing', of 'companioning' and of 'accompanying' on a spiritual journey, are some of the newer ideas being put forward amongst the secular professions. These, of course, are not new to chaplaincy which shows some signs of re-asserting its role as specialist spiritual care advisors but informed by concepts which are rather more humanistic and rather less religious.

Recent evidence that practitioners remain confused about the concept of spirituality, and distinctions between spiritual care and psychosocial or psychological and emotional care, may conceivably be linked to the continuing debate about concepts and definitions in the academic literature, as well as (perhaps) the changing foundations of chaplaincy referred to above. When this is linked to the paucity of evidence about education and training (specific to end of life and palliative care) uncovered in this review, two conclusions may be drawn. First, there is work to be done in applying conceptual debates and theoretical models with specific illustration to end of life care in practice. Second, there is a need for end of life care training programmes at all levels, to build knowledge and understanding (and by implication, confidence) in spiritual care.

Finally, although we identified the theme of 'community', the literature under this theme was both sparse and patchy and in no way addressed the issue raised in the consultation groups of how spiritual care (broadly defined) might operate in the community - both community health settings and the informal context. A small amount of literature is available from the US (for example, applied to family medical practice) but this might not translate into the significantly more secular environment of the UK. The objective of enabling more people to die at home (including care homes) makes consideration of the challenge of providing spiritual care for all, regardless of religious belief or affiliation, particularly urgent.

Recommendations

A number of specific recommendations arise from this review to tackle the issues raised in its commissioning. Some of this work has already begun in the course of the review.

1. There is relatively little work done on the health benefits of the broader understanding of spirituality as used in the UK. There is clearly a need for continuing work on conceptual clarity around generic forms of spirituality and the transposition of that data into empirical studies designed to provide an evidence base for the clinical efficacy of spiritual experience in its broader forms.

2. Further work should be undertaken to translate and communicate the concepts underpinning contemporary understandings of spirituality and spiritual care into the practice of palliative and end of life care. The objective of this work would be to achieve greater conceptual clarity and understanding *in practice*. However, we would not advocate a continuing search for a single definition of spirituality.

3. Further work should be done on distilling the essence of the models and approaches available to produce a simplified range of tools which practitioners might draw upon. The reviewers do not consider that additional models are needed *per se,* but that the current proliferation of models and tools, some based on one study, is confusing for practitioners. However, we are not advocating a 'one size fits all' model but a clear framework, underpinned by established theory, within which practitioners can locate their own professional orientation and work context.

4. It is important that the evidence base for spiritual care is strengthened. In order to evaluate spiritual care practice and produce comparable results, we recommend that work be undertaken to define spiritual care outcomes appropriate to good end of life care.

5. There should be evaluation of the use of models in practice, particularly where generic religious and spiritual care competencies are applied in palliative and end of life care. On the basis of this review we suggest that competency-based and companioning/accompanying models are those with which UK healthcare professionals feel most comfortable and which best fit UK palliative and end of life care services. These might be a good place to start.

6. Competencies and standards define and quantify what staff are already doing. The general recommendation emerging from the literature is that professionals should use competencies and standards:

   - to identify gaps and complementary roles;
   - to consider implications for delivery of religious and spiritual care;
   - as tools to reflect on and improve current practice;
   - to identify training needs.

7. Bearing in mind the identified need to enable and facilitate staff in providing spiritual care there is a need for training and education in spiritual care to be incorporated into the teaching curricula of the healthcare professionals. This should be supplemented by a wider range of learning opportunities and training programmes at different career stages as well as for volunteers and other support workers. Staff support programmes should heed the evident need to provide ongoing support for generic staff in providing spiritual care.

8. There is a dearth of knowledge about how spirituality is understood and experienced, and its relationship to religious affiliation and practice, across cultures. This is potentially a significant inhibiting factor for the provision of spiritual care in the multicultural contexts of UK health services. Further research is necessary exploring the role of spiritual support in end of life care with diverse ethnic and religious groups.

9. Bearing in mind also the expansion of palliative and end of life care to other groups such as people with dementia, the work on spirituality and spiritual care should make links across other DH programmes, such as the Dignity in Care agenda.

10. There is an urgent need to develop policy and practice in community settings to support people dying at home.

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Appendix B – Classification of Sources

	Reference	date	country	discipline	document type	setting	design	Model/scale/tool	focus of study
1	Albaugh	2003	USA	nursing	empirical study	community	qualitative, phenomenological	no	spirituality in the face of life threatening disease
2	Altilio et al	2008 a	USA	social work	literature review			no	role of social work
3	Altilio et al	2008 b	USA	social work	commentary	palliative care		no	social aspects of care
4	Ando & Morita	2007	Japan	interdisciplinary	empirical study	palliative care unit, cancer	structured life review interviews	no	effect of life review interviews on spiritual wellbeing
5	Ark et al	2006	USA	nursing	empirical study	community	secondary quantitative analysis	no	effects of religiosity and religious coping styles on health service use
6	Ashurst	2007	UK	nursing	commentary	palliative care unit		no	role of religion and culture in needs and wishes of patients at EOL
7	Association of Hospice & Palliative Care Chaplains	2003	UK	chaplaincy	policy document			Self assessment tool to audit chaplaincy service	standards and assessment tools
8	Association of Hospice & Palliative Care Chaplains	2006	UK	chaplaincy	policy document			no	standards and assessment tools
9	Baldacchino	2010	Malta	nursing	book				competency in delivering spiritual care
10	Barclay et al	2003	UK	interdisciplinary	empirical study	community	postal questionnaire and quantitative analysis	no	training of GPs in palliative medicine

11	Barham	2003	Australia	palliative care/nursing	empirical study	palliative care unit, cancer	case study	no	Buddhism practice in terminal cancer care
12	Bauer-Wu et al	2007	USA	nursing	commentary	palliative care unit		no	review of major religions and application to palliative care
13	Belcher & Griffiths	2005	USA	nursing	empirical study	hospice	qualitative survey-content analysis of open ended questions	no	spiritual care perspectives and practices of hospice nurses
14	Best	2003	USA	chaplaincy	commentary			no	end of life decisions
15	Beuken	2003	UK	chaplaincy	commentary	community		no	Christian spiritual care in the community
16	Blank et al	2001	USA	medicine	empirical study	hospital	quantitative interviews	no	end of life decisions
17	Bosma et al	2010	Canada	social work	empirical study	social work professionals	electronic questionnaires	no	social work competencies
18	Bradshaw	1994	UK	nursing	book				spirituality and nursing
19	Brandt et al	2005	Belgium/ Netherlands	interdisciplinary	empirical study	nursing homes	questionnaire survey	Palliative Care Outcome Scale (POS)	quality of end of life care
20	Breitbart	2002	USA	Psychiatry		oncology			Spiritual care
21	Bretzke	2008	USA	theology	commentary			no	end of life decisions
22	Brown	2001	UK	chaplaincy	empirical study	hospice	qualitative case studies	no	spiritual assessment and provision

23	Brown-Haithco	2005	USA	chaplaincy	commentary			no	end of life decisions
24	Buckley & Herth	2004	UK/USA	nursing	empirical study	palliative care	quantitative	no	hope
25	Bullock et al	2006	USA	interdisciplinary	empirical study	community	focus groups	no	end of life decisions
26	Burn	2008	USA	chaplaincy	commentary			no	end of life decisions
27	Bush & Bruni	2008	Australia	nursing	empirical study	community	phenomenological heuristic	no	the meaning of spiritual care as described by community based palliative care nurses, complementary therapists and pastoral carers
28	Bussing et al	2006	Germany	alternative medicine	empirical study	chronic outpatients	questionnaire survey	no	complementary medicine and spirituality/religiosity
29	Byrne	2007	UK	nursing	commentary	palliative care unit		Uses FACIR-Sp tool	the language of pastoral care and its place in palliative settings
30	Callahan	2009	USA	social work	commentary	hospice		no	the nature of spiritual care
31	Carroll	2001	UK	nursing	empirical study	palliative care unit, cancer	phenomenological heuristic	no	the meaning of spirituality and provision of spiritual care among hospice nurses
32	Chaaya et al	2007	Lebanon	mental health	empirical study	community	interviews and quantitative analysis	no	relationship between religiosity and depression in older people
33	Chan et al	2005	USA	interdisciplinary	empirical study	community and students	quantitative interviews	no	cultural/religious beliefs and treatment preferences

34	Chao et al	2002	Taiwan	nursing	empirical study	hospice	in depth interviews	no	the nature of spirituality in terminally ill patients
35	Chaplin & Mitchell	2001	UK	chaplaincy	commentary	hospice/hospi tal	study day	no	education in spiritual care
36	Clarke et al	2006	UK	interdisciplinary	empirical study	older people	four listening events	no	end of life care needs/quality of care
37	Clarke	2007	Australia	medicine	commentary	mental health		Maslow's hierarchy of needs	psychosocial and spiritual needs
38	Clarke	2009	UK	nursing	commentary				definition of spirituality
39	Clausen et al	2005	UK	interdisciplinary	empirical study	palliative care	qualitative interviews	no	the role of social work
40	Clegg	2003	UK	nursing	empirical study	community hospitals	qualitative interviews	no	South Asian perspectives
41	Cobb	2001	UK	chaplaincy	book	hospice			the nature of spiritual care
42	Cornette	2005	Belgium	nursing	empirical study	palliative care	postal survey of workers	no	spiritual needs and growth of care givers
43	Countess of Chester Hospital NHS Trust	2003	UK	chaplaincy	policy document	hospital		no	characteristics of different faiths
44	Coyte et al	2007	UK	Interdisciplinary	book				Spirituality and mental health
45	Crang & Muncey	2008	UK	nursing	empirical study	hospice	quality of life measurement tool and unstructured interviews	no	evaluation of quality of life measurement tool

46	Crunkilton & Rubins	2009	USA	social work	commentary			no	psychosocial and spiritual assessment and treatment
47	Culliford	2007	USA	psychiatry	commentary				spiritual assessment
48	Cutcliffe & Herth	2002	Canada/ USA	nursing	commentary			no	hope
49	Daaleman & VandeCreek	2000	USA	interdisciplinary	commentary			mention of McGill Quality of Life Questionnaire, Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being scale and Systems of Belief Inventory	placing religion and spirituality in end of life care
50	Dane & Moore	2006	USA	social work	empirical study	social work professionals	questionnaire survey	no	spiritual care practices
51	David	2008	USA	chaplaincy	commentary	hospital			African American perspectives
52	Davidson et al	2004	Australia	palliative care	augmented literature review	teaching hospital	literature review, analysis of case notes and expert consultation	development of model of integrated consultative care approach	development of model
53	Delkeskamp-Hayes	2001	Germany	philosophy/ medicine	commentary			no	Christian healthcare institutions
54	Department of Health	2009	UK	interdisciplinary	strategy			no	end of life care strategy
55	Department of Health	2009	UK	interdisciplinary	practice guide			Mention of spiritual assessment tool for mental health	chapter on end of life concerns
56	Desbiens & Fillion	2008	Canada	nursing	empirical study	acute care	quantitative questionnaire	no	association between coping strategies, emotional outcomes and spiritual quality of life

57	DH webpage LTNC Palliative Care Working Group	2008	UK	interdisciplinary	case study	neurology		no	care pathway development
58	Duhamel & Dupuis	2003	Canada	nursing	commentary	care of terminally ill		no	interventions and the beliefs of healthcare workers, patient and family
59	Dunne	2001	USA	theology	commentary			no	spiritual needs
60	Ekedahl & Wengstrom	2008	Sweden	interdisciplinary	empirical study	oncology	qualitative interviews	no	coping processes in the multi-disciplinary team
61	Engelhardt & Iltis	2005	USA	interdisciplinary	commentary			no	Christian views of end of life care
62	Exley	2004	UK	health/social care	review article			no	Review of Cobb, M. The dying soul: spiritual care at the end of life Buckingham OUP
63	Fillion et al	2006	Canada	nursing	empirical study	palliative care	intervention development and randomized control trial	model of intervention	development and testing of intervention
64	Frick et al	2006	Germany	interdisciplinary	empirical study	oncology	semi structured interviews and questionnaires	Use of SPIR assessment interview	evaluation of interview as assessment tool
65	Furman et al	2004	UK	Social work	Empirical study				Spirituality education
66	Furness & Gilligan	2010	UK	social work	commentary			no	assessment framework
67	Garces-Foley	2006	USA	theology	commentary	hospice		no	spirituality/religion differentiation and provision

68	Garrad & Sheikh	2002	UK	medicine	commentary	palliative care		no	provision of palliative care near death to Muslims
69	Gilchrist	2001	UK	chaplaincy	commentary	children's hospice	case studies	no	children's spiritual needs
70	Gilligan	2003	UK	Social work	Empirical study			no	Spirituality education
71	Goodwin	2008	UK	interdisciplinary	commentary	oncology		Chochinov model of dignity	Chochinov and dignity
72	Gordon et al	2002	USA	interdisciplinary	panel discussion			no	spiritual traditions and their value
73	Gordon & Mitchell	2004	UK	interdisciplinary	empirical study	hospice	reflective practice sessions	competency model of spiritual assessment and care	development and piloting of competency model
74	Grassman & Whitaker	2007	Sweden	gerontology	empirical study	community	in depth interviews	no	the role of the church in end of life care
75	Grundmann	2003	USA	chaplaincy	commentary	referral hospital for terminally ill		no	elements of spiritual care
76	GSF Care Homes	2009	UK	interdisciplinary	briefing paper	residential care		no	training programme for end of life care
77	Gwyther et al	2005	USA	Social work	Commentary			Competency model	Palliative care competencies for social work
78	Gysels & Higginson	2004 ?	UK	palliative care	literature review			no	chapter 9 spiritual report services
79	Hales et al	2010	Canada	oncology	literature review			no	measures of quality of dying and death
80	Hamilton et al	2009	Hong Kong/ USA	palliative care	empirical study	nursing homes / residential care	structured interviews, quantitative analysis	no	provision of spiritual care

81	Harvey & Silverman	2007	USA	health/social care	empirical study	older people	qualitative interviews	no	spirituality and wellbeing
82	Hastings Center	2005	USA	interdisciplinary	edited research compendium			no	end of life decisions
83	Head of Chaplaincy Services Queen Elizabeth Hospital	2003	UK	chaplaincy	policy document	hospital		no	policy for respect of religious beliefs
84	Hegarty	2007	Australia	palliative care	commentary	palliative care		model of care of the spirit	perspectives on care of the spirit
85	Hemming	2005	UK	nursing	commentary	palliative care		no	pain assessment and management
86	Henry & Hayes	2010	UK	end of life care programme	strategy	palliative care		no	competencies and principles in end of life care
87	Hermann	2006	USA	nursing	empirical study	hospice	qualitative interviews and psychometric analysis	no	development and testing of tool to measure spiritual needs at the end of life
88	Hermann	2007	USA	nursing	empirical study	hospice	descriptive quantitative	no	extent to which spiritual needs at end of life are met
89	Highfield et al	2000	USA	nursing	empirical study	oncology/ hospice	descriptive and content analysis	Uses Spiritual Care Perpectives Scale (SCPS)	preparation/training in spiritual care for nurses

90	Hills et al	2005	USA	interdisciplinary	empirical study	palliative care	quantitative scale measures	use of National Comprehensive Cancer Network Distress Management Assessment Tool, Pargament Brief Religious Coping Scale (Brief RCOPE), Functional Assessment of Chronic Illness Therapy - Spiritual Wellbeing (FACIT - Sp), Puchalski's FICA and Profile of mood states - short form (POMS-SF)	benefits of religion/spirituality to health
91	Hinshaw	2002	USA	medicine	commentary			no	spiritual needs
92	Hirai et al	2003	Japan	interdisciplinary	empirical study	oncology	questionnaire survey	no	effectiveness of psychosocial interventions
93	Hodge	2007	USA	social work	empirical study	social work students	quantitative	Spiritual competencies scale	assessment of spiritual competence
94	Hodgson et al	2004	USA	interdisciplinary	commentary			no	roles in the multi-disciplinary team
95	Holloway	2006	UK	social work	literature review			no	transcultural spirituality
96	Holloway	2007 a	UK	Social work	book			Psychosocial spiritual transition, typology of special deaths	Interprofessional care of dying and bereaved
97	Holloway	2007 b	UK	social work	commentary			No	Spiritual need
98	Holloway & Lymbery	2007	UK	Social work	commentary			No	Community care
99	Holloway & Moss	2010	UK	Social work	book	social work		Fellow Traveller Model of Spiritual Care	spiritual care in social work

100	Hospital Chaplaincy Department Cardiff & Vale NHS Trust	2003	UK	chaplaincy	policy document			no	religious care ward guide
101	Hughes et al	2010	UK	interdisciplinary	empirical study	oncology	questionnaire survey	no	extent of implementation of national guidance
102	Hunt et al	2003	UK	interdisciplinary	commentary	palliative care		assessment model	assessment and standards of spiritual care
103	Hunter	1990	USA	Pastoral Care	book			Dictionary entry	pastoral care and counselling
104	Ignatiev	2003	Germany	chaplaincy	commentary	hospitals		no	European chaplaincy standards, language ambiguities
105	Ireland	2010	UK	nursing	empirical study	palliative care	case study	no	meaning of spirituality
106	Jacobs	2008	USA	chaplaincy	commentary	all end of life care		no	role of chaplains
107	James & Wells	2002	UK	psychology	empirical study	community	questionnaire survey	no	spirituality/religion and wellbeing
108	Jenko et al	2010	USA	nursing	commentary	palliative care		no	life review conduct and patient/nurse relationships
109	Johnson	2003	USA	counselling	commentary			no	value and use of spiritual domain in counselling
110	Jones et al	2007	USA	interdisciplinary	empirical study	oncology	mixed methods with emphasis on phenomenology	no	attitudes to complementary and alternative medicine
111	Kaasa & Loge	2003	Norway	palliative care	commentary	oncology		no	measuring quality of life in palliative care

112	Kellehear	2000	Australia	palliative care	commentary	palliative care		multidimensional model of spiritual needs	model of spiritual needs
113	Kernohan et al	2007	UK	interdisciplinary	empirical study	hospice	questionnaire survey	no	evaluation of national standards for chaplaincy
114	Keyes	2007	USA	Sociology	Commentary	Mental health		No	flourishing
115	Koenig et al	2004	USA	interdisciplinary	empirical study	older people	quantitative interviews	no	spirituality, religion and health
116	Koenig et al	2001 a	USA	interdisciplinary	book			Summation of various models and methods	Meta-analysis of studies re religion and health
117	Koenig et al	2001 b	USA	Medicine	literature review			Summation of various models and methods	benefits of religion/spirituality to health
118	Koenig	2002	USA	medicine	commentary	dying people		no	spirituality/religion and end of life attitudes
119	Koffman et al	2008	UK	interdisciplinary	empirical study	oncology	semi structured interviews	no	ethnic minority beliefs and attitudes
120	Krause & Ellison	2003	USA	interdisciplinary	empirical study	older people	quantitative questionnaire interviews	no	forgiveness and wellbeing
121	Kuin et al	2006	Netherla nds	medicine	empirical study	palliative care	quantitative database analysis	no	extent to which spiritual needs discussed in palliative care consultations
122	Lauder et al	2006	UK	nursing	empirical study	community	cross sectional survey	no	loneliness and religiosity
123	Lee	2007	Malaysia	sociology	commentary			no	individualised spirituality
124	Lhussier et al	2007	UK	nursing	empirical study	palliative care	semi structured interviews	no	evaluation of integrated care pathway

125	Lindberg	2005	USA	nursing	literature review	elderly people		no	meditation and spirituality
126	Lloyd	1997	UK	Social work	Empirical study			No	Social work with dying and bereaved/spirituality
127	Lo et al	2002	USA	medicine	commentary			phrases to elicit patients' concerns	physicians' guide to practice
128	Lundmark	2006	Sweden	nursing	empirical study	oncology	questionnaire survey	no	attitudes to spiritual care among nurses
129	MacConville	2006	UK	social science	empirical study	palliative care	qualitative interviews	Conceptual model	meaning of spirituality and religion
130	Man	2007	Hong Kong	medicine	commentary	palliative care		review of conceptual models of spiritual needs	spiritual care needs
131	Marie Curie Cancer Care	2003	UK	palliative care	practice guide	palliative care		competencies for specialist palliative care	definition of competencies
132	Marie Curie Cancer Care	2003	UK	palliative care	practice guide	palliative care		Competency assessment tools for specialist palliative care	assessment tools
133	Marie Curie Palliative Care	2009	UK	palliative care	practice guide	palliative care		no	care pathway guide
134	Marr et al	2007	USA	medicine	empirical study	palliative medicine fellows	questionnaire survey	no	spiritual training
135	McAfee et al	2006	UK	chaplaincy	empirical study	hospice	qualitative interviews	no	provision of spiritual care
136	McClain et al	2003	USA	psychology	empirical study	hospital	quantitative interviews	Uses spiritual well-being scale	spiritual wellbeing

137	McClain-Jacobsen et al	2004	USA	interdisciplinary	empirical study	oncology	quantitative scale measures	use of questionnaire re belief in afterlife, Functional Assessment of Chronic Illness Therapy- Spiritual Wellbeing Scale (SWB) and scales relating to depression	spiritual wellbeing and end of life despair
138	McGrath	2003	Australia	nursing	empirical study	hospice	qualitative interviews	no	spirituality and religiosity responses to terminal illness
139	McGrath & Phillips	2008	Australia	health/social care	empirical study	community	qualitative interviews	no	cultural/religious beliefs and treatment preferences
140	McGuigan & Gilbert	2009	UK	nursing	commentary	acute care		no	educational programme for acute end of life care
141	McIllmurray et al	2003	UK	interdisciplinary	empirical study	oncology	questionnaire survey	no	faith and psychosocial needs
142	McSherry	1997	UK	nursing	empirical study			no	nurses perceptions of spiritual care
143	McSherry & Ross	2002	UK	nursing	commentary	general practice		no	spiritual assessment tools
144	McSherry et al	2004	UK	nursing	empirical study	hospice/acute	qualitative grounded theory	no	meaning of spirituality
145	McSherry	2006	UK	nursing	empirical study	hospice/acute	qualitative interviews	principal components model for spiritual care	development of model
146	Michiels et al	2009	Belgium/ Netherl-ands	medicine	empirical study	physicians	questionnaire survey	no	end of life information disclosure
147	Miner-Williams	2007	USA	mental health nursing	empirical study	community	qualitative interviews	nurse-patient relationship spirituality model	connectedness/spirituality in the nurse patient relationship
148	Mitchell et al	2006	USA	nursing	empirical study	hospitals	qualitative interviews	no	nurses attitudes and approaches to death

149	Mitchell	2003	UK	chaplaincy	commentary	palliative care		Discussion of competency self assessment tool	standards and competencies
150	Mitchell et al	2006	USA	nursing	empirical study	nursing education	descriptive	Use of care mapping as tool to understand spirituality	education of nurses in spiritual care
151	Mok et al	2009	Hong Kong	nursing	empirical study	hospital palliative care	phenomenological interviews	no	meaning of spirituality and spiritual care
152	Mowat	2005	UK	chaplaincy	empirical study	older people	case studies	no	spirituality in working with older people
153	Mowat	2007	UK	chaplaincy	empirical study	hospital/resid ential care	qualitative interviews	no	spirituality in working with older people
154	Mowat	2008	UK	Chaplaincy	Commentary			Model of the patient journey	Evaluation of chaplaincy and spiritual care provision
155	Mowat & Swinton	2005	UK	Chaplaincy	empirical study			Model of chaplaincy role	Role of the chaplain
156	Mowat & Swinton	2007	UK	Chaplaincy	empirical study			Model of chaplaincy role	Role of the chaplain
157	Munn et al	2006	USA	interdisciplinary	empirical study	hospice/nursi ng home	structured telephone interviews	no	relationship of quality of end of life care to care setting
158	Murray & Zentner	1989	UK	nursing	book				Nursing concepts
159	Murray et al	2004	UK	interdisciplinary	empirical study	hospital outpatients	qualitative interviews	no	significance of spiritual issues in end of life care and means of address
160	Musi	2003	Italy	oncology	commentary	oncology		no	spiritual pain
161	Narayanasamy	1999	UK	nursing	commentary			no	spirituality and nursing

162	Narayanasamy	2007	UK	nursing	commentary	palliative care		no	spiritual needs, assessment and interventions
163	Narayanasamy et al	2004	UK	nursing	empirical study	nurses in older people's services	critical incident description and content analysis	no	spiritual needs of older people
164	National Consensus Project	2009	USA	interdisciplinary	practice guide	palliative care		domains of care conceptual model	holistic palliative care
165	National Council for Hospice and Specialist Palliative Care Services/ Prince of Wales Foundation for Integrated Health	2003	UK	alternative medicine	practice guide	palliative care		no	spirituality in therapies
166	Nelson et al	2002	USA	interdisciplinary	empirical study	palliative care	quantitative scale measures	use of FACIT Spiritual Wellbeing Scale and a religiosity index	benefits of religion/spirituality to health
167	NHS Chaplaincy	2003	UK	chaplaincy	policy document			no	guidance for managers and those providing chaplaincy-spiritual care
168	NHS End of Life Care Programme	2009	UK	health/social care	policy document			no	core competencies in end of life care
169	NHS end of Life Care web page	nd	UK	interdisciplinary	case study	hospital		no	last days of life pathway
170	NHS End of Life Care website	nd	UK	interdisciplinary	case study	hospice		Spiritual care assessment tool	assessment tools

171	NHS End of Life Care website	nd	UK	interdisciplinary	case study	care homes		no	provision of spiritual care
172	NHS End of Life Care website	nd	UK	interdisciplinary	case study	hospice		Spiritual care assessment tool	spiritual and religious assessment
173	NHS End of Life Care website	nd	UK	chaplaincy	case study	hospice		no	spiritual and religious assessment
174	NHS North East	nd	UK	interdisciplinary	practice guide	learning disabilities		no	spiritual/religious support
175	NHS Scotland	2009	UK	interdisciplinary	guidance document			spiritual care delivery	resource document re spirituality
176	NICE Guidance on Cancer Services	2004	UK	oncology	guidance document			Marie Curie competencies	chapter 7 spiritual support, chapter 8 general palliative care services including care of dying patients
177	O'Connor	2002	USA	Chaplaincy	commentary			no	Evidence base for chaplaincy
178	Paley	2008	UK	nursing	commentary	palliative care		critique of standard models and approaches	conceptualization of existential concerns and responses by health professionals
179	Paley	2008	UK	nursing	commentary			no	spirituality and secularization
180	Paley	2009	UK	nursing	Commentary			no	Spiritual need
181	Pargament et al	2000	USA	interdisciplinary	empirical study	students/ hospital	quantitative scale measures	new measure RCOPE	development and testing of RCOPE
182	Parker et al	2003	USA	social work	empirical study	community	quantitative interviews	no	religiosity and mental health

183	Payne	2004	UK	social work	empirical study	hospice	descriptive	no	the role of social work
184	Payne	2006	UK	social work	empirical study	palliative care	literature/database searches	no	the role of social work
185	Payne	2009	UK	social work	commentary	palliative care		no	the role of social work
186	Peterman et al	2002	USA	Behavioral Medicine	empirical study	oncology	quantitative scale measures	FACIT - SP development and testing	measurement of spiritual well being
187	Phelps et al	2009	USA	medicine	empirical study	oncology	quantitative interviews	no	religious coping and end of life care
188	Post et al	2000	USA	medicine	commentary			no	physicians' role
189	Prigerson et al	2009	USA	interdisciplinary	empirical study	oncology	quantitative interviews	no	spirituality and wellbeing
190	Puchalski & Romer	2000	USA	interdisciplinary	interview			FICA spiritual assessment tool	explanation of tool
191	Puchalski	2002	USA	medicine	commentary			FICA	physicians' role
192	Puchalski	2007-8	USA	medicine	commentary			FICA, Biopsychosocial-spiritual Model Assessment and Plan	spirituality as an essential component of care
193	Puchalski et al	2006	USA	interdisciplinary	commentary			FICA assessment tool, interdisciplinary spiritual care model	interdisciplinary spiritual care
194	Puchalski et al	2009	USA	interdisciplinary	commentary			inpatient and outpatient spiritual care implementation models, biopsychosocial-spiritual model of care	improving spiritual care
195	Pugh et al	2009	UK	interdisciplinary	empirical study	acute care	questionnaire survey	no	end of life decisions

196	Reese & Sontag	2001	USA	social work	commentary	hospice		no	multidisciplinary team collaboration
197	Ross	2008	UK	nursing	commentary			no	spirituality and secularization
198	Rumbold	2002	Australia	palliative care	book	palliative care		no	spirituality and palliative care
199	Saunders	1990	UK	Palliative care	book			no	
200	Schrader et al	2009-10	USA	interdisciplinary	empirical study	community	questionnaire survey	no	end of life care preferences
201	Scott et al	2008	USA	chaplaincy	commentary	general hospital		no	National Consensus Project practice implementation
202	Sheldon	1997	UK	Palliative care	book			No	Psychosocial palliative care
203	Shih et al	2001	Taiwan	nursing	empirical study	nursing education	mixed methods	no	validation of teaching course on spiritual care
204	Silver	2004	USA	alternative medicine	commentary			no	holistic end of life care
205	Simsen	1985	UK	nursing	empirical study				patient perceptions of spiritual care
206	Sinclair et al	2006	Canada	interdisciplinary	empirical study	acute care	qualitative autoethnographic	no	meaning of spirituality
207	Skalla & McCoy	2006	Lebanon	interdisciplinary	literature review	oncology		MOR-Vast model -Moral Authority, Vocational, Aesthetic, Social and Transcendent - for assessment of spirituality	spiritual assessment

208	Smith	2006	USA	nursing	commentary	critical care		Synergy Model of spiritual nursing care	spiritual nursing care
209	Society for Spirituality and Social Work	nd	USA	social work	webpage			no	spiritual competencies
210	Speck	2005	UK	nursing management	commentary	general nursing practice		no	spiritual assessment and care
211	Spiritual Care Collaborative	2004	USA	chaplaincy	policy document			no	common standards
212	Stephenson & Draucker	2003	USA	nursing	empirical study	hospice	qualitative interviews	no	nature of spirituality in hospice patients
213	Stirling	2007	UK	interdisciplinary	commentary	hospice		Conceptual model	multidisciplinary perspectives of provision
214	Strang & Strang	2001	Sweden	oncology	empirical study	hospital oncology unit	qualitative interviews	no	nature of spirituality in cancer patients
215	Sulmasy	2002	USA	medicine	commentary			biopsychosocial-spiritual model	End of life care model
216	Swinton	2002	UK	chaplaincy	book chapter			no	chaplaincy role
217	Swinton	2003	UK	chaplaincy	commentary			no	chaplaincy role
218	Swinton	2006	UK	interdisciplinary	commentary			no	critique of spirituality in nursing practice
219	Tan et al	2005	Australia	interdisciplinary	empirical study	hospice	qualitative interviews	no	nature of spirituality in hospice patients
220	Tanyi	2002	USA	nursing	literature review			no	meaning of spirituality

221	Tanyi et al	2006	USA	nursing	empirical study	haemodialysis outpatients	phenomenological interviews	no	implementation of spiritual care
222	Tarakeshwar et al	2006	USA	interdisciplinary	empirical study	oncology	structured interviews	Use of McGill QOL questionnaire, RCOPE, Multidimensional measure of religion/spirituality	role of religious coping in QOL
223	Taylor	2005	USA	nursing	empirical study	oncology	quantitative questionnaire assessment tool	no	spiritual care needs
224	Taylor	2006	USA	nursing	empirical study	oncology	quantitative questionnaire assessment tool	Uses Spiritual Interests Related to Illness Tool	spiritual care needs
225	Teno et al	2001	USA	interdisciplinary	empirical study	various	focus groups	domains of care conceptual model toolkit of instruments to measure end of life care (TIME)	end of life care needs/quality of care
226	Timmins & Kelly	2008	Ireland	nursing	commentary	intensive and cardiac care		Spiritual assessment tool	spiritual assessment
227	Touhy et al	2005	USA	nursing	empirical study	nursing homes	qualitative phenomenology	no	nature of spiritual care
228	Tuck	2009	UK	chaplaincy	empirical study	hospice	audit of patient notes	no	assessment and documentation of spirituality
229	van Leeuwen et al	2007	Netherl-ands	nursing	empirical study	oncology, cardiology and neurology	qualitative focus groups	no	extent and nature of spiritual needs
230	van Leeuwen et al	2008	Netherl-ands	nursing	empirical study	nursing students	quantitative	Uses Spiritual Care Competence Scale	education in spiritual care
231	Vivat	2008 a	UK	health/social care	literature review	palliative care		no	measures of spiritual issues
232	Vivat	2008 b	UK	interdisciplinary	empirical study	hospice	ethnography	no	spiritual care implementation
233	Vogt	2004	USA	theology	commentary			Conceptual model	patience, compassion and hope

234	Waller et al	2008	Australia	interdisciplinary	empirical study	health professionals	qualitative feedback re assessment tool from viewing DVD	PCNAT – palliative care needs assessment tool, includes spirituality	needs assessment tool
235	Walsh et al	2002	UK	interdisciplinary	empirical study	palliative care	quantitative scale measures	Royal Free spiritual scale of religious and spiritual belief	spiritual beliefs effect on bereavement
236	Walter	2002	UK	sociology	commentary	palliative care		typology of approaches to religion/spirituality	spiritual needs nature and extent
237	Wasner et al	2005	Germany /UK	interdisciplinary	empirical study	palliative care professionals	questionnaire survey	Uses Self Transcendence Scale (STS), the spiritual subscale of the Functional Assessment of Chronic Illness (FACIT-Sp) and the Idler Index of Religiosity (IIR).	spiritual care training
238	Watts	2008	UK	health/social care	empirical study	hospital	case study	no	nature of spiritual care
239	Waugh	1992	UK	nursing	empirical study			no	nurses perceptions of spiritual care
240	Westlake et al	2008	USA	nursing	commentary	cardiac disease		models of spirituality and non physical suffering	spirituality and suffering
241	Wheeler	1998	USA	ethics	commentary			no	ethical issues and religion
242	Williams et al	2004	UK	interdisciplinary	empirical study	hospice	questionnaire survey	no	role of the chaplain
243	Woll et al	2008	USA	medicine	commentary			no	religiosity/spirituality definitions and needs in relation to religions
244	Wong & Vinsky	2008	Canada	social work	commentary	social work practice		no	differentiating spirituality and religion
245	Wright	2001	UK	chaplaincy	empirical study	hospice	postal questionnaire survey	no	spiritual care needs and provision
246	Wright	2002	UK	chaplaincy	empirical study	spiritual care providers	phenomenological	no	meaning of spiritual care

247	Wu & Volker	2009	Taiwan	nursing	empirical study	hospice	qualitative, hermeneutic, phenomenological	no	nurses' experience of care
248	Yardley	2009	UK	interdisciplinary	empirical study	hospice	qualitative interviews	no	training in spiritual care

Appendix C - Consultation groups

Summary of points raised

What is spiritual care?

- All people are spiritual beings – we all have something to hold on to – but people may not recognise this as spirituality.
- An individual may provide spiritual care simply by their presence and altruistic and sensitive approach and regardless of any faith position.
- Spiritual care gives an individual space to explore spiritual issues. It involves steadfastness to look at a situation head on and not back off, to be there for the person.
- The care may be accompanying the person on their spiritual journey. This may involve discussing of spiritual matters but the important element is the accompanying presence. If the patient wants to talk football with a minister that is OK because the patient and the minister are thereby engaging in a relationship.
- The fellow traveller may be seen as like seeing someone off at a station and walking along the platform as the train leaves.
- Humanists take a similar approach to ministers of religion in their approach to spiritual care.
- It is important to respect the needs and wishes of the patient rather than impose the individual professional/clergy's own spirituality/prejudices.
- For a chaplain the toolkit to help people has a Christian basis because that is their identity but it is not necessary to impose Christian beliefs.
- How is spiritual care differentiated from other care?
- The relationship between generic spirituality and human wellbeing has been discussed by Corey Keyes using the term "flourishing"
- Prof. McSherry has recently been involved in an on line survey of nurses' conceptions of spirituality. Most saw it as a fundamental aspect of their role.
- Spirituality and dignity are integral to care
- Showing compassion and respect are normal good practice, but is that spiritual?
- Spiritual care involves learning how to listen carefully to both the positive and negatives of spirituality and religion.
- Spiritual care should be an approach, a way in which work is carried out rather than a series of tasks.
- Spiritual care includes respect for the dignity of the person.
- Spiritual care may be awareness of spiritual need and the facilitating of provision by others rather than a meaningful contact e.g referral to chaplain, arranging for sister to stay

What are spiritual needs?

- Referrals to chaplains are of patients with difficulties but these are not necessarily related to religious issues.
- Needs may include
    - Loss of identity, who patients are
    - Talk about meanings – meaning of life in the midst of suffering. May include religion but not necessarily.
    - Pain – may include religious pain but not necessarily
    - Sacraments
- Searches for meaning may be for the meaning of physical pain

- While there is little or no empirical evidence of links between spirituality and wellbeing, there is anecdotal evidence of such links. Research is needed to consider statements such as "I am not religious but.." to explore what may lie behind the "but".
- Spiritual needs should be those expressed by the patient, rather than those identified by a healthcare professional/minister of religion. We should not impose our own spirituality.
- There has been progress in the recognition that spiritual needs cannot be reduced to a tick box yes/no/ C of E.

Religion and spirituality

- Spiritual language – even those who do not have faith use a faith vocabulary because there is no secular language of spirituality that the ordinary person understands. Religious language becomes the grammar of suffering
- Are the majority of people who say they have no religious belief truly secular?
- There may be negative effects of religion. Those with faith may experience a faith crisis when they are faced with a situation which their faith cannot address. These will be those with a narrow faith outlook. Attitudes may be "there is no cure, so there is no God".
- There may be difficulties of provision of completely Christian environments for end of life care in care homes because equality of opportunity employment legislation prevents employment of exclusively Christian staff.
- There may be difficulties for professionals/clergy with faith in relating their own faith position to patient care.
- Fear of indoctrination as seen in education may give rise to problems in attitudes to chaplains and other faith representatives
- The relationship between spirituality and human wellbeing may be regarded as clear where spirituality is expressed through religion but may be considered less clear where spirituality is secular or more personally based.
- Humanists accept that spirituality exists and may be interpreted as coming to terms with life at times of stress.
- Ceremonies may be important as expressions of spirituality as well as words e.g. drawing, baptism.
- However, one discussion group expressed concerns that the baptism in one case study could lead to later feelings of guilt in the widow if she did not follow it through.
- Clergy need to listen to others and be open to varied styles of working.
- There are about 5/6 Humanist NHS chaplains.
- Clergy are not always trained in spiritual care at end of life although chaplains are. For clergy it may be experience that provides resource together with the spiritual support of their faith. Religious ministry is a vocation.
- However clergy are generally recognised as part of the church with a common value base, responsibility to an organisation etc. Clergy tend to be recognised even if they are not dressed as such.
- Clergy and secular professionals share a willingness to focus on the other and put aside their own needs and preferences.
- Spirituality is something that equips an individual to give care, driving what he/she can do for the patient or family. Faith provides support in order to help others.
- There may be resistance to the idea of spiritual care because of its association with religion – many hospices for example are named after saints.
- Chaplains provide companionship, silence etc as well as religious care.
- There is a relationship between personal beliefs and the ability to offer spiritual care.

Assessment of spiritual need/approaches to the subject

- The discussion groups generally felt that spiritual needs should be considered routinely
- More problems were identified with when and who should assess them.
- In an ideal world all working in end of life care would be able to recognise spiritual issues.
- Anybody can start a conversation about spirituality. Nurses and volunteers are often most with the patient and can pick up spiritual concerns while carrying out other tasks.
- The raising of spiritual issues must come from the patient rather than from a healthcare professional.
- Some felt that assessment of spiritual needs should be part of the general care assessment.
- One discussion group felt that assessment should be by a trained person who was independent of the health service. That person should then track progress of spiritual care.
- There may be a danger of Christian chaplains seeing spiritual needs only in terms of Christianity. Identification of spiritual needs by the nursing team may take a wider perspective.
- In Belgium and the Netherlands there were said to be trained independent Moral Support Officers rather than religious chaplains who carry out the initial assessment of spiritual need. There are a few UK based non religious Spiritual Care Advisors.
- The patient needs to be able to choose the individual with whom they feel comfortable to approach spiritual matters. All members of a multi-disciplinary team should be available to such approaches but in reality some will lack confidence. There is therefore a potential issue if a patient approaches an individual who feels unable to meet such a need.
- People at the end of life are not necessarily hospitalised. Spiritual care in the community an issue. Assessment needs to consider other issues such as loneliness and the need for befriending or counselling.
- The assessor should explain available options and find an appropriate provider.
- Some people may consider that they have no spiritual needs and tell a person questioning them to go away. Some may acknowledge that they have needs but these may be being met by themselves or their families. Some may have unmet needs.
- In terms of spiritual need there are those who know what they want, for whom provision is straightforward. There are those who don't know and there are those who don't understand. These are not just those with dementia but also those who are not articulate or do not have the capacity to understand faith matters relative to their own situation. This last group may be the most at risk because they are most isolated.
- Formal assessment may be seen as a help or a hindrance.
- If spiritual assessment was a routine requirement it would not get done as professionals would regard it as bureaucracy.
- Tick box assessments are not helpful.
- If spiritual assessment was made explicit rather than implicit there would be a risk that patients would not answer.
- Assessments may be made when time affords the opportunity – in a palliative care setting there may be more opportunity than in an acute care situation.
- If a patient expresses their problems this may afford opportunity to identify spiritual issues and offer care. If a patient sits with their head in their hands but does not explain the difficulty, will a healthcare get to the roots of the problem?
- There is a need to look carefully at language used in approaches to spiritual assessment. What are your values? Rather than what are your beliefs? Or what's bothering you most?
- Spiritual assessment should be integrated within holistic assessment without using the word spiritual.
- Provision of primer question to assist nurses in the broaching of spiritual issues would be helpful.

- The use of imagery and creative arts in a case study was thought interesting. Art therapy is used in hospices to show spiritual needs. Drawing a picture of how the patient feels. This will only emanate from a particular nurse/patient relationship.
- A chaplain suggested that an opening approach could be asking what are the best/worst things that have happened to an individual and if they could change one thing what would it be?
- Assessment through story telling. Professional should encourage the patient to tell his/her own story. This helps the patient to discover who they are, links to identity, discovery of who you are. Helps the patient to have a new perspective. Biographical stories.
- The professional needs to pick up cues from conversation/stories

Implementation of spiritual care/interventions

- Care in terminology may be important in helping professionals to approach the subject – emphasis on definitions of spirituality may not be helpful, more emphasis on care.
- Problems may include:
  - Confidence to follow up leads from patients – patients may catch nurses off balance in raising spiritual matters
  - Time issues. Taking time to address issues as they are raised or the moment is lost
  - Task based cultures, nurses are doers, conflicts between the task and significant conversations
- Training may help but professionals also need personal ability. People with self awareness and a sense of their own spirituality make the best spiritual carers. Lessons from life help professionals to be confident in spiritual care. If a professional is spiritually grounded they ***may*** have enhanced capacity to stay with people in dark places.
- In provision of spiritual care it is important to be sensitive to what the patient wants and who the patients wishes to provide for that want. Patients choose those they feel comfortable with to talk to, particularly about such personal issues. Different individuals may relate to those in different roles – it may be the student nurse, the nurse auxiliary etc if that is who they feel easiest with.
- A system of referral is needed for referral if the person who is approached feels out of their depth. Sharing of information with the Multi Disciplinary Team can be without breach of confidentiality if the event is shared without the content of the event. Teams have established skills in this way of working.
- There is considerable ambiguity and uncertainty among healthcare professionals about provision of spiritual care.
- Because of high profile media cases, such as the nurse suspended for offering to say a prayer for a patient, healthcare professionals are unsure about what is permissible in their role. Other participants felt that professionals should not be fearful about what they were allowed to do. However such problems are not new, participants pointing to similar restrictions in offering prayer over many years experience.
- Healthcare professionals may feel that spiritual beliefs are private and personal to the individual and therefore fear intruding on those beliefs.
- Individuals should not be shy of answering questions but should be willing to refer on if issues are beyond their capability.
- However a chaplain felt that because meaning for an individual was derived from a different source, it does not mean that support cannot be offered. It is possible to offer to refer the patient for support from a provider with appropriate background e.g. humanist but experience shows that such offers are often refused.
- There may be resource problems in meeting spiritual needs.
- There are competency issues in the provision of spiritual care. Some people may provide spiritual care but not recognise that they are doing it. There is a need for a competency structure.

- There are issues in the decision making after assessment in making referrals. The Humanist representative explained that her local hospice did not refer patients at the end of life to her, even though she had signified her availability. She had learned from families when making funeral arrangements that they would have liked such non religious spiritual care at an earlier stage.
- Healthcare professionals and volunteers need to make clear to patients that spiritual care is available but can be taken up at a later stage. The options need to be made clear.
- There are potential problems n the constraints of time. Spiritual care requires patience as patients may find it difficult to express themselves, because of physical problems in communication as well as diffidence about the issues.
- Spiritual needs do not always arise in office hours but often in the night when only a nurse is around. A qualified multi-disciplinary team is needed 24 hours a day.
- NHS budget cuts may affect provision of chaplaincy services
- Reasons may be fear of the consequences, that they would be opening a can of worms.
- The culture in healthcare does not encourage sharing of faith – recent high profile cases.
- Professionals are already engaging with spiritual needs but practice is not couched in spiritual language and is not therefore identified as spiritual care. It is considered routinely but not explicitly.
- Professionals need to be comfortable with their own spirituality before offering spiritual care. Need for self awareness and maturity.
- Art may be used in nursing training to bring nurses in touch with their own spirituality. In nursing training there is a need for emotional education as well as intellectual.
- Spiritual care may be informal, embodied in an approach and phraseology rather than specific interventions. E.g. the nurse who says to a patient on the way to theatre "I bet you're looking forward to a cup of tea when you get back", providing implicit reassurance.
- Patients choose those with whom they relate – a patient may choose to confide in the cleaner. The person approached should not feel that they are passing the buck if they refer on. Those who provide spiritual care are changed by the experience. They may need support to be able to provide the spiritual care requested or risk burn out.
- There are also time constraints and the conflict of the "busyness" culture with the need to provide spiritual care.

Views on models

- Assessment models are useful for research. How relevant are assessment models in terms of practice?
- Marie Curie Spiritual/Religious Competencies. If a professional does not have primary responsibility for spiritual care they may feel devalued by being assigned competency 3. These should be termed responsibilities rather than competencies.
- The Fellow Traveller Model of Care. Joining – need for spiritual awareness. Listening – need for active listening and the teasing out of the significance of spiritual issues. Spirituality may be a resource rather than an issue. Understanding or spiritual empathy. This may be practised only by workers with an awareness of their own spirituality. This is required in order to recognise and engage with the patient's spirituality which need not be either the same as the worker's current or previous positions. Interpreting this could be provided by a key worker in conjunction with a specialist spiritual care advisor or religious professional. The worker may be supported by the chaplain to enable her/him to carry out the role as some patients may not want personal contact with the chaplain. The worker does not have to be in the same tradition as the patient but needs to understand.
- The fellow traveller model was thought similar to Prof McSherry's own model.
- The Sulmasy model was judged reductionist.

- It is universally accepted that nurses have not engaged with spiritual aspects of the Liverpool Care Pathway.
- Kathy Kindness' Practical Spiritual Care Model . All can contribute to hope fostering practices. Hope is the courage to go on. Contributions to different areas from different disciplines. E.g chaplains to transcendent, psychologist to existential, therapists to creative. All professionals may not necessarily be able to contribute in all areas e.g may be able to help with total pain and existential anxiety but not belief frameworks.
- Puchalski et al's Guidelines for Spiritual Care may be effective within a framework of belief in God. For those with faith there may be tensions where the patient does not have faith. Care to not impose beliefs on the patient may result in a holding back from the relationship.

Multi-disciplinary working

- Chaplains and healthcare professionals have always worked in tandem – this is nothing new
- There is a need for communication across the multi-disciplinary team to provide for patients where a healthcare professional recognises needs but feels that they cannot address them.
- There are different issues in relation to care in the community from that in hospital. Clergy may be able and willing to provide for spiritual needs but are not necessarily kept informed.
- In multi-disciplinary teams, spiritual care should be approached as a team but there should be a leader.
- The multi-disciplinary team should have the strength to care if members communicate and know to whom to refer on.
- There may be overlaps within the multi-disciplinary team.
- The recognition of professional status is necessary for chaplains as part of the multi-disciplinary team.
- Spiritual resources to provide spiritual care may be sought within the self or within the team

Spiritual care in specific circumstances

- In cases of dementia there should be a team approach including the family. However in such cases there may be problems of filtering of information in that younger family especially may not have the same beliefs as the person with dementia.
- A particular case described concerned a dying girl with learning difficulties whose mother could not cope with the situation. MacMillan nurses stayed with the dying girl - a healing presence and loving relationship.
- There is a particular need presently not addressed for spiritual care within end of life care in the community.
- In cases of dementia the person's pre-dementia spiritual needs may be irrelevant. Is the person the same person? Does the ability to articulate affect spirituality?
- There may be issues in relation to the family and their needs as well as those of the patient.
- If EOLC is concerned with the last 48 hours of life, can people address spiritual issues at that time?
- Special problems in relation to EOLC in intensive care and A&E. Still end of life but no time for spiritual histories etc.
- Difficulties of spiritual care when the professional and patient do not share a common cultural/faith background. In some cultures faith can be assumed and if understood provides a basis for spiritual care. A definite belief structure may not provide all the answers but gives a starting base. In the modern British culture fewer assumptions can be made and there is little sharing of experience/belief.
- In cross cultural or trauma situations it is often necessary to rely on proxy information from relatives re spirituality. Filter effects.

International perspectives

- There are differences in perspective between the UK and US. In the US most research relates to white middle class Christians because research funding is often from religious foundations. There has been some work with Muslims, Jews and Black Americans.
- The quantifier for spirituality in US research is generally participation in religious communities and attendance at religious services. Such research has shown relationships with protection from health problems especially mental health. There is a methodological issue as to whether it is the attendance/participation/support provided by this involvement or whether it is the underlying beliefs which offer the protection
- There is not a uniform situation regarding spirituality and beliefs across Western Europe and such an assumption should not be made. In Scandinavia Chaplaincy is very church oriented. Southern Catholic and Orthodox countries have different belief structures. There are tensions in the European Chaplaincy Group between views from the Netherlands and those of other countries as to who should provide spiritual care.

Case studies

Case study 1

Tim had developed a brain tumour at the age of 30. He was referred to Ella (an art therapist at the hospice) by the psychiatrist following a period as a psychiatric in-patient being treated for severe depression. The psychiatric episode appeared to have been triggered by existential despair – Tim had been brought up to believe that if he worked hard, the rewards would follow, and now he felt both cheated and a failure. He refuses to see his wife and baby daughter.

In Tim's notes it is recorded that he is a Catholic, but he had angrily declined to see the priest when in hospital. However, one day, a few weeks before his death, he drew a picture of a man struggling to climb the steps of a church whose door was closed with a large key protruding. Tim presented this picture to Ella, watching for her reaction. Ella guessed that Tim was experiencing barriers in his spiritual life and asked him whether he was able to draw on the resources of his faith. When Tim shook his head, she asked whether he would like the priest from the Church which he used to attend to visit him. Tim nodded and smiled. Over the ensuing weeks in which Tim received Holy Communion each week, his drawings became more peaceful.

Claire, Tim's wife, has been seeing the social worker. She shares her terrible sense of loss of Tim as a parent for their only child. She understands why seeing her and Bethany might be too painful for Tim, but at the same time, worries about how she is going to give Bethany any sense of her father if she cannot create a memory box which includes a photo of the three of them together. She also wants to have Bethany christened before Tim dies. Claire is not a Catholic but they had agreed that their children would be christened as Catholics. However, Tim's diagnosis shortly after Bethany was born had pushed that event onto the back-burner. Somehow she feels that if she could only get Tim to agree to Bethany being christened now, it would create a spiritual bond between them that might help to heal the wounds and make up for the lack of verbal communication.

The social worker doesn't know what to do about this issue. It is not something she has come across before. She talks to Ella about it and discovers that Tim's drawing has led to his re-establishing his own spiritual practices. Ella suggests that she should ask Tim whether he would like to do a drawing for Claire and Bethany. Tim shakes his head but blurts out 'see', pointing to his eyes. Gradually Tim starts to spend time with Claire, and a bit later, Bethany. They organise Bethany's christening together at the hospice, taken by Tim's parish priest, with close family and several members of the hospice team attending. It was an occasion which seemed to bring them all together as a 'family'. The professional team shared with each other how it had seemed to be an occasion of reconciliation which had helped each of them to deal with their own difficulties in supporting Tim and Claire. At the same time it was a celebration of a new life, and representation of hope both now and for the future. These were themes which Tim and Claire carried through into planning for the funeral.

Shortly after the christening, although his art therapy sessions had ceased, Tim did one more drawing which he presented to Ella two days before he died for her to keep (his previous drawings had been discarded). Ella believes that Tim had finally found a new way of valuing his life.

Case study 2

Nicky was a young woman with breast cancer who was admitted to the hospice for the last few weeks of her life. She had a husband, Sam, and 3 year old son, Liam. Cathy admitted her and immediately felt they had a bond as a woman of similar age who also has young children. Nicky was referred by her GP and on admission was assessed as over-medicated. As her medication was changed and the levels adjusted she became much more alert and actively planning the remainder of her life.

Nicky did not want to die at home, because she felt that would make it more difficult for Sam and Liam to continue living there. However, she did want to be as involved as possible in their family life. Cathy had day-to-day involvement in Nicky's care and tried to arrange things to support Nicky's wishes as far as possible. When Nicky's sister (who lived some distance away) came to visit, she arranged for her to stay overnight and organised a room where the sisters could have a 'girly night in' together. Nicky had very much wanted to go with Liam on his first day at nursery, but was too poorly when it came to it. Cathy arranged for someone to video the occasion and for Nicky, Liam and Sam to watch it together later. The social worker had suggested to Nicky that she and Sam might like to create a memory box for Liam, so that they are creating a 'memory' for him of his mother and their early family life which otherwise he would not have. Cathy thinks that the needs of young families where the parent is dying are not well catered for currently in palliative care services, and tries to go the 'extra mile' to meet their individual needs. She feels that they managed to give the family some 'normality' in what was otherwise a desperate situation.

Although Nicky and Sam were very positive in their attitude, actively looking ahead and planning for Liam's and Sam's future, they also had to deal with a lot of anger. They felt that Nicky's cancer had been misdiagnosed initially as mastitis and that maybe her death was needless or they could have

had more time with better treatment early on. Nicky needed to confirm her identity as a mother, through planning for Liam's future, before allowing her grief at hers and their lost future together to come through. Cathy feels that by shouldering some of the burden and struggle for them, the palliative care team gave Sam and Nicky the space to complete these emotional and psychological tasks together. She describes Nicky as having embarked on her last journey when she entered the hospice, investing ordinary events with new meaning which seemed almost spiritual, although Cathy says she herself is not religious.

Case study 3

Martha is 63 years old and has become increasingly confused, forgetful and very withdrawn. Her husband was very concerned and encouraged her to see her GP. A CT scan was preformed which diagnosed vascular and organic changes and a diagnosis of vascular dementia was made. Until her retirement at 60 she had been a highly successful business woman leading a very active and fulfilling life. Her final position before retirement was director of a large international company. Martha is married to Tom they have three children and four grandchildren. Throughout her life Martha has had a strong belief and faith in a God but this has not been expressed formally through a religious institution. In her spare time Martha had enjoyed
a range of activities such as travel, painting and regular cross-country runs in the country. Martha liked to spend time on her own reflecting and keeping in touch with the creative aspects of her personality.

The progression of the disease meant that Martha was very much aware of the deteriorative nature of the illness and the result that this might have upon her life. As the disease progressed she was unable to maintain her interests and activities. She became more withdrawn and isolated within her own inner world. Familiar faces and locations lost their meaning. Martha's modesty and privacy were lost as she began to display inappropriate behaviours becoming incontinent. Her entire personality changed, resulting in aggressive outbursts, shouting verbal abuse at her family and on several occasions household objects were thrown around the room.

Martha had become the complete opposite to everything in which she believed and her husband and family did not recognise the woman whom they had known. The family was worried that as Martha's condition deteriorated and she required more intense care, they would be unable to meet her needs towards the end of her life. They were especially concerned about meeting her religious and spiritual beliefs in the light of her abrupt and dramatic change in personality.

The diagnosis of dementia is challenging for all those involved. Martha's husband and family were angry and described feelings of denial and loss often associated with bereavement despite Martha still being present. In this situation the importance of health care practitioners providing an individualized and holistic approach to care is of paramount importance. By looking at the whole person (physically, psychologically, socially and spiritually) an in-depth knowledge and

understanding of Martha can be obtained and her continuing personhood respected and nurtured. Individualised and personalised care will help Martha and her family to adjust and explore the impact and change that dementia brings while preserving the dignity of all concerned.

Many of the challenges of living with and caring for a person with dementia can be addressed and alleviated through effective communication and collaboration. These interactions must involve Martha, her family and the primary health and social care practitioners. In this situation Martha's health and social care practitioners should consult with her about all aspect of her care, liaising with her husband if necessary, to ensure that any decisions about her care are made in her best interest. These decisions should respect and uphold previously held beliefs and values including her religious and spiritual needs. A biographical approach to assessment which focuses on those things which have been central Martha's life, including those religious and spiritual practices which have provided sustenance and support for her in the past, will need to be undertaken to ensure that these are upheld. This process may be made easier if these have been outlined within any advanced care plan or directive. Good support and communication will help to ease fears meaning Martha and her husband feel safe, secure and empowered seeing themselves as equal partners in the caring relationship.

Appendix D - Tools and Models

1. A, B, C, Ds of preserving dignity in patient care

Chochinov's (2007- see additional references) model for preserving dignity in patient care described by Goodwin [71].

- A is for "attitude"—"What our data have shown, and certainly what we know clinically, is that the attitude and disposition of the care provider has a profound influence on how patients perceive themselves to be seen," he said. "And this has an astonishing influence on patient satisfaction. One of the most ardent predictors of satisfaction with care really comes down to these communication issues."
- B is for "behavior"—"i.e., the things that you do: whether you meet their eye, sit on a bed, or avert your gaze or are distracted. These tiny nuances have a profound influence on a patient's sense of dignity."
- C is for "compassion"—"i.e., the ability to recognize the suffering of another and to attempt to be responsive to it. The BMJ article provides some ways of trying to engender compassion—in essence by, at least for the moment, putting yourself inside of the person who is the patient so you can try and have some kind of subjective experience of what that might be like."
- D is for "dialog"—using, for example, certain phrases and ideas that can help dialog to flow in a sympathetic manner: "We have complex dialogs in medicine, but the reality is that subtleties like 'This must be difficult,' and 'I'm sorry that things are going this way,' can at least acknowledge for the patient that you recognise their personhood."

2. American Association of Critical-Care Nurses (AACN) Synergy Model for Patient Care

Discussed by Smith [208]

The Synergy Model identifies 8 characteristics of nurses and 8 characteristics of patients within the hospital environment. The key to care is the relationship between nurses and patients, so that nurses' competencies coincide with patients' needs. The model is termed the Synergy Model because it posits that by matching nurses' competencies to complement patients' characteristics, something more than the sum of the parts ensues and synergy occurs. Four areas of the model can be related to spiritual care: 2 characteristics of patients—resiliency and resource availability—and 2 characteristics of nurses— caring practices and response to diversity.

Initial screening questions*:

Are there any religious or spiritual practices that would be helpful to you while you are here?

Would you like to see a chaplain?

Additional screening questions†

What can I do to support your faith or religious commitment?

Are there aspects of your spirituality that you would like to discuss?

Would you like to discuss the spiritual or religious implications of your hospitalization?

Other questions‡

Who or what provides you with strength and hope?

Do you use prayer in your life?

How you express your spirituality?

What type of religious/spiritual support do you desire?

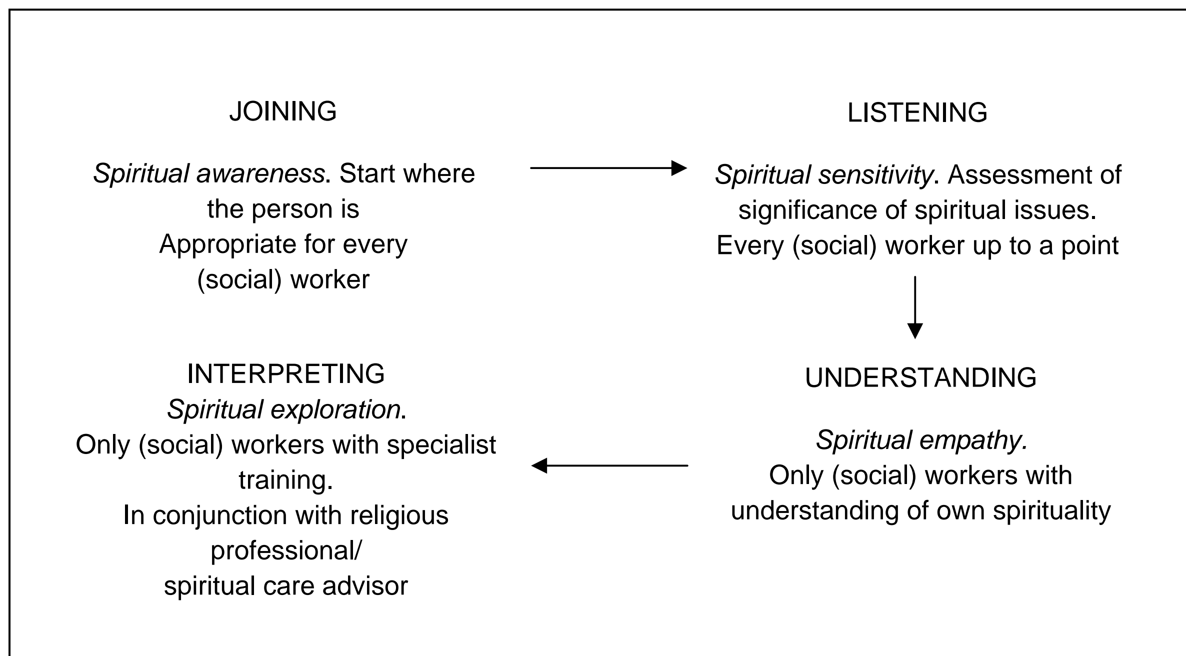
What role does the church/ synagogue/mosque in your life?

How does your faith help you cope with illness?

*Based on the nursing assessment form at the Brigham and Women's Hospital, Boston, Mass.
†As suggested by Clark et al.
‡As suggested by the Joint Commission on Accreditation of Healthcare Organizations.

3. The Fellow Traveller Model for Spiritual Care

Proposed by Holloway and Moss [99]



4. FICA

Spiritual assessment tool designed by Christina Puchalski in 2000 [190] and described by Puchalski [192]

F = **Faith, Belief, Meaning. -** "Do you consider yourself spiritual or religious?" or "Do you have spiritual beliefs that help you cope with stress?" If the patient responds "no," the physician might ask, "What gives your life meaning?"
I = **Importance and Influence. -** "What importance does your faith or belief have in your life? Have your beliefs influenced you in how you handle stress? Do you have specific beliefs that might influence your health care decisions?"
C = Community – "Are you a part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you really love or who are important to you?" Communities such as churches, temples, and mosques can serve as strong support systems for some patients.
A = **Address/Action in Care. -** "How should the healthcare provider address these issues in your healthcare?" Referral to chaplains, clergy, and other spiritual care providers.

5. Functional Assessment of Chronic Illness Therapy –Spiritual Well-being (FACIT-SP/FACIT- SWB)

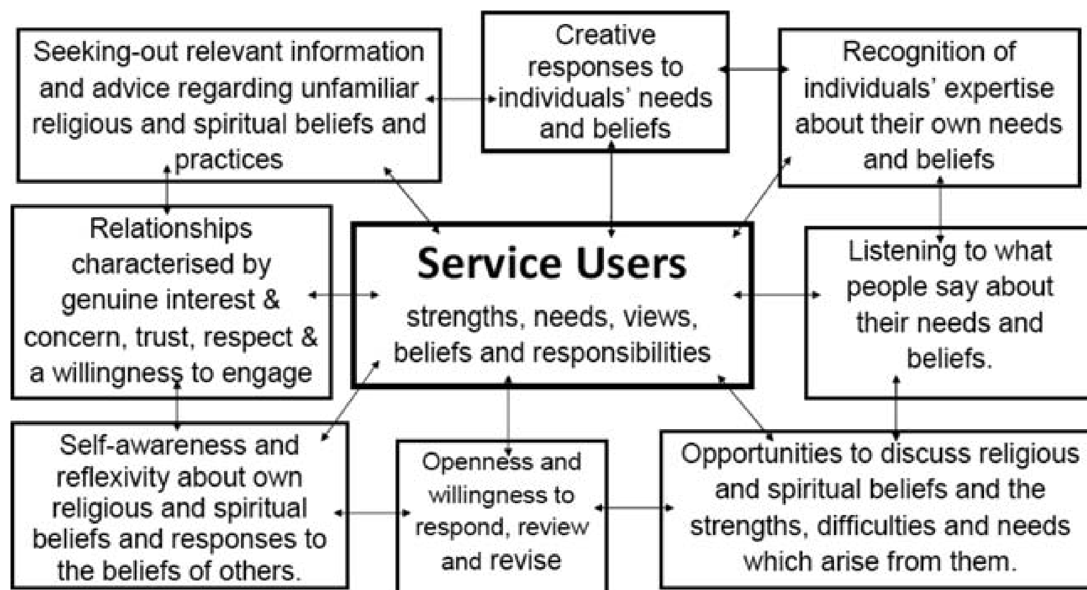
This scale was developed as a subscale of the FACIT with the input of cancer patients, psychotherapists, and religious/spiritual experts in the mid 1990s and is discussed by Brady et al (1999) and Peterman et al (2002) – see additional references. It was designed to measure important aspects of spirituality, such as a sense of meaning in one's life, harmony, peacefulness, and a sense of strength and comfort from one's beliefs, and is well validated. Spirituality is defined as 'the way in which people understand and live their lives in view of their ultimate meaning and value', and therefore is seen as being more basic than religiosity. Responses are based upon a 5-point response scale ranging from 0 (not at all) to 5 (very much), higher values reflecting a higher level of spiritual well-being.
FACIT – Sp items:

1. I feel peaceful
2. I have a reason for living
3. My life has been productive
4. I have trouble feeling peace of mind
5. I feel a sense of purpose in life
6. I am able to reach down deep into myself for comfort
7. I feel a sense of harmony within myself
8. My life lacks meaning and purpose
9. I find comfort in my faith or spiritual beliefs
10. I find strength in my faith or spiritual beliefs
11. My illness has strengthened my faith or spiritual beliefs
12. I know that whatever happens with my illness things will be OK

The analysis of the items measured indicated the presence of two factors. The first factor, Meaning/Peace contains eight items and assesses a sense of meaning, peace and purpose in life and the second factor, Faith contains four items and measures comfort and strength derived from one's faith. The suffixes "Sp" and "SWB" seem to refer to the same tool. In McClain et al [136] the suffix is "SWB" but the paper references Brady et al which uses the suffix "Sp". With the suffix "Sp" it is discussed and used by Wasner et al [237].

6. Furness & Gilligan (2010) Framework for Social Work Practice

This framework, proposed by Furness and Gilligan [66], is intended to assist social workers when religion and belief are significant in the lives and circumstances of service users and suggest how to take sufficient account of these issues in specific pieces of practice.



7. Herth Hope Index

The HHI, an abbreviated form of the Herth Hope Scale (Herth 1992 – see additional references), is a 12-item Likert scale designed by Herth to measure hope in acute, chronic, and terminally ill adults. The items are divided over the three subscales paralleling those of the HHS. Each item is scored on an ordinal scale from 1 to 4, where a score of 1 indicates 'strongly disagree' and a score of 4 indicates 'strongly agree.

Factor 1 inner sense of temporality and future

- Presence of goals
- Positive outlook on life
- Each day has potential
- Scared about the future

Factor 2 inner positive readiness and expectancy

- See a light in a tunnel
- A sense of direction
- Life has value and worth
- Recall happy/joyful times

Factor 3 lnterconnectedness with self and others

- Feel all alone
- Faith that comforts
- Deep inner strength
- Give and receive caring/love

The HHI has been used in numerous studies involving individuals with cancer in various stages and from initial diagnosis to hospice care. The HHI bas been used worldwide and has been translated into five foreign languages, Summative scores can range from 12 to 48, with a higher score denoting greater hope.

Described and used by Herth (1992, 2000 – see additional references)

8. The HOPE Questions for a Formal Spiritual Assessment in a Medical Interview

The HOPE questions were developed as a teaching tool to help medical student, residents and practicing physicians incorporate spiritual assessment into the medical interview by Anandarajah & Hight (2001 – see additional references). Referred to by later writers e.g. Puchalski [192]

The mnemonic is:

H: Sources of **H**ope, meaning, comfort, strength, peace, love and connection

O: the role of Organized religion for the patient

P: Personal spirituality and **p**ractices

E: Effects on medical care and **e**nd-of-life issues

Described as formal tool for spiritual assessment. Examples of Questions for the HOPE Approach to Spiritual Assessment:

H: Sources of **h**ope, meaning, comfort, strength, peace, love and connection

> We have been discussing your support systems. I was wondering, what is there in your life that gives you internal support?
>
> What are your sources of hope, strength, comfort and peace?
>
> What do you hold on to during difficult times?
>
> What sustains you and keeps you going?
>
> For some people, their religious or spiritual beliefs act as a source of comfort and strength in dealing with life's ups and downs; is this true for you?

If the answer is "Yes," go on to O and P questions.

If the answer is "No," consider asking: Was it ever? If the answer is "Yes," ask: What changed?

O: Organized religion

> Do you consider yourself part of an organized religion?
>
> How important is this to you?
>
> What aspects of your religion are helpful and not so helpful to you?
>
> Are you part of a religious or spiritual community? Does it help you? How?

P: Personal spirituality/**p**ractices

> Do you have personal spiritual beliefs that are independent of organized religion? What are they?
>
> Do you believe in God? What kind of relationship do you have with God?
>
> What aspects of your spirituality or spiritual practices do you find most helpful to you personally? (e.g., prayer, meditation, reading scripture, attending religious services, listening to music, hiking, communing with nature)

E: Effects on medical care and **e**nd-of-life issues

> Has being sick (or your current situation) affected your ability to do the things that usually help you spiritually? (Or affected your relationship with God?)
>
> As a doctor, is there anything that I can do to help you access the resources that usually help you?
>
> Are you worried about any conflicts between your beliefs and your medical situation /care/ decisions?

Would it be helpful for you to speak to a clinical chaplain/community spiritual leader?Are there any specific practices or restrictions I should know about in providing your medical care? (e.g., dietary restrictions, use of blood products)

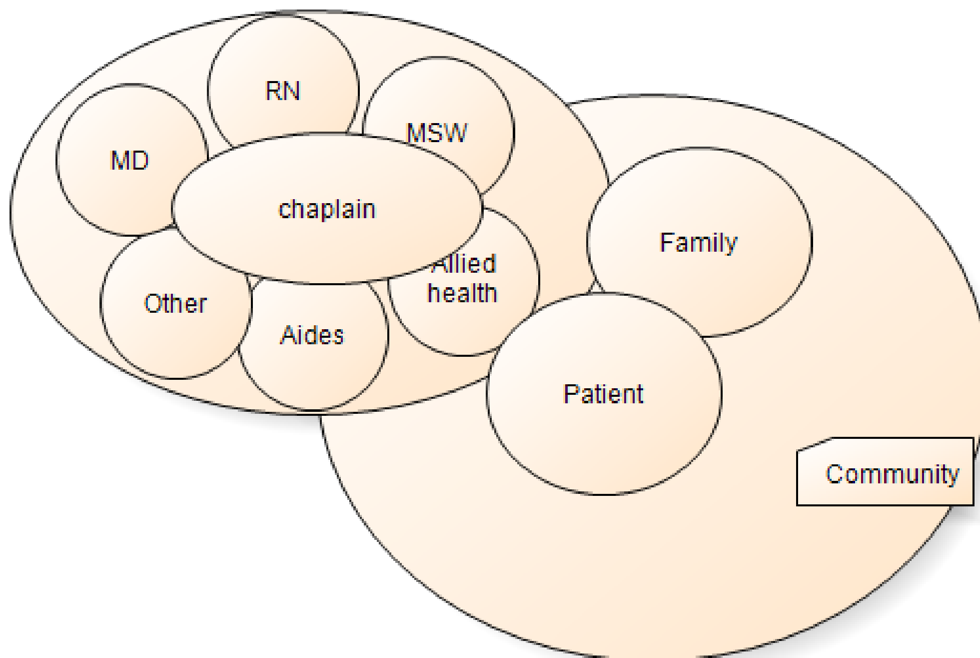
If the patient is dying: How do your beliefs affect the kind of medical care you would like me to provide over the next few days/weeks/months?

9. Idler Index of Religiosity (IIR).

The IIR contains two 2-item scales, one that sums attendance at religious services and number of other congregation members known to the respondent (public religiousness) and the other that sums self-reports of religiousness and receiving strength and comfort from religion (private religiousness). The overall score, ranging from 4 (least religious) to 17 (most religious) represents the level of religiosity in general.
Discussed and used in Wasner et al [237]– refers to Idler 1987 (see additional references).

10. An interdisciplinary spiritual care model

Proposed by Puchalski et al [193]



spiritual care model table:

compassionate presence	intention to openness
	intention to connect with others
	intention to be comfortable with uncertainty
relationship -centred care	partnership
	not agency driven
	listening to patients fears, hopes, dreams, meaning

spirituality of healthcare professional	awareness of own spirituality awareness of own mortality having a spiritual practice
extrinsic spiritual care	taking a spiritual history recognizing patients spiritual issues recognizing patients spiritual problems or spiritual pain recognizing patients resources of inner stregth or lack of resources incorporating patients spirituality into treatment or care plans (presence, referral, rituals, meditation, journaling, arts and humanities, retreat etc) work with interdisciplinary team to develop and implement treatment plan

11. Kellehear theoretical model of spiritual needs in palliative care

Dimensions of Spiritual Need – see Kellehear [112]

12. Marie Curie Spiritual and Religious Care Competencies for Specialist Palliative Care

Level 1: All staff /volunteers who have *casual* contact with patients and their families/carers: This level seeks to ensure that all staff and volunteers understand that all people have spiritual needs and distinguishes between spiritual and religious needs. It seeks to encourage basic skills of awareness, relationships and communication, and an ability to refer concerns to members of the multidisciplinary team (MDT).

Level 2: All staff and volunteers whose duties *require contact* with patients and their families and carers: This level seeks to enhance the competencies developed at level 1 with an increased awareness of spiritual and religious needs and how they may be identified and responded to. In addition to increased communication skills, identification and referral of difficult needs should be achievable along with an ability to identify personal training need

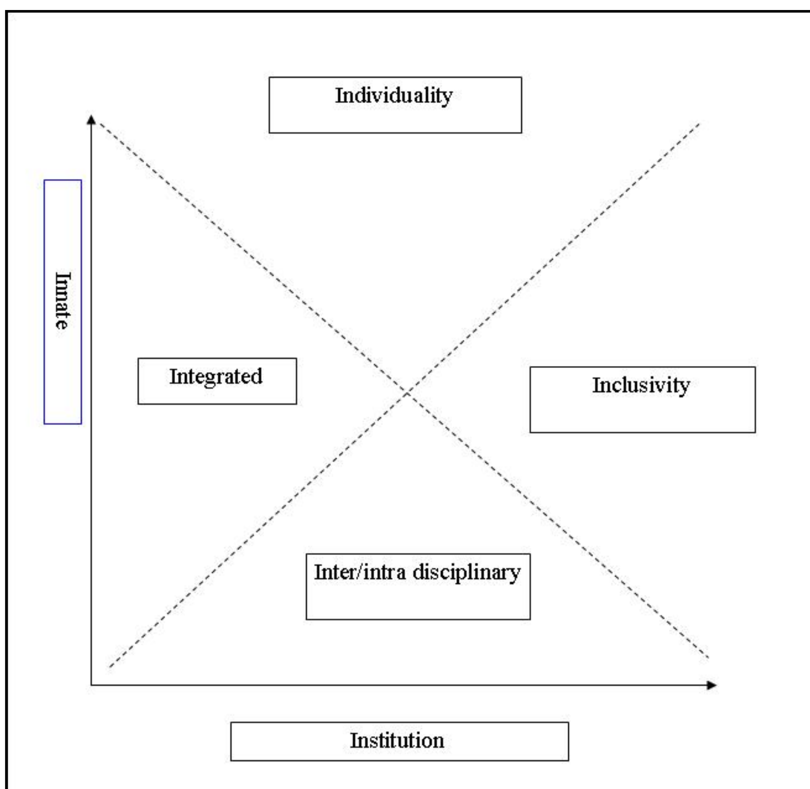
Level 3: Staff and volunteers who are *members of the multidisciplinary team*: This level seeks to further enhance the skills of levels 1 & 2. It moves into the area of assessment of spiritual and religious need, developing a plan for care and recognising complex spiritual, religious and ethical issues. This level also introduces confidentiality and the recording of sensitive and personal patient information.

Level 4: Staff or volunteers whose *primary responsibility* is for the spiritual and religious care of patients, visitors and staff. Staff working at level 4 are expected to be able to manage and facilitate complex spiritual and religious needs in patients, families/carers, staff and volunteers. In particular they will deal with the existential and practical needs arising from the impact on individuals and families from illness, life, dying and death. In addition they should have a clear understanding of their own personal beliefs and be able to journey with others focused on other people's needs and agenda. They should liaise with external resources as required. They should also act as a resource for the support, training and education of healthcare professionals and volunteers, and seek to be involved in professional and national initiatives. *(our italics).* [See 131,132]

13. Maslow's hierarchy of needs

Physical needs need to be met first, then emotional - love, belonging, self esteem. Only then consider 'growth' needs - meaning to things, appreciation of beauty, dignity, life coherence, self transcendence. See Clarke [37]

14. McSherry [145] Principal Components model



15. Mount Vernon Cancer Network (MVCN) spiritual care assessment tool

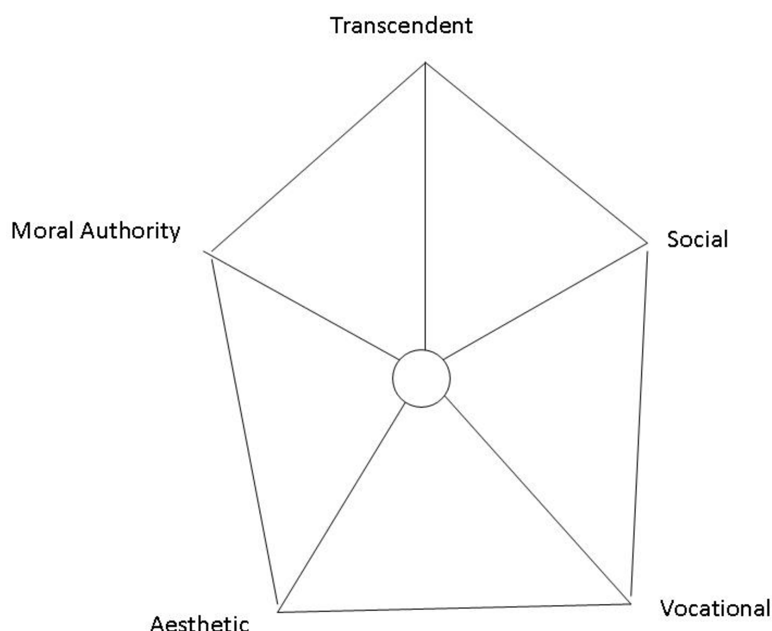
The assessment tool is part of the holistic assessment aide memoir that has been adapted from and incorporated in the PEPSI-COLA tool (PEPSI-COLA Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer). See [172]. It is underpinned by a spiritual referral pathway, based on the Marie Curie spirituality competencies, a spirituality service directory and a network wide education programme.

The MVCN spirituality assessment tool was launched in October 2007 and is based around three cue questions:

- How do you make sense of what is happening to you?
- What sources of strength do you look to when life is difficult?
- Would you find it helpful to talk to someone who could help you explore the issues of spirituality/faith?

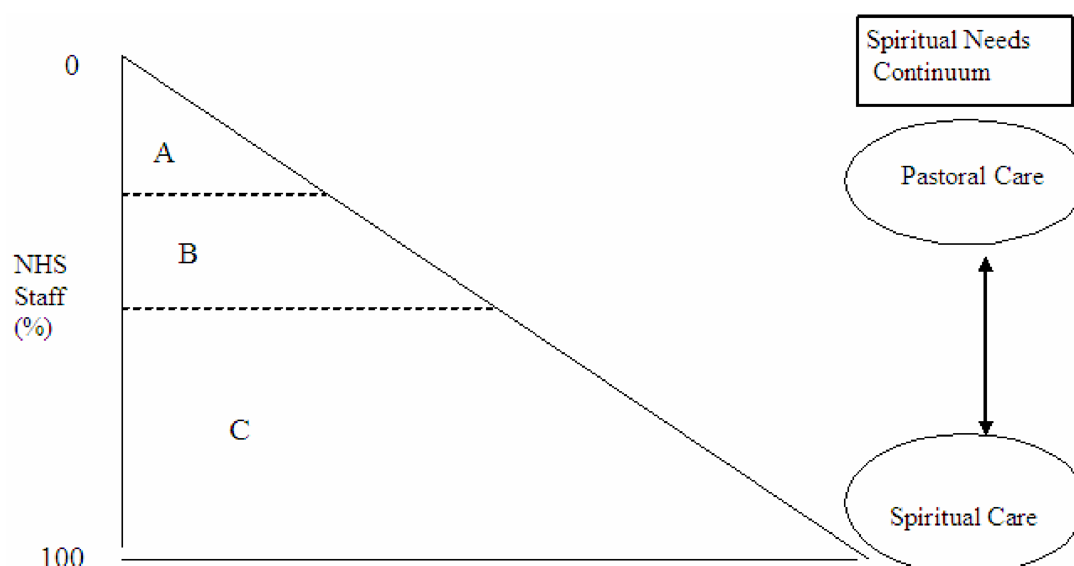
16. Moral Authority, Vocational, Aesthetic, Social and Transcendent (Mor-VAST) model

Skalla and McCoy [207] proposed a Five-Dimensional Model for Assessment of Spirituality**.** The person's spirituality is mapped onto five dimensions and the degree to which each is a strength or a need is assessed. The moral authority dimension is viewed as a sense of moral duty or "the right thing to do." It includes such experiences as guilt, remorse, resentment, forgiveness, compassion, righteousness, self-righteousness, and duty or obligation. An individual's sense of purpose in life is addressed by the vocational dimension. This may include a sense of service or accomplishment or a spiritual sense of vocational calling. The aesthetic dimension apprehends beauty or expresses creativity. It is connecting with nature or the creative process through such activities as making or appreciating art, music, or written work. The social dimension describes family, friends, relatedness in a sense of community, and rituals and practices that support the community. The transcendent dimension represents valuation of aspects of reality that are not material and, therefore, not directly accessible to the senses. The realm reflects awareness of the sacred and experience of the holy.



Dimension	Leading Questions	Follow-Up Questions
Moral authority	Where does your sense of what to do come from? What principles of right and wrong guide you?	Have particular moral struggles challenged or strengthened you? Are there people you need to forgive? Do you need to be forgiven? Are there things you've felt you needed to do? Do you have someone you talk to for [spiritual or religious] guidance [matters]?
Vocational	What gives your life meaning? Has it changed for you? What kind of work has been important to you?	What have you been good at? What has given you satisfaction? How have you contributed to the wider world and the needs of others? What were the challenges and rewards of your "calling"?
Aesthetic	What things do you enjoy doing? Are you doing them now?	Has being sick affected your ability to do things that usually bring you joy or pleasure?
Social	Are you part of a religious or spiritual community? Are there any other groups or people you enjoy spending time with?	Is it a source of support? In what ways? Does this group provide help in dealing with health issues?
Transcendent	What sustains you during difficult times? Who is in control?	What do you hope for? Is religion or spirituality important to you? Has it been important at other times in your life? What aspects of your spirituality or spiritual practices are most helpful to you? How is your relationship with God?

17. NHS Scotland [175] Generic skills and competency framework



This suggests three broad categories (A-C in the diagram) of responsibility and training requirement (See Table).

Staff Title (Examples)	Role/Response	Location	Approx No	Training and Support Style
Chaplain, bereavement/grief counsellor, patient advocate	Complex spiritual and pastoral care	Service wide	Low	Formal qualification, CPD (in house and external) supervision
Spiritual care championing	More complex spiritual care and routine pastoral care	Multidisciplinary team	Min 1/team	In house continuous professional development (CPD) programmes, professional supervision
All NHS staff	Routine spiritual care	All settings	100%	Induction and occasional top up

18. Palliative Care Needs Assessment tool (PC-NAT)

This was developed and described by Waller et al [234]. The one-page PC-NAT includes the following:

1) Section 1: three items to fast track a review by a SPCS: absence of a caregiver; a patient or caregiver request for SPCS referral and the health professional's need for assistance in managing care.
2) Section 2: seven items to assess the patient's well-being, including physical, changes in functional status, psychological, information, spiritual/existential, health beliefs/cultural/social and financial/legal domains.
3) Section 3: five items to assess the ability of the caregiver/ family to care for the patient, including physical, changes in functional status, psychological, information and family and relationship domains.
4) Section 4: two items to assess the caregiver's wellbeing, including physical and psychological issues and bereavement grief.
5) Section 5: one item to assess whether the health professional thought the patient needed assessment by a SPCS.

For Sections 1 and 5, response options were 'Yes' or 'No'. The items in Sections 2–4 were assessed according to the level of concern ('none', 'some', 'significant') they were causing. Prompt questions for each item were included on the back page, providing standard language for health professionals to use when using the tool

Trials found low reliability for spirituality domain

19. Palliative Outcome Scale

This is discussed by Brandt et al [19]. It asks:
Over the past three days.
01 Has the patient been affected by pain? (Item 1 pain)
02 Have other symptoms e.g., nausea, coughing or constipation seemed to be affecting how well they feel? (item 2: other symptoms)
03 Have they been feeling anxious or worried about their illness or treatment? (item 3: patient anxiety)
04 Have any of their family or friends been anxious or worried about the patient? (item 4: family anxiety)
05 How much information has been given to the patient and their family or friends? (item 5: information)
Q6 Has the patient been able to share how they are feeling with their family or friends? (item 6: support)
07 Do you think they have felt life was worth living? (item 7: life worthwhile)
08 Do you think they have felt good about themselves? (Item 8: self-worth)
09 How much time do you feel has been wasted on appointments relating to the healthcare of this patient, e.g., waiting around for transport or repeating tests? (item 9: wasted time)
010 Have any practical matters resulting from their illness, either financial or personal been addressed? (item 10: personal affairs)

20. RCOPE (Religious Methods of Coping)

This tool was developed and validated by Pargament et al [200] to assess religious coping methods. It suggests the following methods:

1. Religious methods of coping to find meaning
    a. Benevolent religious reappraisal – redefining the stressor through religion as benevolent and potentially beneficial
    b. Punishing God reappraisal – redefining the stressor as punishment from God for the individual's sin
    c. Demonic reappraisal – redefining the stressor as an act of the Devil
    d. Reappraisal of God's powers- redefining God's power to influence stressful situation
2. Religious methods of coping to gain control
    a. Collaborative religious coping – seeking control through a partnership with God in problem solving
    b. Active religious surrender – an active giving up of control to God in coping
    c. Passive religious referral – passive waiting for God to control the situation
    d. Pleading for direct intercession – seeking control indirectly by pleading to God for a miracle or divine intercession
    e. Self-directing religious coping – seeking control directly through individual initiative rather than help from God

3. Religious methods of coping to gain comfort and closeness to God
    a. Seeking spiritual support – searching for comfort and reassurance through God's love and care
    b. Religious focus – engaging in religious activities to shift focus from the stressor
    c. Religious purification – searching for spiritual cleansing through religious actions
    d. Spiritual connection – experiencing a sense of connectedness with forces that transcend the individual
    e. Spiritual discontent – expressing confusion and dissatisfaction with God's relationship to the individual in the stressful situation
    f. Marking religious boundaries – clearly demarcating acceptable from unacceptable religious behaviour and remaining within religious boundaries
4. Religious methods of coping to gain intimacy with others and closeness to God
    a. Seeking support from clergy or members – searching for comfort and reassurance through the love and care of congregation members and clergy
    b. Religious helping – attempting to provide spiritual support and comfort to others
    c. Interpersonal religious discontent – expressing confusion and dissatisfaction with the relationship of clergy or members to the individual in the stressful situation
5. Religious methods of coping to achieve a life transformation
    a. Seeking religious direction – looking to religion for assistance in finding a new direction for living when the old one may no longer be viable
    b. Religious conversion – looking to religion for a radical change in life
    c. Religious forgiving – looking to religion for help in shifting from anger, hurt and fear associated with an offense to peace.

21. St Michael's Hospice in Hereford Spiritual Needs Assessment Tool [170]

This includes open questions about support systems and beliefs and how they may have been changed or challenged because of their illness.

The tool covers three main areas – issues of sense, meaning and purpose; individual practice; and spiritual or religious connections. They include questions such as:

- When life is hard how have you kept going?
- Is there anyone or anything that has helped you keep going?; and
- How are you coping with what's happening to you?

22. SBI 15R (Systems of Belief Inventory)

A tool designed to address questions of meaning and purpose, death and dying, illness and pain, value and dignity and relationships and forgiveness. The tool was developed and validated by Holland et al (1998 - See additional references). The tool used a 4 point Likert scale with from strongly disagree to strongly agree or none of the time to all of the time. The questions were:

1. Religion is important in my day-to-day life.
2. Prayer or meditation has helped me cope during times of serious illness.

3. I enjoy attending religious functions held by my religious or spiritual group.
4. I feel certain that God in some form exists.
5. When I need suggestions on how to deal with problems, I know someone in my religious or spiritual community that I can turn to.
6. I believe God will not give me a burden I cannot carry.
7. I enjoy meeting or talking often with people who share my religious or spiritual beliefs.
8. During times of illness, my religious or spiritual beliefs have been strengthened.
9. When I feel lonely, I rely on people who share my spiritual or religious beliefs for support.
10. I have experienced a sense of hope as a result of my religious or spiritual beliefs.
11. I have experienced peace of mind through my prayers and meditation.
12. One's life and death follows a plan from God.
13. I seek out people in my religious or spiritual community when I need help.
14. I believe God protects me from harm.
15. I pray for help during bad times.

23. Schedule for the Evaluation of Individual Quality of Life - Direct Weighting (SEIQoL - DW)

The SEIQol is a method of assessing quality of life in which the respondent is asked to think about their lives and nominate the 5 areas of life (domains) which they consider most important to the overall quality of their lives and use their own value system when describing the relative importance of those domains. It rests on the assumption that quality of is phenomenological in nature and is specific to the individual and should therefore be defined by the individual concerned. The tool is well established (see O'Boyle et al 1993 - additional references). The SEIQoL – DW built on this tool, adding a direct weighting procedure to the relative importance part which is regarded as easier to implement in certain situations. This is described in Browne et al (1997 - see additional references). An evaluation of the use of the SEIQoL – DW in palliative care has been conducted by Crang & Muncey [45].

24. Self-Transcendence Scale (STS)

Self-transcendence is defined here as 'the expansion of one's conceptual boundaries inwardly through introspective activities, outwardly through concerns about others' welfare, and temporally by integrating perceptions of one's past and future to enhance its present'. The key assumption is that a sense of connectedness within the self and with one's environment is an essential characteristic of humanness. Reed (see additional references) developed this measure of self-transcendence using a 15 item self-report questionnaire. Typical questions regard 'helping younger people or others in some way', and 'finding meaning in my spiritual beliefs'. Responses are based upon a 4-point scale ranging from 1 (not at all) to 4 (very much). The final score reflects the overall level of self-transcendence._ The scale is discussed and used by Wasner et al [237]

25. SPIR

Frick et al [64] devised this tool for addressing the spiritual domain, planning referrals and ultimately strengthening the patient-physician relationship. The interview is structured and named by an acronym (SPIR) which helps the interviewer to touch the different issues of the spiritual domain instead of circumventing what may be difficult to approach:

S: Would you describe yourself – in the broadest sense of the term – as a believing/spiritual/religious person?

P: What is the *place* of spirituality in your life? How important is it in the context of your illness?

I: Are you *integrated* in a spiritual community?

R: What *role* would you like to assign to your doctor, nurse or therapist in the domain of spirituality?

26. SPIRIT

This is a 6-point instrument concerned with identifying spiritual beliefs, personal spirituality, integration in a spiritual community, ritualized practices, and implications for medical care and 'terminal event planning'. The mnemonic SPIRIT has been developed as an interviewing tool to aid physicians in spiritual history taking.

S—Spiritual Belief System
P—Personal Spirituality
I—Integration and Involvement In a Spiritual Community
R—Ritualized Practices and Restrictions
I—Implications for Medical Care
T—Terminal Events Planning (Advance Directives)

The tool is discussed by Maugans (see additional references) with sample questions for use in taking the history in this way. Puchalski [192] refers to it.

27. Spiritual Interests Related to Illness Scale (SpIRIT)

This was developed by Taylor and is discussed by Taylor and Mamier [223]

It has two nearly identical versions – the Patient and the Family Caregiver versions. The first part included items reflecting the spiritual needs identified by cancer patients and family caregivers during a prior qualitative phase of the project (Taylor 2003 see additional references). The second part had 20 items inquiring about clients' preferences regarding spiritual care nursing therapeutics, and seven items about requisites of a nurse who would provide them with spiritual care. These items were developed to reflect not only the data received from cancer patients and family caregivers but also contemporary nursing literature about spiritual caregiving. The nursing therapeutics items were introduced by 'In general, I would want my [my loved one's] nurse to:…'. These 20 items had 4-point Likert response options from 'strongly disagree' (coded as 1, 'disagree' (2), 'agree' (3), to 'strongly agree' (4). Two open-ended questions concluded the SpIRIT: 'Are there any other things nurses can do to care for your spirit?' and 'Is there anything else that you would like to tell us about this topic of nurses, spirituality, and serious illness?'

28. Spiritual Care Competencies Scale

This was developed and tested by Van Leeuwen et al 2007 (see additional references). Discussed by Van Leeuwen et al [230].

Some examples of items regarding competencies of spiritual care are:

> 'I am open to a patient's spiritual/religious beliefs, even if they differ from my own'
> 'I can tailor care to a patient's spiritual needs/problems in consultation with the patient'
> 'I can tend to a patient's spirituality during daily care (e.g. physical care)'.

A five-point Likert scale was used (1 = strongly disagree/5 = strongly agree) for the answers to the questionnaire.

The SCCS contains the following subscales:

- Assessment and implementation of spiritual care
- Professionalisation and improving quality of spiritual care
- Personal support and counselling of patients
- Referral to professionals
- Attitude towards the patient's spirituality
- Communication

Psychometric testing of the SCCS has shown that it is a valid and reliable scale for measuring nurse competency in spiritual care (van Leeuwen et al. 2007 – see additional references).

29. Spiritual Care Perspectives Scale

This is discussed by Highfield et al [89]. The SCPS was developed to examine nurse attitudes, beliefs, practices, perspectives, and preparation regarding spiritual care because no appropriate standardized tool was available.

1 . Frequency of providing spiritual care 1 2 3 4 5 (rarely or never) to (every day)
2 . Ability to provide spiritual care 1 2 3 4 5 (weak, limited) to (strong, comprehensive)
3 . Comfort level while providing spiritual care 1 2 3 4 5 (very uncomfortable) to (very comfortable)
4 . Training/education in spiritual care (check list)

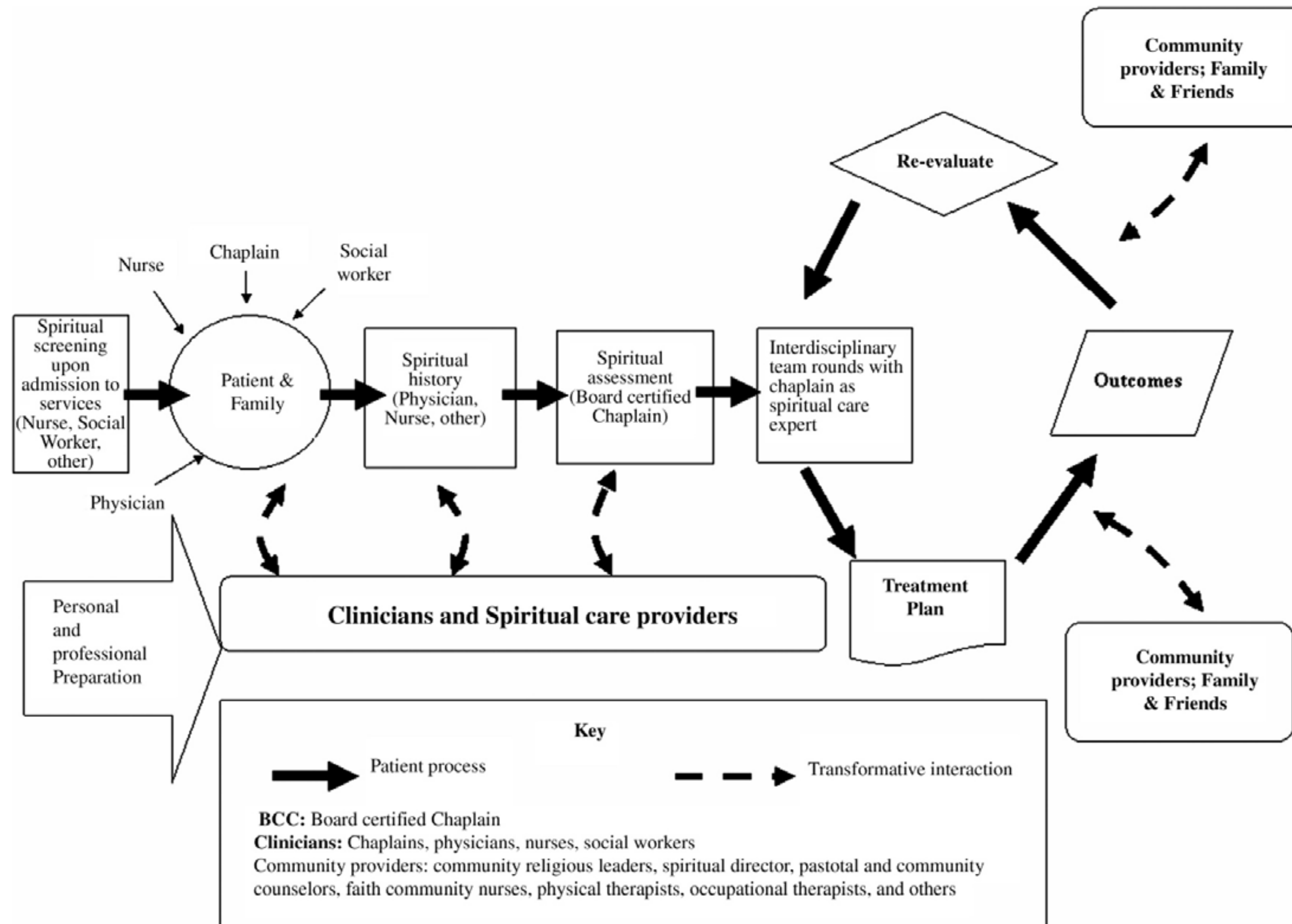
> N o n e
> Spiritual care integrated throughout basic nursing education
> Specific coursework during basic nursing education
> Graduate school training/coursework in spiritual care
> Continuing education in spiritual care
> Reading about spiritual care
> Other training. Please describe: ___________________________

5 . Adequacy of training 1 2 3 4 (inadequate) to (excellent)
6 . Influence of people living with cancer/terminal illness on spirituality 1 2 3 4 (not at all) to (a great deal)

30. Spiritual Care Implementation Models

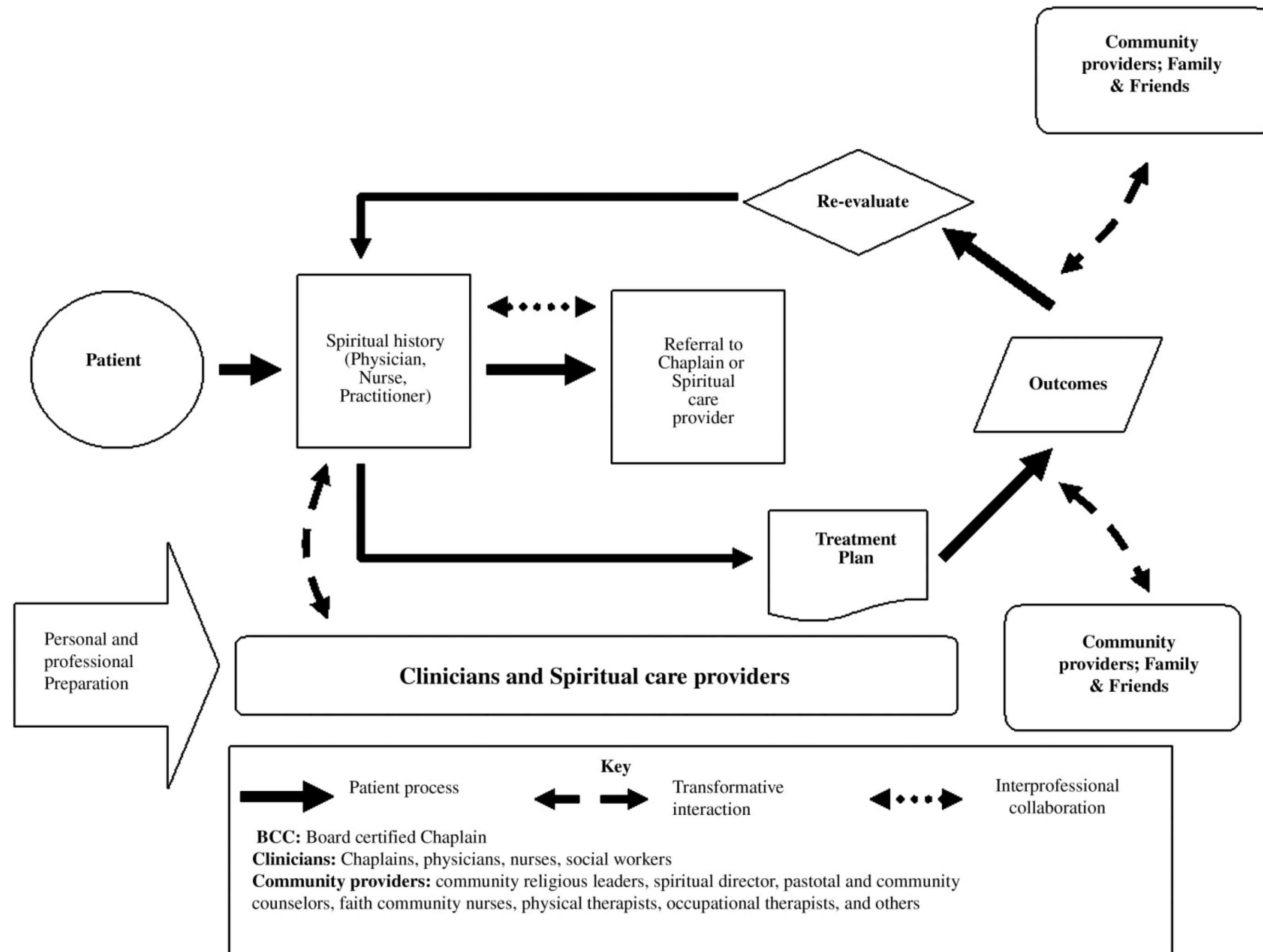
Devised by Puchalski , Handzo, Wintz & Bull, forthcoming 2009 and discussed in Puchalski et al [194]

Inpatient spiritual care implementation model



Source: Puchalski, Handzo, Wintz, and Bull, 2009 (in press)

Outpatient spiritual care implementation model



31. Spiritual Competence Scale

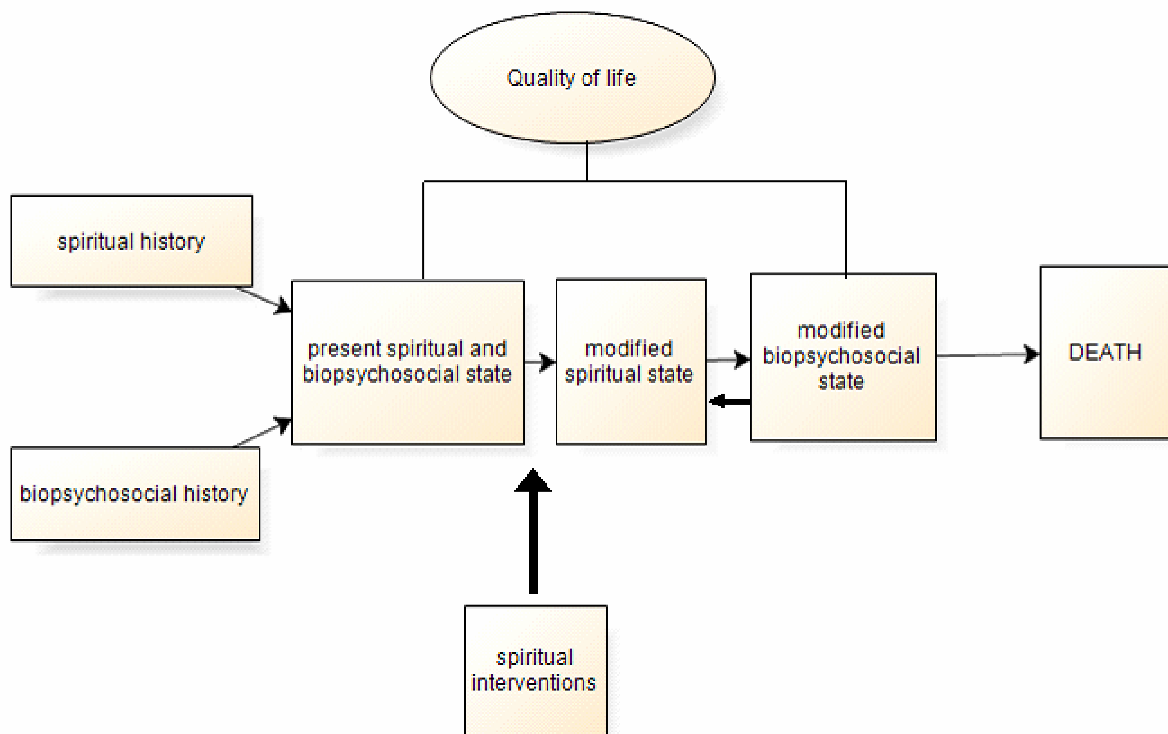
Developed by Hodge [93] as a measure of competence among US social workers
1. To what degree does your social work program foster respect for religious and spiritual cultures?
–5 –4 –3 –2 –1 0 +1 +2 +3 +4 +5
Fosters extreme disrespect---- Fosters extreme respect
2. How acceptable is it in your social work program to share religious or spiritual views?
–5 –4 –3 –2 –1 0 +1 +2 +3 +4 +5
Completely unacceptable -----Completely acceptable
3. To what extent does your social work program foster sensitivity toward religious and spiritual beliefs?
–5 –4 –3 –2 –1 0 +1 +2 +3 +4 +5
Fosters extreme insensitivity -----Fosters extreme sensitivity
4. To what extent does the atmosphere in your social work program foster respect for religious and spiritual perspectives?
–5 –4 –3 –2 –1 0 +1 +2 +3 +4 +5
Fosters extreme disrespect -----Fosters extreme respect
5. To what degree are religious or spiritual believers free to be themselves in your social work program?
–5 –4 –3 –2 –1 0 +1 +2 +3 +4 +5
Must always censor or guard themselves ----Totally free to be themselves
6. If religious or spiritual perspectives are shared in your social work program, to what extent are they valued?
–5 –4 –3 –2 –1 0 +1 +2 +3 +4 +5
Totally disrespected -----Totally valued
7. To what extent does your social work program foster an empathetic understanding of religious and spiritual worldviews?
–5 –4 –3 –2 –1 0 +1 +2 +3 +4 +5
Fosters complete misunderstanding ------Fosters complete understanding
8. When it comes to learning about the religious and spiritual worldviews that clients commonly affirm, how much openness does your
program demonstrate?
–5 –4 –3 –2 –1 0 +1 +2 +3 +4 +5
Completely closed -------Completely open

32. The Spiritual Needs Inventory (SNI)

Developed by Hermann [87]. Spiritual needs (defined as something required or wanted to find meaning or purpose in life) grouped into 5 themes: outlook, inspiration, spiritual activities, religion and community. Items for the spiritual needs inventory (SNI) were developed from a qualitative study of spiritual needs of dying patients. Each subject answered three questions for each spiritual need and whether the need was considered spiritual. The question format was likert scales for suggested needs and yes/no for whether spiritual and is need being

Subscale 1: outlook
Laugh.
Be around children.
Think happy thoughts.
Talk about day-to-day things.
See smiles of others.
Subscale 2: inspiration
Sing/listen to music.
Read a religious text.
Talk with someone about religious or spiritual issues.
Be with people who share my religious beliefs.
Subscale 3: spiritual activities
Read inspirational material.
Use inspirational material.
Use phrases from a religious text.
Subscale 4: religion
Pray.
Go to religious services.
Subscale 5: community
Be with family.
Be with friends.
Have information about family and friends.

33. Sulmasy [215] The biopsychosocial-spiritual model of the care of dying persons



34. The Trent Hospice Audit Group (THAG)

Standard for the assessment, delivery and evaluation of spiritual care developed by a multidisciplinary team at THAG and reported by Hunt et al [102].

Three levels of assessment:

- routine assessment for all patients at time of admission - basic information is gathered at this level that enables the team to understand the person's basis religious and spiritual beliefs and immediate needs.
- multidisciplinary assessment that is particularly sensitive to the spiritual issues, which may be indicated by the patient/carers or observed by members MDT through physical, psychological and social aspects of the person.
- specialist assessment by chaplain (usually) to explore complex issues that require in depth knowledge or skills

35. Walter [236] Four-fold typology of approaches to religion and spirituality

Belief in afterlife

		Yes	no
Belong to a church **Or other formal belief system**	yes	Formal religion – Christianity, Islam, Hinduism, Buddhism	Explicit secularism Humanism Atheism
	no	Folk religion – reunion in heaven, contact through mediums etc Spirituality – New Age, feminist etc	Implicit secularism 'when you're dead you're dead'

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