UNIVERSITY OF
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The clinical assessment
of spirituality in palliative care.

Thesis submitted in accordance with

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for the degree of Doctor of Philosophy

by

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Abstract

Background: The practice of palliative care and the specialty of palliative medicine emerged from the modern hospice movement and its foundational philosophy of treating the whole person. This holistic approach recognises that the needs of dying patients are complex and multifaceted. Spirituality is one of the dimensions of palliative care practice and it was assumed that there was sufficient robust primary data to support a synthesis of evidence. However, a critical examination of the published data found that many studies make use of unexamined assumptions and ambiguous constructs. The research in this field is therefore missing an important methodological step in the inductive cycle by failing to articulate explicit theory or identify critical concepts.

Aim: To construct a conceptual model of spirituality that provides a systematic way of illustrating the essential properties, functions and relationships of how spirituality operates in the lives of palliative care patients that can be subject to empirical testing.

Methods: Conceptual model building was used as a method of theoretical investigation to construct a minimal abstract and indirect representation of the way that spirituality potentially operates in the lives of patients. The model was then subject to empirical testing through generating quantitative and qualitative data from palliative care patients participating in a questionnaire and interview.

Analysis: Quantitative data from the questionnaires was subject to descriptive statistics and exploratory data analysis using techniques of visual representation. Qualitative data was subject to deductive content analysis based upon categories derived from the conceptual model.

Results: A Synoptic Model was developed whose theoretical claims were congruent with the findings from this sample with the exception of the disease construct. 19 patients participated in the questionnaire phase of the study and 10 participated in an interview. Patients discussed multiple aspects of spirituality including their beliefs, practices and experiences. For some patients spirituality provided an orientation to life and helped make sense of illness and its consequences. Spirituality was also a resource for some patients in helping them to face their current situation and their mortality.

Discussion: The Synoptic Model provides empirically supported theoretical knowledge of spirituality that can be utilised in the context of palliative care and has implications for clinical practice in terms of patient care, education and development, and assessment. Further development and testing is required in different settings to refine the Synoptic Model's content and specification.

Declaration

I undertake that all the material presented for examination in this thesis is my own work and has not been written for me, in whole or in part, by any other person. I also undertake that any quotation or paraphrase from the published or unpublished work of another person has been duly acknowledged.

Acknowledgments

Publications from Thesis

The original literature review for this study, covering the period 2000-2010, has been published as: Cobb M, Dowrick C, Lloyd-Williams M. What can we learn about the spiritual needs of palliative care patients

from the research literature? *Journal of Pain and Symptom Management* 2012;43:1105-19. (Appendix G)

The section on 'Personal Beliefs' from Chapter 4 formed the basis of a chapter published as: Cobb M. Belief. In: Cobb M, Puchalski C, Rumbold B, eds. *Oxford Textbook of Spirituality in Healthcare*. Oxford: Oxford University Press; 2012. (Appendix H)

A preliminary version of the Synoptic Model was presented as a poster discussion at The 7th World Research Congress of the European Association for Palliative Care, Trondheim, Norway, 7-9 June, 2012. The abstract published as: Cobb M, Dowrick C, Lloyd-Williams M. A Conceptual Model of Spirituality in Palliative Care. 7th World Research Congress of the European Association for Palliative Care (EAPC). *Palliative Medicine* 2012;26(4) 542-543. (Appendix I)

A later version of the Synoptic Model has been published as: Cobb M, Dowrick C, Lloyd-Williams M. Understanding spirituality: a synoptic view. *BMJ Supportive & Palliative Care* 2012;2:339-43. (Appendix J)

Scholarship

Dedication

This work is dedicated to the memory of Dorothy Kirkham (1922 – 2013), a woman of grace who delighted in the humanity of others.

Chapter 1

Introduction

Spirituality is a constituent part of the standard formulation of palliative care and one of the more distinctive features of this healthcare specialism. There are historical religious reasons for this that have subsequently become translated into more humanistic contemporary concerns, but taken as a whole spirituality finds its raison d'être in palliative care because of the impermanence of human beings and the existential questions and possibilities this presents. Where the arts and sciences of health mark the boundaries of living, and promote the fullness of life until its end, it is spirituality that sets dying and death within a bigger picture and points towards a wider horizon of ultimate purpose and meaning.

As someone who has spent over twenty years in hospice and palliative care it is easy to accept the almost irrefutable given of spirituality and the way it operates in healthcare organisations. As a chaplain, spirituality is my vocation, expertise and primary responsibility, but almost from the start it has also been a subject of curiosity, not least in relation to people who are dying. This much is probably unremarkable and begins to situate this study, but what prompted this research journey was the realisation that spirituality in palliative care was often used in uncritical and incurious forms. Attending conferences, often as the only chaplain, and listening to presentations in which spirituality was referred to without question, became increasingly unsatisfactory. At the same time clinical practice was presenting endless challenges in relation to understanding the spirituality of patients and seeking ways of responding that were

helpful and supportive. Similarly making sense of all this to my colleagues in the multi-disciplinary team required ways of articulating the spiritual in terms that were understood by other professions and could be incorporated into the practical matters of care. There is no finer way of testing this out than being asked to contribute to Grand Rounds, something that I was required to do in my first post at a London hospice presided over by a fiercely intellectual palliative medicine consultant.

Research question and aims

This research journey began with a different destination in mind than the one that I finally arrived at. One of the irrefutable givens I had come to accept was that there was sufficient robust data being produced by researchers to answer the pressing clinical question of how to assess a patient's spirituality to enable supportive care. This appeared to be a matter of reviewing and synthesising the current evidence on the spiritual needs of patients and developing and testing an assessment tool for use in clinical practice. What became obvious, as will be clear from this thesis, is that the evidence is far from complete and unequivocal. However, of more concern was that the underpinnings of the published research were often premised on unquestioned assumptions and much lacked theoretical exposition or consideration. As a consequence the research project became one of intellectual groundwork rather than clinical application guided by the principle question: can the lived spirituality of palliative care patients be represented in a theoretical model? The aims of the study then became (1) developing a proposed theoretical model of spirituality in palliative care that contains the principle conceptual apparatus of this phenomenon, (2) subjecting the model to an empirical test to confirm, disconfirm and/or extend the model, and (3) considering

implications of the model for the assessment of spirituality in clinical practice.

The thesis in outline

It is my contention that spirituality is not a self-evident concept and that outside of palliative care it is regarded as a more contested, complex and fluid concept that has become the subject of more explicit and various disciplinary orientations and interpretations such as sociology and philosophy. Chapter 2 therefore attempts to set the scene for the rest of the study by exploring the ways in which spirituality is understood and debated at large amongst scholars and aims to identify some of the key issues that need addressing in any theoretical articulation of the concept. The chapter concludes by adopting a working definition of spirituality developed by a European multi-professional palliative care organisation that demonstrates the current state-of-art in denoting this concept. This becomes the stepping stone to Chapter 3 which scrutinises published studies between 2000 and 2012 that claim to contribute to knowledge about the spiritual needs of patients in palliative care. The literature followed two main types: investigations of the nature of spirituality and investigations of covariance between spirituality and other phenomena, such as quality of life.

The critical finding of the literature review was the paucity of exposition on the presuppositions of the research that was betrayed in the use, for example, of ambiguous constructs and a functionalist approach to spirituality. I argue that the research in this field is therefore missing an important methodological step in the inductive cycle by failing to articulate explicit theory or identify critical concepts. Consequently instead of extracting data from published studies I have attempted to

address this gap by constructing a conceptual model of spirituality that provides a systematic way of illustrating the essential properties, functions and relationships of how spirituality operates in the lives of palliative care patients. Chapter 4 explains the strategy of model building adopted for this study and presents a Synoptic Model of spirituality with a detailed account of the elements of the model and the real-world features of the phenomenon it aims to represents.

The aim of this study is to produce sound arguments about spirituality in relation to the care of people with life-limiting conditions, and testing the Model depends upon the use and application of sound methodological principles. In Chapter 5 I develop a methodological basis for a research design to test the extent to which the model is representative of the spirituality of patients. Realism is a central feature of this methodology because it supports an epistemic commitment to more than just empirical objects and enables us to include the knowable reality of experience, beliefs, and social and cultural realities. A detailed research design is provided in this chapter with specific explanations of the methods chosen for data generation, collection, analysis and interpretation.

The findings of the test with patients are set out in Chapter 6 and are presented in two main sections. The first section gives an account of the characteristic of the sample of patients who participated in the study and utilises descriptive statistics and exploratory data analysis using techniques of visual representation to explore the findings from a questionnaire used with patients. The second section presents the findings from patient interviews that were subjected to a content analysis based upon the Synoptic Model. This chapter includes extensive quotations

from patients that illustrate the content of the Model and how this aspect of spirituality operates in the lives of patients.

Chapter 2
Understanding Spirituality

A study about the spiritual needs of patients cannot take a step forward until it has given some attention to the subject that is both the focus of its enquiry and the root of a flowering scholarship and discourse. Whilst this should be welcomed as a fertile ground for study, it is also the reason to pause before we begin, because despite the commonplace use of the term and its cognates, what is meant by spirituality is not clear, stable or without dispute. This problem is compounded by the ways in which spirituality has been adopted and interpreted by healthcare, of which palliative care has its own particular provenance and tradition. The work that the term spirituality is expected to accomplish is therefore wide-ranging and it is typically presented along a continuum through a plurality of forms from atheistic at one end to highly differentiated and specified religious forms at the other. This becomes manifest in the diverse varieties of definitions of spirituality and the purposes these definitions are put to, all of which require approaching carefully and with an understanding of the arguments they are employed in and the inferences the term is expected to justify. This is to be expected when different disciplines examine a subject: for example a medical view on spirituality as a healthcare intervention uses a very different conceptualisation to say an archaeological view on spirituality as enacted in material culture. However, in addition to semantics and disciplinary dispositions, spirituality also faces the challenge that its premises are fallacious or something of an afterglow of a receding mode of understanding and behaviour that is no longer compatible with the modern world. Inevitably,

whatever claims are made for spirituality it is implicated in some form of a relationship with religion.

A starting point therefore is to acknowledge that the varieties of spirituality in use are invested with different meanings and are produced for different purposes. Spirituality, whatever universal and ultimate claims it points towards, is grounded in culture, history, and the politics of discourse and definition. This may account for its malleability, but it also suggests that searching for an abstract timeless form is meaningless. Spirituality is clearly a useful and used language system that has evolved over time and continues to be shaped and reformed as it circulates among people. This leaves the challenge, for scholarly and analytical purposes, of attempting to describe it with clarity and precision. This is often contrasted to the much easier task of denoting religion, even though Bauman considers that, "'Religion' belongs to a family of curious and often embarrassing concepts which one perfectly understands until one wants to define them."[1] [(p.165)] A similar sense can arise when grappling with a term that is found in both secular and religious contexts, and whose implications Bender has neatly summarised:

> As a constellation of concepts and discourses, the contextual force of "the spiritual" and the relationships in which it is implicated are hardly clear, let alone self-evident. In fact, this obscurity seems to account in part for the power that spirituality has for many who would invoke it: it is both ostensibly self-evident and obstinately elusive, both manifest as a factor in social and religious life and yet difficult to pin down with any precision. [2] [(p.5)]

A first step in overcoming this indeterminacy for the purposes of this study is to propose that spirituality concerns the way people relate to a

transcendent reality, and therefore the relationship between the human and what many religions refer to as the sacred. The experience of transcendence has been described as by the psychiatrist Bragan as, "…the awareness which carries not only a recognition of the immediate and the concrete, but also a sense of the abstract and timeless; the awareness that life cannot be encompassed by rationality but extends into an unknown…". [3(p.11)] James, somewhat earlier, addressed this question in the third of his twenty Gifford Lectures on *The Varieties of Religious Experience* with the title "The Reality of the Unseen". James suggests in broad terms that the life of religion "…consists of the belief that there is an unseen order, and that our supreme good lies in harmoniously adjusting ourselves thereto."[4(p.41)] Religions propose a variety of ways to view the world and live in relationship to it that is meaningful and fulfilling, and Nagel argues that this question remains even if materialism or theism provide unconvincing answers.[5] Nagel's secular philosophical response to this large question however is a pointless exercise to Dawkins; the question does not exist because the universe has, "…no design, no purpose, no evil and no good, nothing but blind, pitiless indifference."[6(p.133)] James and Nagel mark something of the range of responses to the existential question that Dawkins dismisses altogether, and they illustrate the book ends of contemporary spirituality from religious traditions[7], to forms of atheism.[8, 9] Scientists (contra Dawkins) also attempt to relate to this domain, as science in broad terms seeks to understand the world and our place within it.[10, 11] Johnson, for example, in reflecting on the ancient people of New Mexico and the recent arrival of scientists in the region (relatively speaking) suggests that:

> All are trying to make sense of life's overwhelming complexity, to come to terms with the fact that, for all our well-laid plans, we are buffeted about by contingency and chance. Each of these

subcultures, in very different ways, is trying to replace randomness
with order, to spin webs of ritual and reason, to try to convince
itself that if we don't actually live at the center of creation, at least
we can comprehend it - that there is reason to believe that the
human mind can pierce the universal panoply.[12(p.26)]

This cosmic outlook provides an expansive backdrop against which this
study must take its next step in outlining the subject of enquiry. This is
another move towards systematically excluding content in order to
provide a realistic focus on the subject and it comes from the clinical aim
of the project. The concern here is with the way people living with a life-
limiting illness make use of, practice and struggle with spirituality. This
foregrounds the spiritual in lived experience and situates it in a practical
context placed within a wider social setting and culture. The ways that
patients express spirituality will be the subject of the next chapter when
the research that patients' participate in will be the subject of a critical
review. This chapter will therefore examine the social and cultural setting,
the ways that spirituality and religion feature as part of it and the
inflections of spirituality found in healthcare.

Features of the spiritual landscape

Patterns of religion and spirituality are not universal and require
specificity. The patterns of religious behaviour in Europe, for example, are
an exceptional case in global terms where religious vitality is more
prevalent than the comparative secularity of Western Europe.[13] For the
purposes of this study we shall be limited to a geographic country
boundary, but by implication this also involves a wide range of
dependent parameters such as history, culture, and politics, and the
dynamics playing out in a population through demographic changes and

social shifts. The European Commission, for example, considers that:

> …the presence of religion in the public sphere cannot be reduced
> to the public role of the churches or to the societal relevance of
> explicitly religious views. Religions have long been an inseparable
> component of the various cultures of Europe. They are active
> "under the surface" of the political and state institutions; they also
> have an effect on society and individuals.[14(p.11)]

A question on religion was included for the first time in the British Census in 2001. The question was voluntary and asked simply, "what is your religion?". Respondents had the choice of ticking one of eight options: "None", one of six religions, and "Any other religion" which included the option of completing a small free-text box. These are the standard classifications used by the Office for National Statistics[15], and they were repeated in the 2011 Census and answered by 93% of respondents.[16] (Table 1)

	Census 2011	BSA 2011
Christian	59.3	46.1
No religion	25.1	45.7
Religion not stated	7.2	0.8
Muslim	4.8	3.4
Hindu	1.5	2.2
Sikh	0.8	0.4
Jewish	0.5	0.8
Buddhist	0.4	0.2
Other religion	0.4	0.4

Table 1: Census & BSA data: Religion in England and Wales

The Census question is not dissimilar to the type of question a patient is asked on admission to a hospital and produces comparable results.[17]

However, census data about religious identity is inherently problematic for the figures are representative of a complex, dynamic and nuanced human phenomenon that is hostage to diverse interpretations, evaluations and conclusions. One reading of the figures is that they provide a crude snapshot of the way in which people identify with a religion. A tick in a category box tells us nothing about the strength of this identity, the extent to which it is associational or active, or explains why people chose to identify or not identify with a particular response category. For example, Smith suggests a hierarchy (or ladder) of relationships (Table 2) between religious identity and religious community involvement.[18]

| Leadership (external representative) |
| Leadership (internally) |
| Activism (as volunteers doing work internal or external to the organisation) |
| Membership (paying dues, subscriptions, voting rights) |
| Participation in public worship/prayer/festivals |
| Affiliation/Identity Affirmation/tick in Census box |
| Ascribed identity/born into the faith |

Table 2: Levels of religious community involvement

The British Social Attitudes (BSA) surveys are currently based on representative samples of around 3,500 adults (aged 18+) each year, selected by probability methods from private addresses with data collected via a computer-assisted personal interview and a follow-up self-completion questionnaire. The results of the 2011 BSA survey produced significantly different results to the 2011 Census (Table 1). This is partly explained by some of the methodological problems involved in enquiring

about religion and spirituality. One source of the difference is likely to originate in the way the survey was conducted and the questions asked. These are pertinent factors for any instrument designed to capture spirituality and religion including those used in the clinical setting. In this case participants were asked: "Do you regard yourself as belonging to any particular religion? If Yes: Which?". No options were provided or prompts given in the survey. Two categories with equivalent nomenclature illustrate the different results generated by the two methods: 46.1% of respondents declared themselves Christian in the BSA survey in contrast to 59.3% in the Census; 45.7% of respondents declared they had no religion compared to the 25.1% who identified themselves with this category in the Census.[19]

The different methodologies and the way questions were presented (for example the nature and sequence of the questions preceding the religion questions) are likely to have an impact upon the way the question was interpreted by participants. This has led some to suggest that the Census reveals more about a person's sense of national identity than their commitment to a faith community.[20] Even national identity is not without its complexity in terms of the way people respond to questions. For example the British Citizenship Survey is based on a nationally representative sample of approximately 10,000 adults in England and Wales with an additional sample of around 5,000 adults from ethnic minority groups. All ethnic minority groups (80%) were more likely to consider religion as an important factor than White people (44%), although White people were more likely to mention this than Chinese people (32%). Muslim (90%), Sikh (91%) and Hindu people (80%) were more likely to say that religion was important to identity than Christian people (51%).[21]

If self-identification of people with a religion indicates something about their relationship or alignment to a faith community, however imprecisely, we can infer little from this about what people believe or how beliefs operate. Attempts at understanding what people believe are equally fraught with difficulties in methological and definitional terms. A European study illustrates some of the problems. The European Commission regularly seeks the opinion of the public in its member states known as a *Eurobarometer Survey*. In 2005 a face-to-face poll was undertaken on views of European on ethics in science and technology that included questions on belief. When asked how frequently people think about the meaning and purpose of life, three in four respondents confirmed that they do (35% "often" think about this and 39% "sometimes" do). Only 8% of respondents declared that they never have such philosophical reflections. In each country surveyed, at least three in five citizens confirmed that they ponder on the meaning and purpose of life. In the UK 69% of respondents think about such things sometimes (37%) and often (32%). Four in five EU citizens have religious or spiritual beliefs. Just over half of EU citizens believe there is a God (52%) and over one in four (27%) believe there is some sort of spirit or life force. Only 18% declare that they don't believe that is any sort of spirit, God or life force. In the UK sample, 38% reported they believe in God, and 40% that they believe there is some sort spirit or life force.[22] Similar levels are found in the nearest BSA Survey by date, from the year 2000, which enquired about people's belief in God by asking them to indicate which statement came closest to expressing their belief (Table 3). Whilst the sample was smaller than the other surveys referred to (n=977), 56% of respondents indicated some form of belief in God, which rises to 72% when this includes belief in a "Higher Power".[23]

	%	n
Don't believe in God	9.90	81
Don't know if there is a God	15.00	122
Higher Power	13.51	110
Believe sometimes	14.36	117
Doubt, but believe	22.78	185
Know God really exists	21.41	174
Don't know	0.00	0
Not answered	3.08	25

Table 3: Belief in God

These large social surveys are predominantly organised and structured around indices of religion, and equally, of secularization. Many rely upon self-reports and identifications that are framed for very particular purposes. Whilst they may be helpful to pattern-builders and in identifying preferences they are likely to be less useful in discerning the ways in which spiritual traditions are implicated in cultural and political forms or entangled in other aspects of life. For example, Martin summarises American and European studies of secularization and contemporary spirituality and concludes that:

> There are some broad trends, such as detachment from ecclesiastical loyalties and habits, coupled with some disillusions with institutions as such, and a search for manifestations of the spirit. This search can find satisfaction in highly personal therapeutic engagements and small intimate cells or in the most ancient forms of the religious impulse, the festival, the pilgrimage, or the prayer in the numinous or scared location.[24(pp.54-55)]

The space of contemporary spirituality

One of the anomalies or disparities evident in the many and various survey figures on religion, particularly in relation to Christianity, is that alongside low levels of active religious participation and practice there remains a relatively high belief in some form of God. Davie cautiously described this situation as *believing without belonging*; an evocative phrase that has passed into the canon of the sociology of religion.[25] An illustration of this can be provided by comparing figures about the constitutionally established Church of England. In a BSA Survey for the year 2008 there were 23% of respondents (n=4,485) who declared that they belong to the Church of England. The provisional statistics from the Church of England for this year show that 2,647,200 of all ages attended church at Christmas.[26] This represents 5% of the population of England for persons of all ages. The BSA survey is among adults, but if this is accounted for there remains a wide gap between the people who state they belong to the Church of England and those who attend at one of the most significant festivals of the Christian calendar.

Disbelief appears to be relatively uncommon in contemporary Britain, but this does not imply that the form and content of the belief that people express is necessarily of a conventionally religious form or confined to a particular religious or spiritual tradition. Some have argued that the evidence suggest the form of belief more prevalent is "… a vague willingness to suppose that 'there's something out there', accompanied by an unsurprising disinclination to spend any time and effort worshipping whatever that might be."[27] Others propose that in order to understand contemporary society we should move away from tradition-based classifications of orthodox belief and practice to account for the patterns and varieties of relationship expressed between the divine, the human

and the natural order that co-exist on a social and personal level. One such scheme identifies three forms across a spectrum: religions of difference, religions of humanity and spiritualities of life.[28] Spiritualities of life are an example of a form of belief and practice that many surveys constructed around orthodox religious typologies will not be sensitive to and may therefore be under-represented in the data.

An example of the way spiritualities of life are manifest is from a study of religion and spirituality in the town of Kendal in the UK.[29] They report that two distinct forms of belief and practice exist in the community: one is the traditional religious domain related to theistic authority structures and the other is what they refer to as the holistic milieu evident in spiritually informed activities (e.g. yoga classes[30] and reflexology) that promotes sources of authoritative significance within the unique subjective experience.

The presence of alternative spiritualities or the emergence of new spiritualities in Britain has not been well defined or studied beyond a few notable examples, such as New Age Spirituality.[31] In general these spiritualities describe in various ways the relationship between the human (and often specifically the self), the divine (deistic rather than theistic) and the world (nature and the cosmos) with an emphasis on personal spiritual experience. Despite the inherently individualistic nature of these beliefs there are cohesive aspects and shared identities that help give them some definition. However, Lynch proposes that rather than thinking of them as worldviews they are understood as lived ideologies related to spiritual and cultural practice:

> When thinking about progressive spirituality, it is less useful to see it as the universally held world view of a particular group, and to

ask instead what kinds of practices, identities, experiences and relationships the ideology of progressive spirituality makes possible. The value of progressive spirituality for its practitioners lies less in its coherence as a world view or piece of systematic theology, than its usefulness in shaping meaningful religious identities and rituals, providing a framework for making sense of personal religious experience, and nurturing important relationships and social activism.[32(p.41)]

People who identify themselves as spiritual but not religious occupy an area on the empirical map that is waiting for more exploration and description, and much remains to be understood about what it consists of. In this penumbra is a highly varied territory that includes un-churched believers, so called "no religionists" or those who choose the "none" option on a questionnaire, those who are searching for their own experience of the sacred and spiritual quest, and many others who may not strongly relate to a category or pre-defined identity. Whilst these beliefs can be differentiated from mainstream religions they are far from polar opposites as they share a belief in a transcendent reality, although in the former the direction may be more inwards and self-sufficient. Much of contemporary spirituality and religion is likely to be found in this middle ground of undemanding belief embedded lightly in a given authoritative framework or mediated only in part through a loose or distant association with a religious community. Consequently people are open to assemble their own beliefs and theologies and may hold multiple beliefs and attitudes that may not form a coherent systematic scheme.[33] For example people who self-identify as Christian may hold beliefs about reincarnation.[34]

This chapter is concerned with the general population but a relevant question is, to what extent do these general surveys apply to patient populations? In a study of patients admitted consecutively to the cardiology (n=125) and gynaecology services (n=126) of an inner London teaching hospital 100 cardiology (80%) and 97 gynaecology patients (78%) professed some form of spiritual belief, whether or not they engaged in religious activity.[35] In a survey of general medical and surgical patients (n= 234) approximately three out of four patients indicated that spirituality or religious beliefs were important resources that help them cope with being unwell (74%) and can contribute to their recovery from illness (77%). The survey was also undertaken with staff (n=225). A higher proportion of staff thought that spiritual beliefs can contribute to health recovery and adjustment to illness (81%).[36]

	Neither religious nor spiritual %	Religious not spiritual %	Spiritual not religious %	Both religious and spiritual %
Personal God	7	11	1	79
Spirit/life force	32	7	31	31
God within	31	10	20	38
Don't believe	78	1	21	0
Don't know	71	3	22	4
Total	33	8	17	42

Table 4: Results from the European Religion & Moral Pluralism Survey

An analysis of the European Religion and Moral Pluralism (RAMP) survey illustrates some of diversity present in this domain (Table 4).[37] Participants in the RAMP survey (n=12,166) were not allowed multiple choices and it is helpful to notice some features that this produces. The largest response

is from those who identify themselves as both religious and spiritual and express a belief in a personal God. Those who choose the option "God within" (which may be considered an unorthodox/ non-traditional belief) includes 10% who are religious and not spiritual and 38% who identify themselves as both. People who consider themselves as spiritual and not religious identify their beliefs as immanent or internal whereas those identifying with some form of religion are more likely to choose an option involving some form of God. The RAMP survey finds that, in general terms, there are relatively few atheists or agnostics, and the researchers offer a cautious interpretation that:

> … many of those whom Davie and others conceptualise as 'believing but not belonging' are best not thought of as 'believers' at all. They do not have ('fixed') propositional beliefs; they might not have a sufficiently strong sense of the truth of their sensibilities to 'believe in' anything much, that is in the sense of 'having faith' or 'placing trust' in whatever 'sacrality' might be 'taken' to be. Yet this is not to say that their 'apprehensions'—of what lies 'deep' within the self or nature, of what lies 'beyond' the universe in the case of Einstein—is inevitably lacking in significance for their lives.[37(p.93)]

The meaning of this significance is awaiting further exploration and interpretation although it appears to be more humanistic than theistic in nature and may be an example of a spirituality of life. The findings may also point to the forms of the sacred in society and people's engagement with them that are no longer considered religious but which also express normative realities, have symbolic power and to which people orientate their lives. In his sociology of the sacred, Lynch, argues that whilst the sacred might be problematic and pluralistic in contemporary society, it

remains inevitable: "Indeed, to try to place ourselves beyond any sacred claims would be to remove ourselves from the framework of meanings through which social life itself is possible, and, in that sense, to make ourselves less than human." [38](p.129)

Spirituality, faith and belief

If some sense of the sacred is inevitable in society then faith is an inevitable, if often unnoticed, habit of people in living their lives. Ordinary faith in ourselves, in others and in the world we engage with helps us make sense of the reality we experience, sets out a direction of travel and enables us to avoid being stuck in endless decision-making, testing and reflection on every next step. Faith then can be considered a profound attitude of trust; it is a way of conceiving or imagining a situation as it possibly could be without having all the facts to hand. This is not primarily an intellectual or philosophical exercise, nor is it simply a matter of choice: "It is more common to find oneself believing something than to make a conscious decision to do so – or at least to make such a conscious decision because you find yourself leaning that way already."[39](p.137)

Faith has been succinctly described as the capacity to believe,[40] and faith and belief, though simple enough terms, have complexities and nuances evident in how the terms are used linguistically, what they are intended to mean and what they refer to. For example Žižek argues that there is a difference between faith and belief: "one can *believe* (*have faith in*) X without *believing in* X…. we do not have to believe IN IT in order to believe IT, to feel bound by some symbolic commitment".[41](pp.109-110) These subtle philosophical distinctions may not be as sharp in the everyday language people use, for example, people have faith in science,

medicine or democracy and live accordingly, but their beliefs in such institutions may not be as coherent or dependable. To be more specific, faith is not primarily a belief in a set of specific propositions and it need not involve facts, but it can alter the way we interpret facts. Midgley sites Marxism and Taoism as examples of faiths that do not involve extra factual beliefs:

> Both call centrally for changes in attitude to the facts one already accepts – changes in connection, in emphasis, in attention, in selection, in the meaning and importance attached to particulars – in short, a changed world-picture. [42(p.16)]

These secular faiths display many of the characteristics of religious or spiritual faith and may even be manifest in practices and habits similar to that of a religious faith community or group. Think for example of a dedicated environmentalist who belongs to national organisation, meets with members of a local group, accepts the teaching of authoritative writing by leaders in the field, holds particular beliefs about the environment, and takes part in shared activities. It is the substance of a faith and its belief claims, even when they are not formalised, that can inspire and give purpose to life. However, although people can have faith in an all-encompassing worldview, there are also some necessary faiths that are more mundane and limited. Not all faiths serve the same purpose, and failing to distinguish between them can be problematic: "It is right to have faith in a car as a means of transport, but not as a divinity." [43(p.23)]

The focus of this study is spirituality and therefore a relevant question is whether there are forms of faith and belief related to spirituality that can be distinguished from other varieties of faith? It seems reasonable to expect that the former will involve normative claims about our world and

about what it means to be human, and this provides one approach to understanding the ways in which different faiths may operate. Another may be found by exploring distinctions in the particular paradigms that faiths occupy: for example between environmentalists and Buddhists. In simple terms science, as a form of faith, has some strong claims to make about the physical world, whereas a religion has strong claims to make about the meaning and value of existence. Audi has enumerated seven different forms of faith that appear in major literature in philosophy, religion and theology: propositional faith, attitudinal faith, creedal faith, global faith, doxastic faith, acceptant faith, and allegiant faith.[44(pp.52-65)] Whilst some of these hold for secular forms of faith, religious forms of faith are considered by Audi to be conditional on at least four of the forms of faith. Firstly, but not sequentially, a religious theistic faith implies belief in God (attitudinal) and, secondly, faith that God has particular attributes or dispositions (propositional). Thirdly religious people accept, or hold, particular tenets or doctrines (creedal), and fourthly people belong to religions as communities and social groups, and thus they are people of a specific form of (global) faith rather than an individualistic form of faith known to and practised by the person alone.

In Audi's scheme formal religious faith provides sufficient content and specificity to be distinguished from other forms of faith. As the data from surveys suggests the real-world is more complex, and whilst there are evidently people who satisfy the necessary conditions for religious faith, society also contains people with very different faith commitments and expressions of faith, some of which have no theistic content but are similarly significant and entail cognitive and practical orientations. Beliefs, as part of what constitutes faith, may provide a further way of distinguishing varieties of faith and may indicate different characteristics

of spirituality, for example, the beliefs of those in the RAMP survey who identified themselves as "Spiritual not Religious" and whose main mode of belief was in a "Spirit/Life force" rather than a "Personal God".

Beliefs, like faiths, whatever their content depend upon how the human mind functions, and this provides another line of enquiry. Psychologists propose that beliefs arise from mental processes that generate assumptions about the world we experience. Barrett, for example, drawing upon cognitive studies of religion and the mental systems they use, concludes that, belief in God is nothing unusual (either statistically or psychologically) and arises "…from the operation of natural processes of the human mind in ordinary human environments. Belief in God does not amount to anything strange or peculiar; on the contrary, such belief is nearly inevitable."[45] He argues that belief in god-concepts and religious ideas can be distinguished from other forms of beliefs by a number of characteristics:

1. They have a small number of counterintuitive features which violate the category of the object we have determined by our senses or a property that the object is expected to have.
2. They are identified as having agency and attributed with intentionality or motivation.
3. They possess strategic personal information, for example moral and social information, which relates typically to survival or reproduction.
4. They are capable of acting in the world (through objects or events) in detectable ways.
5. They motivate personal and corporate behaviours that reinforce belief, for example regular congregational prayers in

a mosque provide an explicit demonstration of belief and promote resilience to sceptical scrutiny.

To illustrate these characteristics Barrett provides a novel comparison of potential candidates for a god-concept but who fall short of the grade (Table 5).[46] His prime candidate is Santa Claus, but portrayals of him in film and surveys often reveal him as an ordinary human being. He is clearly an intentional agent but possesses only limited strategic information, however, it is believed that he acts in the real world by some people and he motivates their behaviour but in limited ways and only once a year. Mickey Mouse is a cartoon character and cannot act directly in our world. The Tooth Fairy is reactive to dental events and shows no concern for any other aspect of people and therefore fails to possess all but highly specific strategic information. Finally, George W. Bush served as the President of the United States of America between 2001 and 2009, and whilst not without merits his presidential legacy was typically assessed by the British press as something of a disaster.[47] He therefore did not contradict any of the properties of being a flawed human being, and so he along with the others fails to achieve any credibility as a god-like being.

	Counter-intuitive	Intentional agent	Possessing strategic information	Acts in real world	Motivates reinforcing behaviour
Santa Claus	Inconsistent	Yes	Marginal	Yes	Marginal
Mickey Mouse	Yes	Yes	No	No	No
Tooth Fairy	Yes	Yes	No	Yes	Yes
George Bush	No	Yes	Yes	Yes	Yes

Table 5: Candidates for god-concepts

Beliefs have been the subject of philosophers for centuries, and more recently psychologists, who have produced various theories about how beliefs 'work' such as the mental state theory and the disposition theory.[48] Barrett is following a relatively new line of enquiry being developed in the interdisciplinary field of cognition studies and cognitive science that is interested in what the human mind must be like to have beliefs and the cognitive processes that enable beliefs to function. This is an attempt to understand how people conceive and experience spiritual and religious 'objects', and how the practices and behaviours associated with them impact upon cognition. More specifically cognitive science is interested in how the various and interrelated cognitive processes may function in relation to spirituality and religion, such as perception, conceptualisation, decision-making and imagination.[49] One of the distinctive disciplines contributing to cognitive science is neuroscience whose neurobiological theories have benefitted from developments in neuro-imaging technology. A particular concern of such enquiries is to identify the neural correlates of spiritual and religious beliefs and experience,[50, 51] and in particular what is going on in the brains of people who meditate.[52] However there are serious methodological problems with this approach and Tallis, an atheist, is an eloquent critic of what he refers to as the "neutralization" of religion, which he considers, adds nothing to our understanding of religion and not only diminishes belief but is an affront to this expression of humanity. He reserves his strongest criticism for when the reductive neuroscience of God is coupled with Darwinism: "Darwinizing the idea of God makes prayer and the holding of theological beliefs a mere organic function, a bit like secreting urine."[53(p.333)]

Spirituality and religion need to be situated and contextualised in the bigger picture of humanity to be understood. This does not and cannot figure (for methodological reasons) in the neurosciences but it is central to sociological enquiries.[54] The study of religion has been and remains a fruitful subject for sociology, and religion has advantages over spirituality in that it is generally organised and institutionalised which makes it easier to grasp and define. However, a nascent sociology of spirituality is beginning to emerge in response to shifting patterns of belief and practices in society, and it is one in which there appears an inherent tension between interior and exterior expressions of spirituality that are associated with spirituality as part of religion and spirituality as distinct from religion. This results in two different but related agendas, firstly in relation to "…the individual, subjectivity, expressivism and responses to the rootlessness postmodernity expands", and secondly in relation to organised religion and its "…tradition, ritual, symbol, external authority and communal practices within which the individual operates."[55](p.256) This distinction provides some clarity and explanation, but empirical studies are reporting problems with this conceptual logic. Bender, for example, following a recent study of mystics and spiritual practitioners in a town in America concludes that spirituality in this context is deeply entangled and embedded in religious and secular fields, structures and histories, rather than the assumed individualistic displaced and disassociated forms of spirituality that are often assumed.[56]

The contemporary context of spirituality is one of multiplicity and plurality and any study of spirituality therefore needs to remain sensitive to the variety of forms people inhabit and live. Despite these challenges, belief appears to be a helpful and useful lingua franca in the study of spirituality for people to describe and explain their spirituality, and as a

way for understanding what spirituality might mean and how it operates in people's lives. The language of belief can therefore do far more than provide content to the object of a belief, and this more nuanced approach is illustrated by the work of Day in her study of belief based upon people aged between 14 and 83 living in towns and villages in northern England.[57] Day argues that belief arises from human interactions and reflections and is manifest in relationships, actions and activities, and this results in a multidimensional construct of belief: the content of beliefs and their source, how beliefs are practiced, the salience or importance of a belief, how beliefs function in people's lives or what it enables them to do or be, and the relationship of belief to time and place.[57(pp.158-173)] These aspects expand the cognitive dimensions of belief and disclose something of the contextual and social nature of spirituality and religion.

Spirituality and Healthcare

Healthcare and religion have historically been inseparable bedfellows. In western Europe by 1100 a movement dedicated to caring for sick people was under way, the Order of St John, which survives to this day in countries throughout the world as a provider of first aid and nursing care. The first public hospital of the Order was in Jerusalem and dedicated to the service of the 'holy poor'. This institution was run by a master assisted by nursing brothers and sisters. The great hospital in Jerusalem took in the poor, whatever their religion or nationality. It could accommodate 2000 men and women in eleven wards, one of which was devoted to obstetrics. When it was overflowing the brothers slept on the floor and their own beds were used by the sick. If the patients were not strong enough to make it to the hospital then they were brought in. Four physicians, four surgeons and a number of bloodletters were employed. Each physician was obliged to visit his patient each morning and evening

to inspect their urine and take their pulse.[58] In the Middle Ages, hospitals flourished in western Europe, based upon monastic houses, but in England these underwent what might be considered the first of many politically motivated re-organisations with the dissolution of the monasteries under Henry VIII.[59]

It is perhaps not surprising with this type of heritage that when the National Health Service was formed in 1948 the newly nationalised hospitals were directed to employ chaplains and to provide chapels, most of which were already in place.[60(pp.40-46)] Hospital authorities at the time were advised to make provision for the spiritual needs of patients and staff[61] and thereby confirmed spiritual care as part of the DNA of the health service. Since then spirituality in the NHS has developed alongside the society it serves. It has become more plural[62], contested[63] and articulated,[64] and although chaplains continue to be regarded as the primary profession in this field, it is recognised more generally as an aspect of holistic healthcare that other professions should understand and contribute to.[65] Consequently spirituality has become the subject of multidisciplinary guidelines,[66] integrated models of care,[67] and general[68] and speciality-specific clinical textbooks.[69]

The scope, complexity and fecundity of the field of spirituality in healthcare is perhaps testimony to the persistent significance that the spiritual dimension can bring to understanding and caring for people facing illness and injury. The next chapter will provide a systematic review of literature relating to palliative care patients, but as a general overview to spirituality and healthcare La Cour and Hvidt provide a typical example that attempts to summarise the various religious, spiritual and secular traditions manifest in the discourses and practices in this

field.[70] 'Existential meaning-making' is their proposed portmanteau term over a conceptual terrain to which they argue that all three traditions contribute to in distinctive ways and across three psychological/sociological dimensions of knowing/cognition, doing/practice and being/importance. [70(p.1298)] What is a notable feature of this framework is its sensitivity to the Northern European context in a field that is dominated by American approaches to the subject. In particular, and betrayed in their chosen term, La Cour and Hvidt pay regard to the philosophical and theological discourses about the nature of human existence, and the human activity of making meaning, that became known formally as existentialism.[71]

In general terms illness can represent an existential challenge to patients and their carers that biomedical responses alone cannot address. Illness, and the suffering that may accompany it, can be a profoundly disturbing human experience of finitude, vulnerability, dissolution and disruption.[72] This is why for Pellegrino medicine must be concerned with all the dimensions of personhood that impinge on human wellbeing, and why in his memorable formulation medicine should be, "the most humane of sciences: the most scientific of humanities.".[73(pp.309-331)] Similarly, all approaches to healthcare require a clear ethical response to treating the patient as a person[74], a humanistic commitment to the provision of care as both a practice and a value[75], and an understanding of the aspects of human life that such caring is about.[76]

Spirituality in healthcare, perhaps at its simplest, can be considered as both a practice of meaning-making and a value of personhood. Attempts to understand and define spirituality, such as that by La Cour and Hvidt, appear to signify at least four things: (i) a rational justification or

(empirical) assertion of the existence of the phenomenon in the midst of a bio-medical paradigm, (ii) the essential and distinguishing properties of spirituality in terms of classification and categorisation, (iii) an understanding of the phenomenon in how it is expressed, known and represented, and (iv) the relationship of spirituality to health and healthcare in terms of a causal explanation. This is an ambitious and unresolved agenda because it relates to a dialectical dimension of personhood in dialogue with wider society and culture, and it is influenced by a scholarly community whose disciplinary boundaries and methodologies have sometimes inhibited more fruitful approaches to understanding this pervasive aspect of human life. Spirituality in healthcare has therefore also come to represent a nexus of inter-disciplinary thought and practice in which the curious, the sceptic and the believer find hospitality. One such example of this provides a working definition of spirituality adopted by this study. It comes from the Spirituality Task Force of the European Association for Palliative Care and represents their consensus opinion:

> Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred. The spiritual field is multidimensional:
> 1. Existential challenges (e.g. questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy).
> 2. Value based considerations and attitudes (what is most important for each person, such as relations to oneself, family,

friends, work, things nature, art and culture, ethics and morals, and life itself).

3. Religious considerations and foundations (faith, beliefs and practices, the relationship with God or the ultimate).[77]

Conclusion

Attempts to understand and describe religion and spirituality are a fraught exercise constrained by methodological constructs, practical limitations of enquiry and uncertain interpretations. It is also a contested field given the political, moral and social implications of religious belief and practice.[78] In summary, the evidence shows that religion and spirituality are highly prevalent in Britain although manifest in a wide variety of forms. Many people identify themselves with some form of Christianity or other mainstream religion, and many believe in some form of God. But there are also a significant number of people, often in the penumbra of existing social research, who hold beliefs and claim identities that do not fit easily within existing predetermined descriptors.

Religion and spirituality can neither be understood, nor interpreted, as plain terms but require careful handling as polysemous categories. Behind the definable surface of a category lie many confounding variables, nuances and sensitivities, and in addition there are the contexts and histories in which people are embedded and entangled. One of the weaknesses of this chapter is that is has chosen to ignore the subjective accounts of religion and spirituality present in qualitative research and narrative accounts. The richness and individuality of these accounts gives human form to religious and spiritual beliefs and practices and demonstrate the meaning of such beliefs in human lives. The next chapter

will therefore turn to the published empirical studies that aim to understand what spirituality might mean to patients in palliative care.

Chapter 3

A Critical Review of the Literature

Introduction

The practice of palliative care and the specialty of palliative medicine emerged from the modern hospice movement and its foundational philosophy of treating the whole person. This holistic approach recognised that the needs of dying patients were complex and multifaceted and therefore required going beyond a conventional biomedical understanding of disease and its treatment. One of the most influential concepts supporting this wider view of the dying person was that of 'total pain',[79] developed by Cicely Saunders (the founder of the modern hospice movement) which embraced the physical, mental, social and spiritual problems of a patient.[80] This integrated multidimensional ontology became pervasive in palliative care and remains a normative philosophy evident in the descriptors and definitions of learned societies and professional bodies,[81, 82] national policies and strategies,[83, 84] and major texts on the practice of palliative care.[85, 86]

Saunders approach was rooted in her Christian faith and developed during a period in which the modern Christian ecumenical movement was flowering. Spiritual care in this historical context was therefore strongly related to exercising a Christian vocation in serving human need.[87] The contemporary context is different again with a decline (in Western Europe) in the influence of traditional forms of Christianity and the emergence of new forms of religion and spirituality.[32] Consequently current discourses and practices in the spiritual dimension of palliative

care have tended to shift away from socially oriented religious faiths and a vocational ethos of care towards subjective forms of belief, the personal search for meaning and wholeness, and the professionalization of care.[88, 89]

Despite the unfolding etymology of "spirituality" it persists as a prominent term and signifier within palliative care literature,[90-92] enquiry[93, 94] and guidance.[95, 96] Whilst there is general acceptance of spirituality it has been criticised in terms of its purported universal utility and validity,[97, 98] its confusion with existential issues,[99, 100] its dis-embedded relationship to traditional communities of practice,[101] and its implicit ambiguity and imprecision.[102] Consequently attempts have been made to construct descriptive models,[103, 104] and achieve greater definitional clarity and nuance in terminology.[105, 106] More specific has been the pursuit of valid and reliable instruments to measure spirituality. One of the earliest from the 1980s was a scale to measure spiritual wellbeing[107] and since then a raft of scales and subscales have been developed.[108, 109] Many of these were not developed specifically for palliative care but are considered relevant[110] and a subset assess aspects of quality of life and wellbeing related to spirituality.[111, 112] Spirituality instruments also allow for relational studies between spiritual variables and measures of other factors including coping,[113, 114] despair[115] and depression.[116, 117] Research to date is relatively undeveloped in this field and studies often throw more light on conceptual and methodological issues than produce reliable data that can be synthesized and translated into clinical practice.[118, 119]

There is currently insufficient and coherent primary research data to support the systematic review of spiritual interventions in palliative care, although a Cochrane Review of spiritual and religious interventions for

well-being of adults in the terminal phase of disease includes five Randomised Control Trials, and reports that there is inconclusive evidence of the impact of these interventions on wellbeing.[120] However, a small number of systematic literature reviews have been published that report on the state of research into spirituality in palliative care,[121, 122] provide a thematic and conceptual analysis,[123, 124] and present evidence of the concepts, tools and models that support spiritual care in practice.[125] There is only one literature review to date that has attempted a meta-data analysis and synthesis: in this case an a sociological meta-study of 19 qualitative studies using an ethnographic method.[126]

The purpose of the following literature review was to critically examine the data on the spiritual needs of palliative care patients available in published empirical studies. Expert opinion, healthcare professionals and caregivers are used in some studies to speak on behalf of patients[127] or the distinctive perspective of the patient is subsumed within a larger data set or analysis and combined with data from carers and healthcare professionals.[126] This review focussed on studies that contain data derived directly from patients and not represented solely by proxies. There is an extant analysis from 2006 of the qualitative literature on the spirituality of adults at the end of life[128] but this review has included studies using quantitative and mixed methods as well as literature from the intervening four years.

Method

The objective of this study was to identify published literature that reports evidence of the spiritual needs of palliative care patients. The search strategy was based upon online bibliographic sources supplemented by a wider search of the grey literature, reference lists of landmark papers,

topic-specific editions of journals, selected subject-specific journals and the advice of colleagues. Bibliographic sources included specialist academic databases and the search engine *Google Scholar* was used as an adjunct to the other sources with the anticipation that it may retrieve references beyond the biomedical corpus and conventional publications.[129-131]

Inclusion and Exclusion Criteria

The population being studied was adult patients whose disease was not responsive to curative treatment. Studies were therefore included of patients with advanced and end-stage chronic disease reporting primary empirical research data of the spiritual needs of patients either derived from qualitative methods (e.g. narrative interviews), through quantitative methods (e.g. measurement tools) or mixed methods. Literature was excluded that did not contain empirical data including expert opinion, the results of focus groups of professionals and/or caregivers, commentary and personal reflections. Specifically literature that only used a proxy for the patient (e.g. a caregiver) and literature about the spiritual needs of professionals and caregivers was excluded.

Search terms

The databases and search engines accessed do not share a consistent method of running a search enquiry and therefore a specific set of terms had to be developed for the search of a particular source. Most databases have some form of controlled vocabulary to describe subjects and subject headings but these are not consistent. The search strings developed for each literature source are set out in Table 6. The intention at this stage in the search was to achieve an inclusive definition and filter out literature in subsequent stages.

Source	Search string
AMED	spirituality AND palliative care
ATLA	Keywords: spiritual* AND palliative (mp=abstract, title, series, related work title, heading words, formatted contents note, note)
CINAHL	Spirituality (Word in Major Subject Heading) AND Palliative Care (Word in Major Subject Heading)
COPAC	Spirituality AND palliative care
Google Scholar	"palliative care" intitle:spirituality
NHS Evidence	"palliative care" AND spirituality
PsychINFO	spirituality AND palliative care
PubMed	Spirituality (MeSH Major Topic) AND Palliative Care (MeSH Major Topic)

Table 6: Search strings for specific literature sources

Screening of Literature

All literature identified was subject to a first stage screening that used the title, and where available, the abstract or synopsis of the work so that it could be assessed for eligibility against the inclusion criteria. Many of the searches, for example, identified a significant number of studies involving staff or caregivers as a proxy for patients that were not eligible for the selection. Supplementary findings were also identified at this stage mainly from subsequent citations. The resulting literature was then retrieved and the full paper, book or thesis read and subjected to a second stage screen against the inclusion and exclusion criteria (Figure 1).

Appraisal of the literature

Literature included in this study was critically appraised with the objective of evaluating the quality of the studies and the strength of the evidence reported to determine if any of the data could be pooled for meta-synthesis and meta-analysis. The quality of a study typically refers to the rigour of the research and validity of results, with methodological

quality defined as "the extent to which a study's design, conduct, and analysis has minimized selection, measurement, and confounding biases."[132] Studies in spirituality and palliative care span the natural and social sciences and therefore validity in some studies (for example those using narrative methods) may refer more to the congruity between the experience of participants being investigated, its representation in the findings of the study, and the way conclusions are substantiated.

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┌─────────────────────────┐
│   Search question +     │
│ inclusion/exclusion     │
│       criteria          │
└─────────────────────────┘
            │
            ▼
┌─────────────────────────┐
│   Search engines +      │
│ bibliographic databases │
└─────────────────────────┘
            │
            ▼
┌─────────────────────────┐      Number of studies
│  Identified literature  │   = 882 (including duplicates)
└─────────────────────────┘
            │
            ▼
┌─────────────────────────┐
│    1st stage screen     │      = 76
└─────────────────────────┘
            │
            ▼
┌─────────────────────────┐
│   Supplementary finds   │      + 14
└─────────────────────────┘
            │
            ▼
┌─────────────────────────┐
│    2nd stage screen     │      = 39
└─────────────────────────┘
```
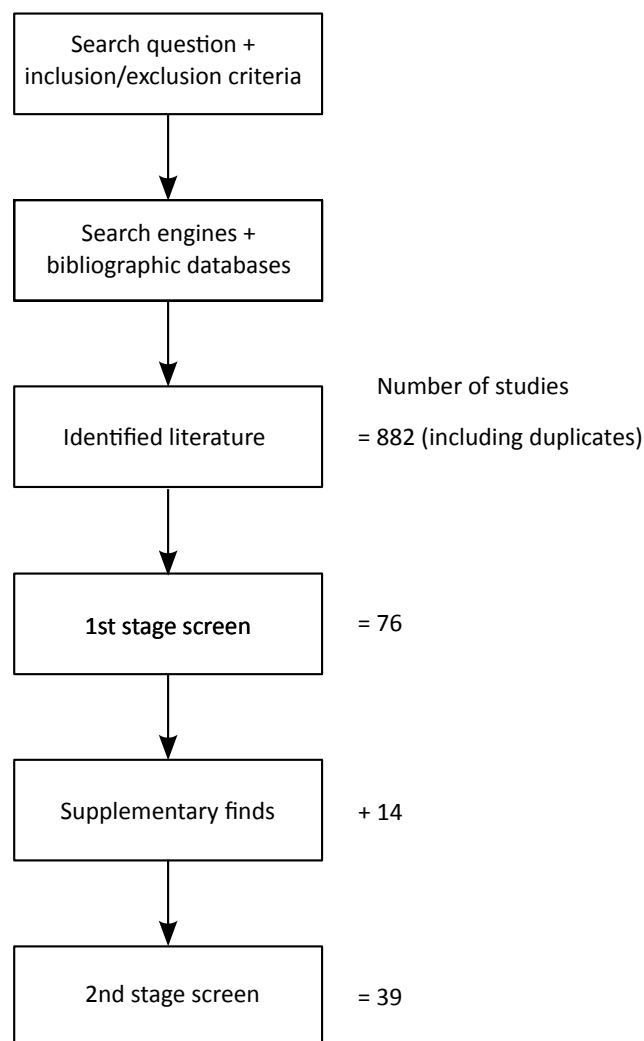
Figure 1: Literature screening process

Evidence is defined in this study as the explicit empirical findings derived from a planned and systematic process of enquiry. The strength of evidence is related to its application (e.g. practice guidelines) and the

level of certainty required for this purpose.[133] Consequently nine criteria were derived from published evaluation frameworks and assessment criteria:[134-137] clarity of research aims; exposition of the main assumptions and concepts; justification and rationale for the study design; description of context and population; rigour of data collection; formulation of analysis (described and constructed); derivation and interpretation of findings from data; extent to which its findings can be generalised to similar population, and reflexivity of the account. MC evaluated the studies in this review against these criteria using a simple nine point system with one point being awarded per criterion where there was evidence of it in the published study.

Results

Characteristics and Morphology of the literature

39 studies survived the two-stage screening process (Appendix A) consisting of 38 studies published between 2000 and 2012 across 25 journals and one study published exclusively in a book.[138] Common reasons that literature was excluded were populations of non-palliative care patients, non-advanced disease (e.g. Karnofsky Performance Status >80[139]), correlational studies with no patient data, proxy reports of patients' spirituality through carers or healthcare professionals, and studies to validate the psychometric property of tools which did not report any data on patients' spiritual needs. The quality of the remaining 39 studies ranged from five to eight on a nine point scale with studies commonly failing to provide an exposition of their theoretical and conceptual backgrounds, not explaining how findings had been interpreted or not providing any reflexive considerations. No study made any claim that their data could be generalised beyond their particular

population and the strength of evidence was generally consistent with the restricted claims of the studies and their recommendations.

Four out of five studies were conducted in countries where English is an official language with just over two-thirds of the studies conducted in the USA or the UK (27 of 39). Study sizes ranged from case studies of one patient to a sample of 120 patients (mean=41) equating to a total 1,558 patients. Around three out of five of the studies (24 of 39) used qualitative methodologies for data collection such as semi-structured interviews, and the remaining studies used either quantitative (11 of 39) or mixed methods (4 of 39). The latter used a range of measures of spirituality including the Fetzer Institute Multidimensional Measure of Religiousness/Spirituality[140], Religious Coping: RCOPE[141], Spiritual Well-Being Scale: SWB[107], Functional Assessment of Chronic Illness Therapy Spiritual Well-being Scale: FACIT-Sp[142], the Ironson-Woods Spirituality/Religiousness Index[143], the Spiritual Needs Inventory: SNI[144] and the Daily Spiritual Experience Scale[145].

Content of literature
Studies commonly made positive assertions about the role of spirituality in palliative care and pointed to extant literature to justify their claims, for example "The beneficial effects of spirituality have been reported in numerous studies."[146] Most studies were designed to gather data that could be used to understand the spiritual needs of patients, improve patient assessments, develop interventions and improve outcomes. Research questions were therefore typically constructed around exploring the meaning and role of spirituality in the lives of patients[147] and the extent to which spiritual needs were met.[148] Studies that used quantitative methods addressed questions about the relationship of spirituality to various factors including depression[149], pain[150], quality of life[146]

distressing symptoms[151] and coping strategies.[152] Two studies had a particularly religious focus, one focussing on the religiosity of patients[153] and the other on the religious coping in relationship to an individual's image of God.[154]

The literature frequently used the term *spiritual* along with *religious*, often differentiating the two,[155] and sometimes conjoining them: "spirituality/religiosity".[152] There were a few examples of studies referring to *existential* aspects of spirituality.[148] It was unusual for the authors of studies to provide more than a brief explanation or background to how they were using this terminology but some included succinct literature reviews in the introduction to their studies.[156] Simple statements were the norm: "Spiritual care responds to both religious and humanistic needs by meeting the requirements of faith and the desire for an accompanying person to 'be there,' 'to listen' and 'to love.'"[157] However, some studies were designed to elucidate what patients understood by the terms and therefore did not pre-empt this with their own definitions.[158]

The demographics of the study populations were typically people over 60 years of age, English speaking, and with a religious affiliation to either Christianity or Judaism[159] reflecting the predominance of Anglo-American studies (69% of patients). More extensive reports of demographic characteristics were included in studies using quantitative methods where variables such as gender, socioeconomic status and educational achievement could be analysed as confounding variables.[146] One study for example examined differences in the use of spiritual coping between African American patients and their White counterparts with advanced cancer.[160] Socio-cultural and philosophical differences were

acknowledged in studies located in Japan, Taiwan and Hong Kong,[161] but there was only one study that addressed issues of sexual identity.[162]

Two-thirds of studies identified specific disease groups in their sample with 21 studies including patients with cancer (n=1,056), four studies including patients with congestive heart failure (n=190), two studies of patients with ALS (n=70), one study included patients with COPD and motor neurone disease, and there was one case study of a person with AIDS. The remaining studies provided no specific data on diagnostic categories and used generic terminology about their sample, such as patients who were seriously ill [163] or terminally ill [164], and one study describing their sample of patients as having "… a life-threatening diagnosis (with a usual prognosis of days to weeks) requiring aggressive symptom management and end of life care planning".[165] Where specific diagnostic data was provided some studies included related prognostic data such as the Eastern Cooperative Oncology Group (ECOG) Performance Scale,[166] Karnofsky Performance status [159] or the New York Heart Association level.[153] Co-morbidities were reported infrequently unless the study was designed to account for disease-related factors that might contribute to spiritual needs such as symptoms of pain, fatigue and constipation[151] and depression.[163]

Settings for the studies were hospitals, hospices and patient dwellings in the community with 19 studies including patients admitted to hospital, hospice or palliative care facilities. The data collection was typically synchronic, but some were diachronic (i.e. data accrued over time) to enable the patients' narratives to be built up over several sessions, and one study was longitudinal (i.e. repeated observation over time) as it aimed to examine how spirituality might change as people perceived the

end of their lives approaching.[149] Not all studies restricted their participants to patients, some combined patients and caregivers.[163] One paper explained that the most important relative to the patient was usually intensely involved in the life and care of the patient and that they may be able to provide information the patient was reluctant to disclose or unable to communicate because of impairment.[167] Another study reported that there was no difference between the spiritual experience of client and the caregiver.[156] Studies investigating spirituality exclusively from the perspective of healthcare professionals involved in palliative care practitioners were excluded from this review.

Primary findings of studies

The heterogeneous aims of the studies in this review resulted in a set of findings that were broadly coherent at the level of demonstrating that patients with advanced terminal diseases could describe and respond to questions and instruments intended to capture spiritual aspects of their experience. The data also provided evidence of sufficient weight and quality to support a general finding that there are patients in palliative care with spiritual needs for whom spiritual beliefs and practices are meaningful and active. At a more specific level results could be grouped in two types: firstly, studies that investigated the nature of spiritual experience, and secondly studies that examined the relationship of spirituality to other phenomena.

The first set of studies typically used interpretive qualitative methods to understand spiritual phenomenon in relation to patients' experience that generated synopses, themes and schema to describe their findings. An example was an enquiry using in-depth interviews of the spirituality of six terminally ill patients which resulted in ten emergent themes grouped into four categories: Communion with Self, Communion with Others,

Communion with Nature, and Communions with Higher Being.[168] Some studies reported patient narratives and provided commentary and interpretive explanation[169] while others developed their thematic interpretations into illustrative schemas[170] and proposed theoretical models.[138, 159] Several studies also aimed to explore how the patient understood the provision of spiritual care and the role of healthcare professionals. Patients reported that they wanted to discuss their religious beliefs with their doctor,[166] and doctors should acknowledge that spirituality and religion are important for many patients and should treat the subject with respect.[155] A study of hospice patients found a clear view that spiritual care should be integral to hospice services and is a legitimate activity for all healthcare professionals.[171] However, another study of hospice patients reported that none of the participants expressed a desire for healthcare workers to perform spiritual care interventions.[158]

The second set of studies were investigations of covariance between phenomena using quantitative or mixed methods. The relationship between spirituality, religious coping, and symptoms of distress was an example of this type of study that reported that "Negative religious coping (i.e., statements that suggested punishment or abandonment by God) in this group was positively associated with distress, confusion, depression, and negatively associated with physical and emotional well-being, as well as quality of life.".[151] Other covariant studies reported different relationships which cannot be amalgamated and must be listed individually: spirituality is more likely to be identified as an important source of "meaning in life" for palliative care patients when compared to a representative sample of the population;[172] belief in a non-personal (image of) God is a significant positive predictor for coping strategies in patients;[154] gender, years in education and place of residence but not

socio-economic status were each significant variables in relationship to spiritual needs;[146] spirituality or religion influenced treatment options and attitudes toward the dying process in patients with ALS;[173] the ethnicity and spirituality of cancer patients is related to preferences and actions near the end of life although these associations did not always reach statistically significance;[160] the longevity estimates of patients with chronic heart failure were related to changes in spirituality;[149] the quality of life of spirituality orientated patients is positively related to hospices with spirituality based policies;[152] and the characteristics of spiritual care providers were not linked to better outcomes, but some types of spiritual caregiving were correlated with greater satisfaction and perceived value.[163]

The design of studies remained largely within the bounds of conventional forms and methods in qualitative and quantitative research. One study included a five week period of participant observation on a hospice ward,[138] but the majority of designs relied upon semi-structured interviews, questionnaires and data collection instruments. Few authors offered reflexive accounts of how they were approaching the subject, the form of data collection or its impact on participants. A study to understand the perspectives of hospice patients on spiritual care reported that patients want to be known as individuals and did not want spiritual assessment to be a 'tick box' exercise.[171] The author of a case study of a man with multiple myeloma contested that measuring spiritual needs is a form of depersonalization and concluded that spiritual needs were substantially situational and biographical and therefore could only be met by someone with shared memories and in the context of longstanding and valued relationships, something therefore not possible for healthcare professionals.[174]

Discussion

In this review of research literature it is evident that when spirituality is scrutinised using social and scientific methods of research it yields empirical data that may contribute to clinical knowledge and practice. The majority of studies and their findings can be broadly classified as exploratory in that they investigated the lived experience of palliative care patients, described phenomena, inferred explanations and generated theoretical models. This extended to the investigation of potential contributory factors and the identification of causal relationships, for example between spirituality and quality of life. There were no explicit claims that the sample of participants were representative and therefore that findings could be generalized to similar populations, however this was sometimes implied in the concluding sections of the literature where the strength of evidence was extended beyond its original level of certainty. Findings were typically aimed at implications for palliative care practice but seldom were issues in knowledge translation between the study and a clinic discussed.

Many of the studies reviewed were designed around the practical and economical convenience of a local population, which in turn set a limitation recognised by most studies and leading to suggestions that further research is required across different palliative care populations. Demographic homogeneity was therefore a notable characteristic of studies some of which can be explained through the predominance of Anglo-American studies (leaving aside religious differences) and some may be related to the majority of studies using populations of patients with cancer, a disease with certain demographic characteristics. This could be an advantage in research terms because it suggests some similarity in the dying process.[167] Studies infrequently accounted for

socio-demographic variables including age and gender despite these being known as significant variables particularly in terms of religiosity.[175] Similarly many studies did not differentiate or categorise disease progression or attempt to account for death salience (with the exception of Park[149]) even though awareness of mortality was described as a motivator of spirituality. The lack of differentiation across socio-demographic, contextual and illness variables could result in a perception of similarity which in reality is absent to a significant degree. More importantly a gloss of coherence may obscure more specific differences to the ways in which spirituality is experienced, expressed and understood by patients that could result in spiritual care that is insensitive, biased or incapable of responding to diverse needs.

The very fact that there are studies of spirituality in palliative care points to a number of assumptions about the subject; primarily that the methods of enquiry allow for the possibility of metaphysics and can detect and describe the spirituality of individuals. The concept of spirituality employed in these studies generally went without much critical commentary. The implied assumption was that spirituality had the potential to be beneficial and it was exceptional for ethical considerations to be discussed beyond the role of professionals. Quantitative studies may be particularly prone to this assumption because complex phenomena are typically operationalized as small sets of variables, and variables as metrics are ethically neutral. Outside of the mainly irenic discourse of palliative care, scholars appear to be both less shy of debate, such as those attracted by the proliferation of prayer studies, [176] [177] and perhaps more realistic about potential negatives such as Pargament's wise caution that "Spirituality" is not a synonym for "goodness". [178(p.129)]

There remains a paucity of exposition on the ontological presuppositions of this research field of which these studies are no exception. Similarly, there is minimal discussion on the impact and limitations of social-scientific methods and analysis on the subject being studied, such that "What one finds is contingent upon what one looks for, and what one looks for is to some extent contingent upon what one expects to find.". [179] The treatment of spirituality in most of these studies is functionalist in that spirituality is conceived as something that may contribute to a health outcome or a personal benefit.[180] This approach has the reductive advantage of enabling categorical comparison and the possibility of establishing objective knowledge and associations with health-related outcomes. However, it is not apparent from much of this literature whether studying function can provide a sufficient account of spirituality in relation to healthcare or whether the theological and philosophical content, and socio-cultural context of spirituality are also required.

The study by van Laarhoven et al [154] was a unique example of an enquiry into the theological content of the beliefs of palliative care patients using a 14-item instrument that differentiates between three images of God: personal, non-personal, or an unknowable. It is notable that the research team included a member of a Faculty of Theology that has an established approach to empirical theology. Similarly there were few studies that acknowledged or accounted for the cultural inflections and contextual determinants of spirituality. For example in the only study from the two-thirds world[181] Mishra et al reported that 98% of their sample of palliative care patients declared belief in God but there was no discussion about the content of this belief given that the patients identified themselves as Hindu, Muslim and Sikh. This lack of contextual analysis and reflexivity on underlying structures and propositions may suggest that researchers

share a normative account of spirituality and a lingua-franca that is self evident or established. However, these studies neither explain nor question such assumptions. For example one of the Japanese studies aimed to explore patients' experiences of distress associated with spirituality, "…that is, with their feelings about the meaning and aim of life in this situation in which their personal existence was threatened.".[182] However the word *spiritual* is never used in the interviews, but the responses are interpreted within a spiritual framework. Stanworth alone presents an extensive discussion on the linguistics of spirituality and the use of non-religious language arguing that spirituality cannot be approached or understood using second order propositions but through "…metaphors that disclose, mediate and structure…" the reality of meaning for people who are dying. [163(p.97)]

Limitations of this review

This review of research literature has a number of significant limitations primarily related to the reliability and consistency of the terminology of spirituality, and secondly to the accuracy of inclusion criteria in determining studies of palliative care patients. The key search terms did not map consistently onto the sets of standardised vocabulary used to index bibliographic databases, and this is compounded for spirituality because it is a subject that is ill-defined and has an under-developed subject structure. The initial search returned 882 studies (including duplicates) suggesting that the terms used may have lacked sensitivity and specificity. Most of the literature identified and none of the screened literature was published before the year 2000. This is partly explained by the fact that the study of spirituality in health is a developing field and *spirituality* was not introduced as a MeSH term until 2002. Secondly, studies involving patients with advanced and end-stage conditions present more ethical and methodological challenges that are compounded by

explorations of spirituality. Researchers and ethics committees may therefore be still learning about good approaches to this subject, and funders may be wary of applications. The dominance of cancer-related studies in this review possibly reflects the historic focus of palliative care and it is only in more recent years that other terminal conditions, such as chronic heart failure and renal disease, have begun to be included within the practice and publications of palliative care. A further limitation is associated with screening the literature to ensure that the study populations fulfilled the palliative care inclusion criteria as this could result in a level of uncertainty when studies lacked necessary descriptors or clinical information. Finally, there may be a publication bias in the studies as there is no evidence in dissent in the generally positive view of spirituality in palliative care and it may be difficult to propose or publish studies that are not consistent with this apparent consensus.

Conclusion

The studies in this review provide accounts of what spirituality means for palliative care patients and evidence of how it operates in the lives of people with life-limiting disease. The results are substantially positive and beneficial thus confirming the place of spirituality in the holistic construct of palliative care. However, if we consider spirituality to be a major ontological category alongside physical, psychological and social dimensions of personhood then there are significant limitations to what can be learnt from 39 studies representing a total of 1,558 patients contained substantially within Anglo-American populations of similarity in terms of disease, age, religious background and general cultural context. If the literature included in this review is representative of the study of spirituality in palliative care patients then it is apparent at this time that we neither have a systematic knowledge or tightly structured

discourse but signs of the emergence of a developing body of research with a shared aim: to understand and address the spiritual needs of terminally-ill patients.

The prevalence of enquiries into the function of spirituality is a relevant approach in healthcare studies but it is unlikely to be sufficient. The reductive presentation of spirituality in many studies results from the type of methodologies used motivated by the challenges of making complex phenomena intelligible and producing explanatory and predictive knowledge. In the case of healthcare research there is an additional requirement to interpret and translate this knowledge to support evidence-based practice. Therefore a critical question for empirical studies into spirituality is to what extent they enlarge our understanding and increase epistemic access to the subject. The evidence constituted by these studies is limited by a range of factors including the scale of the research, the methodologies deployed and the unexamined assumptions upon which the research is based. Finally, most research is conducted by health professionals within healthcare communities who are clearly demarcated from disciplines and interpretive traditions of spirituality. Perhaps one of the unintended benefits of these studies is that they become a means for opening up inter-disciplinary dialogue, building shared understanding and providing a more complete account of how the spiritual needs of patients may be understood and supported.

Chapter 4
A Conceptual Model of Spirituality

The results of the literature review and the background contextual review of contemporary spirituality have provided the basis to reflect upon the ways in which spirituality is operationalized in palliative care both in clinical practice and research. From this deliberation, and drawing upon the wide-ranging discourses and studies of spirituality, a conceptual model will be proposed that will attempt to explain what constitutes the spirituality of patients and how it relates to what may be considered the internal and external reality of the person including mental phenomena (e.g. beliefs), personal and social experiences (e.g. illness), and practices and behaviours (e.g. meditation).

The purpose of this account is not to provide a comprehensive unifying theory of spirituality in the context of palliative care but rather an adequate account for the practical purposes of understanding and responding to the spiritual needs of patients. The model will therefore provide the conceptual apparatus and mechanisms missing from much of the current research and provide a conceptual platform upon which to develop methods of clinical assessment. If academics and clinicians do not articulate what they know about spirituality in the lives of patients and how they know it, or explain how and why palliative care should recognize and respond to spirituality, then attempts to develop knowledge and improve practice may be hindered.

One approach to this task is to adopt the strategy of the modeller who aims "…to gain understanding of a complex real-world system via an understanding of simpler, hypothetical system that resembles it in relevant respects."[183] Models are ideal representations of phenomena that illustrate a system's essential properties, functions and relationships. Constructing a model of spirituality enables us to go beyond the problematic epistemology of this term to open up a means of exploring how it might operate in a real-world context. The model provides a systematic way of discussing the features and characteristics of spirituality and enables its resemblance with empirical observations and practical knowledge to be tested.

One of the earliest models of spirituality developed for a healthcare context is that proposed by Farran and her colleagues who use a functional definition of spirituality operating through seven major dimensions such as belief and meaning, authority and guidance, and ritual and practice. These dimensions are set within a context of universal events and experiences (such as health, illness, pain and suffering), which provide the possibility for expanded or limited spiritual functioning and spiritual growth.[184] Models of spirituality have also been developed explicitly for palliative care. Kellehear's model is focussed on the need of patients to find meaning beyond their suffering through situational, moral–biographical, and religious transcendence.[103] Wright proposes an inclusive model of spirituality based on a synthesis of ideas that includes activities of 'transcending', 'connecting', 'finding meaning' and 'becoming' that operate through the dimensions of the self, others and the cosmos.[104]

These examples of spiritual models demonstrate some of the potential that these techniques may have for understanding the spirituality of patients and developing the practice of palliative care. They also illustrate some of the limitations evident in these examples that are substantially descriptive schemes, or descriptions of models, that rely largely on assertion and provide little in the way of explicit propositions, descriptive adequacy, causal reasoning or consideration of the wider context. There may remain methodological advantage here, but what is lacking is any substantive theoretical contribution or a conceptual model of the whole within which specific spiritual phenomenon and causes can be located and explained.

The method of model building to be adopted here is to construct and analyse a minimal abstract and indirect representation of the way that spirituality potentially operates in the life of a patient. It aims to achieve similarity with the real-world phenomenon reported in the literature that is associated with spirituality. The model will therefore aim to be an adequate representation of the significant features of spirituality within the palliative care context. This implies certain conditions must apply to the model such as the need to take account of progressive disease. The strategy of modelling therefore provides a method of theoretical investigation, which Weisberg argues happens in three stages:

> In the first stage, a theorist constructs a model. In the second, she analyzes, refines, and further articulates the properties and dynamics of the model. Finally, in the third stage, she assesses the relationship between the model and the world if such an assessment is appropriate. If the model is sufficiently similar to the world, then the analysis of the model is also, indirectly, an analysis of the properties of the real-world phenomenon.[185(p.208)]

The starting point for the proposed model is to set out the intended scope of the phenomenon of spirituality that will be explicated as the elements of the model are articulated. Spirituality, or the ways in which people relate to and seek an ultimate or sacred reality, is part of our mental, personal and social life: it is both experienced and expressed, it refers to both the tangible and the immaterial. In relation to palliative care spirituality narrates and interprets illness and dying: it is manifest in treatment decisions and in the experience of care, it provides a way of engaging with ultimate reality and facing mortality.

The physical world behind human experience is accessible to rational inquiry, and this should be pursued to develop a scientific understanding of the scientific questions about spiritual phenomena (such as the effect of prayer on the pain pathways). Spirituality also exists in a wider life-context: it has rich personal, social, cultural, historical textures that contribute to a holistic understanding and require other forms of enquiry, methods and explanations such as the theological or philosophical. Dupré considers how we understand human behaviour as a complex feature and capacity of human life and argues that, "Without in any way refusing the extraordinary range of knowledge that science has provided for us, there are subject matters that require a more synoptic and integrative vision than the analytic methods of science allow".[186(p.185)]

Spirituality is a complex feature and capacity of human life, and consequently a Synoptic Model of lived spirituality is proposed (Figure 2) based upon the key features of spirituality explored in Chapter 2. It aims to be realist in the sense that it includes both observable entities, such as practices and disease, and unobservable entities that purport to have causative effects, such as the abstract objects of belief and the content of

values. Where this model differs from others is that spirituality is a feature and capacity of the system as a whole in which people express and experience spirituality individually, through others and through 'objects' that effect and mediate spirituality in the world.
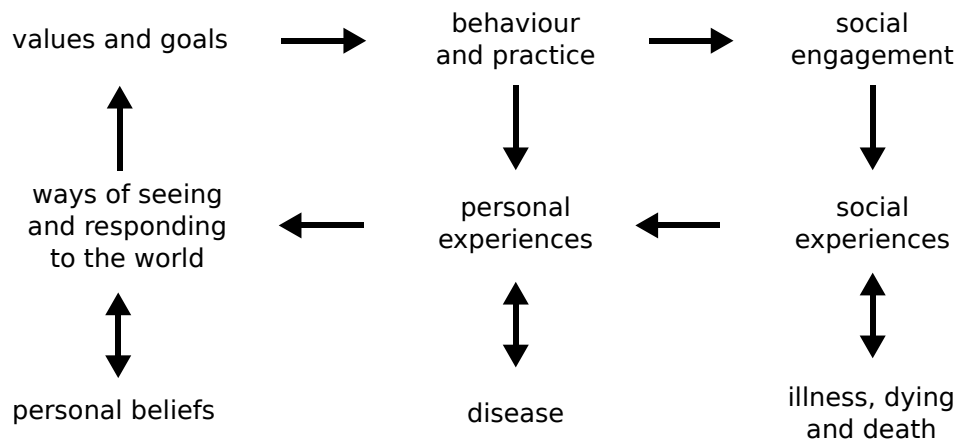
Figure 2: The Synoptic Model

The elements of the Synoptic Model

In what follows each element of the model will be given definitional content in terms of its properties and functions, and the connections between elements will be described. The Synoptic Model is a dynamic integrated system and therefore there is no start and end point. The following sequence in which the elements are explained is therefore a matter of convenience rather than a logical order.

Personal Beliefs

Beliefs are part of people's everyday lives and such is their ordinariness that they easily go unnoticed. Beliefs are seldom identified explicitly although they are manifest constantly in thinking, speaking and acting. Beliefs figure in the everyday ways in which people engage with the world: they shape people's understanding of this experience and orientate their response. Beliefs therefore help people to navigate the world by

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functioning as irreducible guiding commitments. To believe something, in the general sense, is to have conviction in the proposition to which it refers, to the extent that even if the circumstances never arise in which beliefs are acted upon and can be observed, they will still make a difference to a person's thoughts and disposition about these aspects of the world.

A distinguishing feature of beliefs is that they relate to things people classify as either true or false. Beliefs carry an implied claim to truth such that what we believe we consider true. When a person says that they believe the water is safe to drink we take it that the person accepts the proposition to be true and will drink it. A simple acceptance that something is true is insufficiently strong to be equated with belief. We may hold the idea that smoking causes cancer and continue smoking regardless of this thought, but if we believe this proposition then we are prepared to act as if it is true, which in this case would mean not smoking or trying to stop smoking. This direct causal relationship is lacking in the state of mind in which we hold ideas. Truth is a regulator of beliefs but it is sometimes a weak regulator, for example in wishful thinking. This does not mean there are varieties of truth and therefore varieties of correct beliefs, but the basis of some beliefs may not need to be as substantial because the interests we have in some belief propositions are less significant. For example the belief of a pregnant mother in the ability of her midwife is of a high degree of interest compared to the belief she has that her partner will look after the houseplants.

In order to hold a belief a person has to be capable of acquiring relevant information about the object of belief, and therefore a belief is conditional upon what a person can learn or comes to know. [187] The acquisition and

formation of beliefs is not simply a matter of intentionally inferring a true and warranted conclusion from what we count as evidence. There may be factual, evidential and epistemic grounds for arriving at certain beliefs, but beliefs are also formed through processes of cultural transmission, social interactions and practices, and through other perceptual, emotional and non-reflective experiences through which we come to know aspects of reality with a high certainty of truth.[188(pp.47-56)] Human beings do not need to put much effort into developing beliefs in general, as Steglich-Petersen has commented, "Many, in fact most, of people's beliefs are formed through subconscious processes of perception and inference which are not in any interesting sense controlled by the intentions of the subjects who have them." [189(p.502)]

People hold intuitive beliefs that are grounded in perceptions or inferred from those of others, and perceptions are generated from the basic human senses, prior information and knowledge of the world.[190] People therefore have the cognitive ability to form representations (or models) of the real world without conscious effort, but they also have meta-representational ability. Where people infer certainty, or creedal attitudes, from concepts beyond basic intuition these are termed reflective beliefs, and these are typical of religions.[191] However, the primary characteristic of religious beliefs is their content, or propositional object, which refers to nonphysical agents, of which a belief in God is a common example. A belief in God signifies an ultimate reality that transcends the natural world and is contingent upon a supernatural premise described variously as the sacred, the holy and the divine.

Some claim that there is substantial evidence that makes probable the existence of God, and without such evidence there is no reason to

believe. Natural laws and the millions of people who have experiences they attribute to God are such examples.[192] However, whilst a proposition about God may explain the evidence, a lack of evidence may not be a sufficient reason to disbelieve the existence of God. There are beliefs, such as free will, that cannot be conclusively demonstrated evidentially or through compelling argument alone but which are not irrational to hold. Similarly there is an epistemic warrant for a belief in God that does not rely exclusively or substantially upon evidence or argument.[193] A belief in the self does not depend on proof but it is a necessary presupposition to think and act and which provides meaning to life and enables individuals to make sense of the world. It is therefore a basic belief that is the source of other beliefs and it is therefore an absolute presupposition that we cannot get behind, test as a hypothesis or empirically verify. Similarly a belief in the existence of God for some is a basic or absolute presupposition from which other second-order beliefs are derived and made rational, such as miracles. This is why miracles to an atheist are irrational but the arguments used by an atheist are unlikely to convince the theist.[194]

Religious beliefs can be informed by propositional knowledge but more typically they relate to forms of practical knowledge and experiential knowledge. However, to hold a religious belief requires a conviction beyond a level of ordinary acceptance that is more like a profound trust or allegiance to a truth. This capacity is referred to as faith, and Bishop contends that the essence of faith involves more than the intentional deliberation of what the evidence shows to be true and is an active risk such that, "…faith involves *beliefs* which are held 'by faith', in the sense that holding them is an active venture which goes beyond – or even, perhaps, against – what can be established rationally on the basis of

evidence and argument.".[195(pp.471-472)] Consequently beliefs held by faith are never tentatively held, or the simple endorsement of propositions, but irrevocable truths to which people are committed and which orientate their perceptions, thoughts and actions.[196]

In his exploration of the psychology of religion William James considered that, "Were one asked to characterize the life of religion in the broadest and most general terms possible, one might say that it consists of the belief that there is an unseen order, and that our supreme good lies in harmoniously adjusting ourselves thereto. This belief and this adjustment are the religious attitude in the soul." .[197(p.41)] A belief in God therefore suggests a way of regarding the world or a stance that expresses something of how we intend to live in the world. [198] We can contrast the extent and impact of the religious life that James is referring to with the life of the devoted golfer who holds golf to be the most important thing in her life and organises her life around it as if it were a religion. Golf impacts upon people's lives in terms of commitments, skill and membership of a group, but it is difficult to see how the commitments required to play golf could extend into a way of regarding the world or to its possibility as a supreme good. Devoted golf players may risk hitting their ball into a bunker, but golf does not require a doxastic venture of faith about truths that give meaning and value to the whole of life.

Taylor proposes that contemporary religious faith is defined by a double criterion: "…the belief in transcendent reality, on one hand, and the connected aspiration to a transformation which goes beyond ordinary human flourishing on the other.". [33(p.510)] This latter quest refers to the spiritual life and its associated beliefs some of which tends towards immanent concerns. Whereas religious beliefs can be referenced to the

official creedal formularies of a faith community and its institutions, it is the personal experience of the subjective life that can validate spiritual beliefs. [29, 32] The point here is less about the label of the belief but the contemporary conditions for such beliefs that admits a plurality of forms and widens the gamut of beliefs to give as much space to the immanent as to the transcendent. This means that beliefs do not necessarily determine religious or spiritual identity or determine practices. For example a person may declare a Christian identity, not attend church, practice meditation and believe in reincarnation.

Finally, contemporary conditions for belief include secular philosophical responses to the questions of what it means to be human, how people can make sense of their lives, and how people should live their lives within a larger framework of existence and the universe. Nagel recognises that, "Existence is something tremendous, and day-to-day life, however indispensable, seems an insufficient response to it, a failure of consciousness."[199(p.6)] He sets out three main responses, and the first simply declares that there is nothing missing, the universe is meaningless and the bigger picture is one adequately described by the sciences. The second is humanism that proposes that we are part of a universal humanity that collectively is the source of value and meaning beyond the individual. The third response is a form of Platonism in which we are conscious of being part of a larger cosmic process that is intelligible and purposeful (though not designed). Nagel concludes that such questions cannot be avoided, [199(pp.7-17)] however, it may be that people in their everyday considerations of the meaning of life do not conform to the analytical demarcations of philosophers or theologians, and in reality they adopt a variety of responses depending upon their circumstances and needs.

Ways of seeing and responding to the world

Beliefs provide the cognitive background or propositional framework to the way we perceive and relate to the known world. Beliefs in this sense are representational metaphors and symbols that help us relate the internal and external realities that constitute human experience. Searle distinguishes the way beliefs establish a relation between our mind and the world from other forms of intentional states by observing the direction in which the propositional content is matched to the reality it represents:

> Beliefs, perceptions, and memories have the mind-to-world direction of fit, because their aim is to represent how things are; desires and intentions have the world-to-mind direction of fit because their aim is to represent not how things are but how we would like them to be or how we plan to make them be. [200(p.102)]

In this model the "seeing and responding" component is a critical interface or place of transference where experiences are interpreted and intentions determined through beliefs. It is therefore more than the part of the system for perception or conscious awareness, but is intended to represent where lived experience based upon these elements is interpreted and made sense of within a system of beliefs and a personal and social context. This construction of reality is evident in the ways in which we create narratives of our lives through which we structure personal experience and incorporate it into our continuing biographies, the social narratives that we participate in, and the cultural traditions of shared meaning and beliefs.

The narrative that derives from the interplay between the empirical world and our personal experience provides an historical basis for our current and future identity and sense of self. The telling ourselves and others of

our story thus creates a personal reality, and establishes not only where we are now, and where we have come from, but also what is possible for the future. Thus Bruner argues that "...the ways of telling and the ways of conceptualizing that go with them become so habitual that they finally become recipes for structuring experience itself, for laying down routes into memory, for not only guiding the life narrative up to the present but directing it into the future." [201]

Ways of seeing and responding to the world involve perceptions, beliefs, and both conscious and unconscious processes. These have been investigated in relation to cognitive and behavioural procedures that are prompted by health events and which result in health-related habits. In particular self-regulation models of health take account of illness representations (constructed from the external reality of somatic changes, experiences of healthcare and the social and cultural forms of illness representations) and self representations (constructed from the internal reality of perceived vulnerability to disease and acquired health beliefs).[202] This illustrates how this element of the model is a necessary interface where external stimuli, and salient experience, perceptions, beliefs and representations are processed and made sense of in ways that can determine goals and behaviours.[203]

Spiritual traditions and religions have their own representations of humanity and of illness that may become salient when a person is diagnosed with a terminal condition. These may be representations already active, or they could be latent representations re-appraised as a result of illness. Patients may also be prompted to explore and seek new spiritual representations as a result of their illness. There is evidence that people use religious and spiritual cognitions and behaviours in coping

with and adapting to an illness, and this appears to be particularly relevant when it is life limiting,[113] and can include seeking and experiencing God, and participating in ritual.[204] Spirituality, as a way of understanding and responding to the world, can therefore provide a resource for making sense of and interpreting illness, dying and death. This in turn may moderate a patient's treatment and care planning goals, and have physical, psychological and social consequences:

> Individuals' beliefs and goals are often pervasively influenced by dimensions of their religiousness and spirituality; these beliefs and goals, and the values and purposes and decisions that follow, likely influence health and wellbeing on multiple levels and through multiple pathways. In particular, individuals' ways of dealing with life's stressors, large and small, as well as their general orientation towards life (e.g., optimism, hope, compassion) would be expected to have long-reaching effects on both mental health and physical health across time. [205(p.328)]

Value and goals

Narratives that help us to make sense of our lives and experiences are diachronic and provide the necessary continuity to relate the past, present and future. The narrative possibility of the future enables us to move forwards in expectation and hope. This movement is guided by goals that plot the course to a future state and provide it with connection with the current state. The goal maybe familiar or it may describe a state or object that has not been encountered before and requires searching out or exploring. A goal is therefore a commitment to discover or arrive in particular place or state, and it therefore provides the basis to act and the purpose and meaning of those actions. It is to be expected that our goal-directed actions are for some end, even if this is simply to achieve

forward movement, and that this end may contribute to or result in something of value. In other words our goals can align to our values, and values provide a moral orientation to our actions and hence our goals. The values we hold, and in particular our basic moral values, provide a point of reference to evaluate particular actions, and hence provide a reason to take one course of action over another (an ethical reason).

Values provide a basis for our convictions and dispositions that enable us to operate in the world consistently in ethical terms. Values signpost the practical consequences that our beliefs imply and enable us to decide and act without lengthy introspection or deliberation. We therefore exercise and replicate our values in our actions, and our lives express the character of our values. Actions are not solely determined by our values, but if values are ethically substantial then they will have a certain priority.[188] Where people hold spiritual and religious beliefs these will be expressed in their values and goals, indicating an orientation to the world in terms of their intentions and commitments.

The question of what has value for a person is intended to indicate more than a matter of everyday preferences, desires or those things that satisfy an appetite. Value in this model refers to peoples' critical interests in living well and their striving for a good life.[206(pp.195-199)] These are substantive, or what might be termed ultimate values that matter to human wellbeing. Griffin, for example, argues that it is prudential values that give life a point and a purpose, makes it worthwhile and gives it substance, such as liberty and autonomy: "Choosing one's own course through life, making something out of it according to one's lights, is at the heart of what it is to lead a human existence. And we value what makes life human, over and above what makes it happy."[207(p.67)] Ultimate values

therefore are necessary for the teleological nature of life as they orientate people and point then to their life-goals and destinations.

Religions promote substantive values related to their beliefs systems that generate commitments that shape the way people live their lives: "Religion is a practical discipline, and its insights are not derived from abstract speculation but from spiritual exercises and a dedicated lifestyle." [208(p.305)] In theistic religions, for example, the supreme value is that of God and to believe in God is to live a life orientated to a transcendent purposeful reality.[209] Buddhism is a practise orientated around the Noble Truths that values wisdom and moral action.[210] Beyond the values associated with faith traditions and belief systems there are values that can do similar collective work in society, but without reference to any metaphysical claims. These are the values generated by sacred forms and symbols, such as human rights and nationalism, and which Lynch defines as: "… what people collectively experience as absolute, non-contingent realities which present normative claims over the meanings and conduct of social life." [38(p.47)]

It may be that values of this nature come to the fore when life is limited and existence is challenged by illness. Agency and autonomy may be compromised by physiological decline, planned for goals become unachievable with a limited prognosis, and the pleasures that can enrich life are diluted and diminished by intrusive symptoms and existential concerns. Two dependent values in particular seem relevant to palliative care, that of life and death. The intrinsic and relational properties of human beings give people a full and equal moral status [211] that creates an obligation of care towards the dying and places worth and value on living until death. Death completes life and it can have value for some in the

way it throws life into stark relief, or because it may resolves the torments of dying:

> Death is fundamental to life, it is a critical determinant of human existence, and it bears a profound significance because it marks the end of what we value as intrinsically precious... Death matters not just because of the oblivion or salvation it may signal, but also because it is the end of everything we have known and lived.[212(p.49)]

Behaviour and practice

We manifest our intentional goals and articulate our values through being embodied and involved in the world. We make contact with this external reality through physical and social interfaces that come into play when we practically and psychologically interact with the world through movement, speech and the individual and social practices we have developed over many years as persons. Structured or organised practice, patterned on past experience, can be considered as what defines behaviour, and behaviours as particular forms of practice attract social endorsement or censure that are context dependent. The Muslim prayer ritual of *salat* is normative behaviour in a mosque but on a hospital ward may be considered more problematic.

The 'natural' world requires certain practices without which we would not survive: for example fleeing from predators and avoiding jumping from great heights. Similarly the social world permits (or encourages) behaviours that build up the common good and contribute to the group. Practices and behaviours (as the name of the former implies) are rarely spontaneous and not only emerge from prior attempts and mastery, practical knowledge and physical capabilities but are motivated by commitments, inclinations and dispositions. In other words some of our

behaviours and practices are a necessary means to achieve our goals and are therefore related to our beliefs. This is evident in practices such as prayer that have a spiritual motivation and purpose that require a commitment to a transcendent reality.

Human activity is the way that people express their concerns and commitments in the world and exercise a physical relationship between their interiority and the external reality of life. This is a dialectical process between self and the world that both situates the self within a larger context and distinguishes the self from the objects it encounters. Archer argues that it is this independence of the world that gives direction to human action and enables that which is outside of the self to be discovered:

> Consciousness is therefore essentially a lived involvement in a series of concrete situations. Progressive differentiation between the two entail practical action and such action always involves work, which is undertaken in the interests of our natural needs. Praxis is, as it were, a personal technology which transforms the world in conformity with anterior human needs.[213(p.131)]

Spiritual practices are also ways of being involved and discovering a spiritual reality that thought alone cannot accomplish. These may be routine practices or disciplines, such as reading holy scriptures or meditating, that have become integrated into the pattern of someone's life, or they may be behaviours premised on spiritual beliefs and traditions that are manifest in dispositions, attitudes and personal ethics. Behaviour and practice result in lived experience, and where this action is directed towards the spiritual it can affirm beliefs and enable encounters with the numinous or the divine. Acting in the world is also the way that people

register and experience their existence, and when this is threatened through disease it may intensify the need for behaviours and practices (secular, spiritual or religious) that affirm the meaning and value of life,[70] and prompt ways of preparing for death.

Personal Experience

As actors on the world's stage we both impact upon this external reality and feel it acting upon us. Engaging with the world results in a personal experience in the form of knowledge, emotion or sensation. This feedback is most obvious when we engage with the empirical world and are subject to Newton's laws of motion, however we may also experience indirect feedback. A great work of art for example may not only cause us to be (physically) rooted to the spot but it can affect us physiologically and challenge the way we understand the world. The cultural world is made up of such objects, symbols and sounds that are deeply rooted in human experience and 'speak' to us, move us and enrich our lives.

We also have experiences that are not related to specific physical objects but to events, circumstances and situations that rely not simply on direct physical stimuli but on intuitions and perceptions. A walker may suddenly experience a sense of awe in reaching the top of hill and looking back over a magnificent view. A soldier may experience a sense of solidarity with colleagues when they accomplish a difficult mission. A listener to a Bach fugue may experience a state of transcendence and be moved beyond the immediate and personal. Similarly a spiritual experience, such as the sense of the numinous, may result from the meaning or significance of a particular place, symbol or event. For an experience to be considered spiritual the person requires a belief in a transcendent (ultimate) reality. The belief is not necessary a priori but such a leap of faith may be required post hoc to make sense of the experience. Thus experience can

initiate a belief, corroborate it and also be the grounds for its revision: most beliefs are not immune from doubt.

Experience comes from a situation taken as a whole and not purely any sense of a distinct objective reality. The entirety of a situation is physical, social, cultural, visual, psychological and so forth, and this constitutes the primary quality of experience from which emerge not only objects but meanings, emotions and sensations. [214(pp.69-78)] The extent to which an experience is counted as spiritual or religious is determined more by the self-description of the subject of the experience than by its characteristics. However, aware of this caveat, there are some general characteristics, particularly of intrinsic religious experiences, that are evident in texts, poems and other literary works that draw upon such experience and involve at least one the following factors:

> …the sense of the presence or activity of a non-physical holy being or power; apprehensions of an 'ultimate reality' beyond the mundane world of physical bodies, physical processes, and narrow centres of consciousness; and the sense of achievement of (or being on the way to) man's *summum bonum*, an ultimate bliss, liberation, salvation, or 'true self' which is not attainable through the things of 'this world'.[215(pp.30-31)]

Social Engagement

We interact with one another and with the wider social world of communities, institutions and the plethora of social entities constituted by objects and persons. We also express our commitments and affiliations with other people and participate in social groups out of self-interest and personal necessity. There are also certain functions and powers (often associated with important values) that we agree collectively should by

assigned to particular social entities as we consider that these functions and powers are best promoted (or only possible through) organisations and institutions rather than through individuals.[216] Justice and taxes are examples where the majority of people attribute and in turn recognise the power of the courts and the government. Consequently our practice and behaviours are moderated through the groups and institutions we engage with by the opportunities they provide, the obligations they impose and the values and behaviour they structure and promote:

> Most of what we do in everyday life is mercifully free and
> reversible. But when actions touch important issues and salient
> values or when they are embedded in networks of
> interdependence, options are more limited. Institutionalization
> constrains conduct in two main ways: by bringing it within a
> normative order, and by making it hostage to its own history.
> [217(p.232)]

Engaging with these institutions requires that accept and endorse these functions and powers, and that we orientate our practices to those that are codified or socialised by the institution. Attending an outpatient clinic may provide an opportunity to improve my health but I have to recognise the power of the hospital with respect to the appointment and the doctor who will see me whilst ensuring I arrive at the appointed time and provide the information required. The social involvement we have with the wider world therefore involves regulated relationships constituted by normative orders exercised by social entities.

Religious institutions are social entities that promote spiritual values, structure and normalise spiritual experiences, and have assigned social functions and powers to perform certain acts (for example rites of

passage). A particular mechanism of social engagement associated with religions (though by no means confined to them) is that of ritual, which has been described as "… the social act basic to humanity." [218(p.31)] Rituals involve people as participants, require performance, and are often distinguished from ordinary behaviours and actions by what they signify and the meaning they communicate. Religious rituals, for example, enact and manifest the meaning of the sacred and the Holy, and through their performance enable participants to experience this meaning. As a social act, rituals establish shared meaning, foster belonging and bridge the boundary between the personal and the social.

Social Experiences

In the company of others in similar circumstances, exposed to similar stimuli or situations, or as participants in the same event, we have experiences that are not possible in isolation as individuals. The social and psychological dynamics and interactions of a group that we are involved with provide interpersonal and collective conditions that socialise experience. In addition the social is enmeshed in a wider cultural context that influences experience through shared language, symbolic meaning, beliefs and traditions (conventionally promoted by institutions). Social experiences are not therefore simply what occur in a group but result from the interplay of social realities and practices, and the possibilities and perspectives that they enable.

The social narratives formed through these experiences in turn provide us with ways to make sense of our personal experience: a bigger story within which to locate our own. Thus social experiences and the wider cultural traditions that they relate to can inform and frame what is experienced and understood by the individual and shape a sense of identity. In terms

of religious experience it is authoritative traditions that conventionally validate personal experience:

> Religious experience is supportive evidence that we do engage an ultimate reality. Religious pluralism is evidence that we frequently and perhaps typically make mistakes in attaching cognitive content to those experiences. We are wise to rely on vast wisdom traditions to structure our imaginations and to guide the way we describe our religious experiences. But religious pluralism shows that, at best, these traditions offer an engaging perspective on ultimate reality. As such, this perspective is true at its level, and often reliable for guiding life, but expressed in symbols that necessarily fail to refer with complete accuracy even as they successfully engage us with their logical objects. [219](p.85)

Disease

There are many ways in which the symptoms of ill health are described, interpreted and represented. "A man coughs; he spits blood; he has difficulty in breathing; his pulse is rapid and hard; his temperature is rising… Together, they form a disease, pleurisy." [220](p.146) It is the clinician, Foucault explains, who discovers the disease in the patient and through the process of pathological designation and description transforms (or reduces) a patient into an abstract disease. Despite the problematic nature of the terms the biological phenomena and physiological effects of disease are significant to a model of spirituality operating in the context of palliative care. Disease remains the critical factor that determines access to healthcare, treatment choices, medication, prognosis, and the attention of particular specialists. In summary, "Disease calls for actions by the medical profession towards identifying and treating the occurrence and caring for the person." [221](p.657)

It could be argued that disease plays a minor role in palliative care because it deals with patients whose disease are no longer curative and attends to the palliation of symptoms. However, it is difficult to imagine that the alleviation of symptoms could be achieved without knowledge of the underlying disease or its physiological consequences. Further, a disease may be significant to the patient with regard to what it may represent, in other words the disease as metaphor: "Any important disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance." [222(p.60)] This may include a spiritual significance, for example the onset of a disease may be associated with the suffering humankind endures when it fails to attain enlightenment.

Biomedicine alone is insufficient to provide care and support to people with a terminal disease, and it has been argued that, "palliative treatment should always be targeted at the disease as experienced by the patient or at the disease that is likely to be experienced by the patient…". [223(p.195)] In this subjective concept of a person's disease however there remains objective significance of the disease in the form of biological explanations, prognostic assumptions and treatment indicators. Disease in this model therefore, whilst problematic in definitional terms, may have more than one function of which an objective pathological status and a subjective significance may be the most relevant.

Illness, dying and death

Michael Mayne wrote during his treatment for terminal cancer that, "To treat a disease is to inhibit it and hopefully help the body to destroy or control it: to treat a patient is to observe, foster, nurture and listen to a life.".[224(p.236)] Medical anthropology and sociology oppose the physical reductionism of the standard biomedical model of disease by

differentiating illness as the experience of the patient, disease as the pathology classified by medicine, and sickness as the social significance of the illness for the person. Gabbay and Le May expand this triadic scheme further into a highly differentiated levels of constructs about illness and disease that include the abstract propositional knowledge associated with the term *disease* and, "…a person's knowledge, beliefs and experiences of their (or their charge's) clinical condition; 'the patient narrative'.",[225(p.185)] associated with the term *illness*.

The body is the nexus of illness, dying and death and it is the embodied self that experiences the physicality of a life-limiting condition and the personal and social consequences of progressive illness. If disease can be understood as a call to action then terminal illness may be considered a question about life's values and goals, and ultimately about the nature of existence and human destiny. This is more than a personal question because people live in dialogue with the world, and society reflects back its own understanding of illness and shapes how those living with illness can be in the world:

> …illness is not simply a problem in an isolated physiological body part, but a problem with the whole embodied person and her relationship to her environment. Because the lived body is not just the biological body but one's contextual being in the world, a disruption of bodily capacities has a significance that far exceed that of simple biological dysfunction… one's entire way of being in the world is altered.[226(p.73)]

If disease is a term that is hard to pin down, then it appears illness does not offer a less contested term, and dying remains a notoriously vague concept to define despite its obvious importance to practice.[227] Even what

determines the definition of death is not without controversy and contention.[228] In this model illness, dying and death are intended to be markers on a continuum between a living person and a lifeless corpse, and this element of the model is intended to represent the social constructions of life-limiting conditions, dying and death and the ways that society (including religious and healthcare institutions) interpret and socialise these realities. In other words the social and cultural context of a person with a terminal illness will inform and influence how it is understood, what it means and how it is explained. The social representations and constructs of illness, dying and death (including the theological and medical) therefore structure and order reality both for patients and clinicians and provide formative narratives of experience.

Death in this model refers to the end to life as anticipated by the palliative care patient. Mortality and impermanence are the concerns here rather than the consequences and experience of death by others. In her analysis of the literature Holloway identifies thirteen different recurring concepts of death, some of which are considered positive (for example, death as freedom), some are negative (for example, death as tragedy), and some are dialectical in conceiving of death as paradox or mystery.[229(pp.52-27)] The research evidence is equivocal on how significant the paradox of living with a terminal illness is to patients, but some assert that, "…the paradox of death awareness lies in its potential to be both psychologically paralyzing and instrumental in mobilizing a tenacious will to live.".[230(p.128)] Death is unequivocally a concern of spiritual traditions and the world's religions locate death within a wider horizon of meaning and present strategies to be reconciled with death.[231] These strategies are both practical, such as meditation or rituals, and symbolic in the ways in

which death is placed within a larger narrative about the world and the reality existence.

The dynamics of the model

The elements of the model are connected to each other through a set of directional arrows that indicate how each element is related to others. The dynamics indicated represent a movement from the internal world to the external world and then a return. This movement consists of two cycles: one that is personal and the other that extends out to the wider social and cultural world. In both cycles there is an impact related to the life-limiting condition. Disease (the clinical condition and its biological consequences) is experienced by the person through its effect on the body. Illness, dying and death (social discourse and practices) is experienced in the social interactions of the patient. The dynamics of the model are intended to represent the movement between the internal and external and account for, (a) the contexts and paradigms that shape and structure our experience, and (b) the beliefs, narratives and values by which we make sense of our experiences and navigate our way through the world.

If the model bears a reasonable resemblance to reality then spirituality is a multi-faceted construct that forms part of a dynamic intra-personal, inter-personal and social system. This suggests that a patient's spirituality is not simply an additional attribute but an indivisible and interactive property of the person: spirituality is expressed and shaped through the dimensions of personhood including the cognitive, experiential, practical and social dimensions. In respect of people living with terminal conditions this implies that the spiritual will become enmeshed in the experiences, meanings, narratives and beliefs about illness, dying and death that are

encountered in the person's social and cultural context. Part of this context is healthcare and the model suggests that the culture, practices, values and beliefs of healthcare services and clinicians will also impact (positively or negatively) on a patient's spirituality.

It is notable that this conceptual model differs from some of the representations of spirituality in palliative care that treat it as a potentially problematic symptom (such as its contribution to pain) or as a mono-dimensional personal need (such as the need for religious observance). A dynamic system approach to spirituality described in this model suggest ways in which palliative care may disrupt or dislocate a person's spirituality and the potential opportunities clinicians and services may have to understand, support and enhance the spirituality of patients. Consequently the model may have utility in helping us study spirituality in palliative care and may have the theoretical potential to be used as a predictive tool (*what* it does), or an explanatory tool (*why* it does it).

Limitations of conceptual models

Modelling is a particular approach to theorising that in this case is intended to have a certain utility. As a tool to represent and understanding spirituality in the context of palliative care it has undoubted appeal over other theoretical strategies such as a philosophical approach of reasoned argument or a theological approach of applied belief, tradition and practice but it is not without limitations. Models are not comprehensive, they contain essential elements to explain how a system functions but remain schematic; they emphasise some elements and exclude others. Models do not have direct counterparts in the real world: whilst there content refer to and resemble actual 'objects' we must not confuse what they aim to represent with their equivalent in our lived experiential world.

This is a mistake made by some researchers in this field where, for example, the score of a research instrument may be reported as a denoting a person's spirituality rather than being an abstract or indicator of it. However, comparisons between the abstract properties and structures of the model and the world can be attained where there is sufficient similarity between the behaviour and characteristics of properties in the model and the real world. These resemblances are necessary if the model is to serve a useful purpose such as helping us understand more about the phenomenon in question. Further where these resemblances tend toward fidelity (agreement or correspondence) with the real-world phenomenon the model may have a stronger explanatory or predictive function.

The functional content of the model should help explain how spirituality operates in patients' lives in ways that that can be verified by experience and subject to rational enquiry, including but not limited to analytic methods. The synoptic model can therefore provide perspective on the discrete studies that focus upon particular effects of spirituality and be a reminder of aspects of spirituality that remain neglected by researchers. In relation to palliative care the model helps inform practice by demonstrating the breadth of lived spirituality, expanding ways of understanding and supporting a patient's spirituality, and avoiding mistaking one aspect of a person's spirituality for the whole. Finally, the synoptic model enables the contribution of different disciplines and different ways of thinking. Palliative care should be capable of providing a hospitable space to alternative perspectives on spirituality including those of the arts and humanities; however, this approach may also expose the somewhat parochial precincts of palliative care to the healthy and sometimes robust debates that exists in other quarters about spirituality.

Methodology, Design & Methods

The aim of this study is to produce clinically and academically relevant research about spirituality in relation to the care of people with life-limiting conditions, and this depends upon the use and application of sound methodological principles. In Chapter 3 critical attention was paid to the state of existing knowledge on the subject and as a result a theoretical proposal was developed for the ways in which spirituality is experienced and expressed in the lives of patients: the Synoptic Model. In this chapter a methodological basis for empirical research will be described, and a study design and methods will be described to test to what extent the model is representative of the spirituality of patients.

Methodology

A study about spirituality based upon a model that includes observable and unobservable entities is faced with some basic philosophical issues on the way to adopt a methodology. We have already encountered in Chapter 2 some of the definitional challenges that face any account of spirituality, and behind these are the more philosophical questions of what kind of concept spirituality is and how spirituality fits into the ways we understand the fundamental nature of the world? Inevitably this brings us to a metaphysical question: whether what seems to be fundamental constituents of spirituality for many people, the transcendent and the supernatural, can be part of the world and our understanding of reality? Scientific methods may be sufficient to understand the empirical content or effects of these entities (such as behaviour related to the worship of a

god), but it seems reasonable to claim that there are aspects of spirituality empirically inaccessible to science because:

> … the features of the world described by metaphysics are not manipulable or testable the way the features of the world described by science are. There isn't the faintest glimmer of an idea of what sort of instrument (and much less of an idea of how to build one) we could use to detect the presence of numbers, or the presence of composition, or of necessity… [232](pp.17-18)

For Paul, and for other contemporary advocates of metaphysics, this is not a defence for metaphysics against any inconsistencies with scientific theories of the world and its derivative evidence, but it is to recognise that a metaphysical understanding of the world may involve properties and features of the world that cannot be supported by direct observation or physical manipulation, and hence the use of thought experiments, such as counterfactuals, as one technique to evaluate metaphysical claims. An alternative methodological strategy is to pursue a form of naturalism, where natural here means that which is studied and known by science, and which infers that the universe is constrained by a closed self-generating system without the possibility of the supernatural. Price however, describes this view as *object naturalism*, as it concerns the objects and properties that science deals in, a view that has no account, for example of meaning or value. The difficulty for Price and others is that, "Object naturalism gives science not just centre-stage but the whole stage, taking scientific knowledge to be the only knowledge there is (at least in some sense)." [233](p.22) However, there are other ways of being a naturalist and of responding to the challenge of making meaning out of the materiality of existence without reference to any external or supernatural content. Whilst there are loud advocates for a narrow

naturalism employed specifically with an anti-religionist intent, there are more nuanced naturalists who approach the mysteries of the universe with more reticence than volume. Flanagan exemplifies this latter view as he explores the spiritual tradition of Buddhism to see if any of it is useful and truthful, particularly in relation to human flourishing. He therefore seeks a form of Buddhism:

> …. that is compatible with the rest of knowledge as it now exists and specifically, because this is always a problem for spiritual traditions, whether Buddhism can be naturalized, tamed, made compatible with a philosophy that is empirically responsible, and that does not embrace low epistemic standards… [234(p.xiii)]

Buddhism is a spiritual tradition that has gained the interests of neuroscientists because of the mental states it aims to achieve, and Flanagan applies his epistemic standards as much to claims of neuroscience as to the philosophical version of Buddhism that he engages with. In science, epistemic standards are seen as relevant to the inferences of scientific theories, but the theories may contain unobservable entities with causal properties that result in known phenomena, for example the inferred existence of dark matter to account for the observations of the expanding universe. Consistency requires a metaphysical analogy and the possibility therefore of commitments to unobservable entities to explain our known phenomena. Thus the project of logical positivism to contain science to empirical discourse, according to Ladyman "…floundered in part because of the impossibility of making an explicit the observational basis for claims highly theoretical claims in science." [235(p.36)]

Realism in science is an epistemic commitment to what scientific theory infers about the world, but it stops short of endorsing the forms of

knowledge we acquire through everyday experience because it has no prima facie mind-independent objectivity. The fullest reality of the world exists to a large extent independently of any of us, but this does not prevent us knowing, referring and interacting with this. Rudder Baker claims that trying to distinguish what is real from what it not real on these terms is a futile project because the world is full of minds who act on the basis of commitments to practice. This is a common sense conception of reality of objects, artefacts and people that facilitates our lives and our encounters with the world, and it is this which Rudder Baker argues for inclusion in our understanding of the mind and of our beliefs. The dominant assumption about the mind, or what she refers to as the *Standard View*, claims all lived experiences are physically based and therefore can be explained by physics. The *Standard View* is problematic because it is premised on a commitment to a theory of materialism that rejects anything that does not fit the theory. The *Standard View* is in effect a theory about the comprehensiveness of science. Rudder Baker's alternative proposal is a practice-based theory, that she calls *Practical Realism,* which brings theory and practice into a form of reflective equilibrium and seeks a level of compatibility. In this approach practical knowledge, in contrast to systematized theoretical knowledge, is derived from everyday life and is recognised as a source of knowledge that has its own epistemic legitimacy because, "Practices are implicated in much of what is real, not just in our knowledge about it." This is the knowledge that supports human flourishing and enables us to live in a world of persons as well as particles, and it is realistic, "because it affirms the unvarnished truth of the language that partially constitutes successful practice.". [236(pp.20-22)] Practical realism does not therefore devalue, or assume as unreliable, the knowable reality of our everyday experience of the world. Science is a different way of knowing reality that is also partial,

and therefore, "It would be a senseless pruning of reality to confine cognition to science.". [236(p.224)] Scruton provides an example of this, the human smile, which we perceive and respond to as persons relating to one another, whereas in the book of science they are absent save for a physiological description of facial muscles. [237(p.95)] It is evident that some of the methodological tools at our disposal frequently ignore the unobservable or appeal to a materialist manoeuvre that claims a comprehensive physical explanation of everything is possible. That this is thought even possible relies to a large extent on the omission of aspects of humanity from the natural order or their collapse into the physical elements. This is not to suggest that the physical sciences and their use of reductionist strategies have not been productive and of immense benefit, particularly in relation to medicine, but it is to acknowledge their limits, and to allow for different forms of knowledge and different ways of understanding the world. Midgley articulates the point simply:

> We have begun to understand that the real world actually is complicated, and particularly that people in it are so. Because they are complex, we need to ask many kinds of question about them, not just one. To answer them, we need to use many different ways of thinking, and this is why we need to use many different disciplines. [238(p.50)]

Pain is an example of the need to use different ways of thinking to understand its reality. Neurophysiology is inadequate of itself to understand the experience and meaning of pain for the individual that is enmeshed in the person's socio-cultural context. It has therefore been argued that the reality of pain is neither in the subjective or objective dimensions but is created in their dialectic. [239] The reality of spirituality is similarly not simply an exercise in detective work in which there is a

discoverable objective reality 'out there', because spirituality is also entangled within the broader social and cultural contexts in which people experience, interpret and express their lives. This is the dynamic of spirituality that the Synoptic Model aims to capture and it requires different ways of thinking and asking questions about spirituality than just those of science. There are evidently observable aspects of spirituality that can be subject to empirical enquiry but practical realism also requires that we pay attention to the practical knowledge of what we may consider 'everyday spirituality', in other words that which is lived and experienced by people as part of their everyday lives, which is in contrast to the systematic knowledge of spirituality formulated in the official texts and practices of the organised spiritual traditions.

Realism has been a point of debate in theology in reference to the existence of God: whether there is an actual entity that our language of God refers to which is independent of our thinking about God (ontologically distinct) and whether this entity is transcendent and in some ways knowable (epistemically accessible). These two forms of reality, ontic and empiric, can be expressed in theoretical and practical keys, but from the everyday perspective (of practical realism) it can be argued that the ordinary reality of God is based upon the dialectic between cognitive commitment (belief) and existential experience.[240] It is likely therefore, that in a study investigating spirituality, we will encounter people for whom (a) reality includes God, (b) God is a cognitive norm usually within a confessional community with which they are associated, and (c) knowledge about God is acquired through individual and social experiences as well from codified propositional forms. The proposal that experience may yield knowledge of a transcendent reality is, in highly simplified terms, what interests much that is denominated as 'empirical

theology'[241], where the empirical is understood to be naturalistic, situational, and socially and historically dependent. Confessional communities and communities of practice are the interest of religious studies, but unlike theological disciplines they recognise the social reality of religion without the need for any metaphysical commitment:

> To be a realist about religion is to talk about religions as forms of life that exist in the world. It is to hold that religions have achieved the kind of intersubjective reality that, unlike my plan to visit my parents or my admiration of Michael Chabon's novels, they do not depend for their existence on what I think. [242(p.109)]

A final form of realism that we should consider in relation to the subject of spirituality is that of critical realism, a philosophy originally associated with Bhaskar and since developed and extended more widely.[243] Critical realism rejects positivist empiricism and has a clear ontological premise that there is a reality independent of the human mind and a socially and historically conditioned knowledge of reality. The empirical domain, from a critical realist perspective, is where we may experience the reality of events that are the consequence of causal mechanisms, and this presents opportunities for a critical understanding of contingent knowledge.[244] God's existence is a 'paradigm case' for some critical realists to test out the philosophical balance they hold between ontology, epistemology and rationality. This results in some methodological critique of the ways that spirituality and religion are studied, and most significantly in the ways in which the empirical can be privileged in these accounts. Firstly there are studies that consider the nature of spiritual experience without paying attention to the object of the experience[245], and secondly there are social studies of practice that neither engage with subjective experience of the transcendent or the metaphysical claims to which they relate:

In both science and religion, our beliefs are actually in dialogue with the world. Thus, methodologically to bracket the world is in essence to break apart a dialectical process and to examine only one element - the social element - in isolation… such a methodology renders it impossible from the start to understand either science or religion as anything other than a social construction. The social is the only token allowed on the board. [246(p.13)]

Summarising this methodological discussion in relation to the study of spirituality we can see that realism permits the claim that there can be a transcendent reality that is not directly observable but which may be inferred from everyday experiences of the spiritual and their implicit beliefs. The Synoptic Model is a theoretical proposal about spirituality and realism requires that this is testable, which means subject to empirical examination.[247(p.60)] The testability of the Synoptic Model will depend on the extent to which the elements of the model are adequately specified and can be expressed and operationalized in a valid and reliable research method. The purpose of this procedure is to enable the generation of data about spirituality in the lives of patients with palliative care needs from which to infer that the Synoptic Model can be confirmed, disconfirmed or extended.

Research Design & Methods

Designing a research study and choosing its constituent methods is rarely a simple linear process of assembling the necessary tasks and procedures into a coherent strategy that addresses the aims of the study. In this section the iterative process of research design will be described for the

study with specific explanations of the methods chosen for data generation, collection, analysis and interpretation.

Research Design

Designers remind us that design is reflective and iterative process that has been described using the four phases of exploration, creation, reflection and implementation.[248] Design does not begin by finding a solution, but commences with finding the problem through methods that explore and understand the situation and context. The generative phase of creation is solutions-focused and remains exploratory until the move to the reflective phase in which ideas and concepts are prototyped and tested. The prototypes and artefacts of design become in themselves ways of thinking by translating the abstract into a tangible form that allows us to explore and evaluate an idea. Finally, the tested and refined solution is committed to implementation, a planned process to introduce the design solution that is monitored, reviewed and evaluated. The phases can be fruitfully applied to research design to expand and elaborate a process beyond the short-circuited approach that is sometimes described as selecting a research method from a standardised menu in response to the aims and objectives of the research enquiry.

In the case of this study it was anticipated that the exploratory phase, which took the form of reflection on practice-based knowledge and a systematic literature review (see Chapter 3), would confirm the original research question that aimed to develop a clinical effective method to assess the spirituality of patients. The evidence trumped the expectation and prompted a redefinition of the problem of how we understand the spirituality of patients. This identified a deductive gap that suggested the need for theory building resulting in the theoretical proposal contained in

the Synoptic Model (see Chapter 4). The research design brief was therefore further refined to that of a deductive problem and refracted through the lens of a realist methodology. This formulation of the problem makes particular demands upon any proposed design solution, namely that the study must be empirically responsible, admit metaphysical claims to a transcendent reality, recognise that the experience of spirituality may have epistemic legitimacy, and be capable of capturing data resulting from the dialectical process between belief and the world. In addition to methodological considerations a significant factor in the ideation of viable research designs for this study was the participation of patients with advanced chronic disease. This introduced ethical and practical conditions that the study had to operate within such as the ability to schedule interviews outside of programmes of palliative treatment and supportive care, the uncertainty of the survival of patients with unstable symptoms and advanced disease progression, and the introduction of a subject likely to prompt patients to reflect on their life-limiting illness. Finally, pragmatic and regulatory conditions had to be introduced relating to the requirements of the study sites, research governance and the scrutiny of independent scientific and ethical reviews.

Developing a prototype study inevitably involves trade offs to satisfy the different conditions that the study has to operate within, achieve high standards of reliability and validity, and advance knowledge about spirituality in relation to palliative care patients. Maxwell, a methodological realist, suggests that research designs are the result of real phenomena of beliefs, goals, experience, ideas and a priori concepts which researchers need to be aware of and reflect upon. Research designs themselves are also real phenomena in the sense that when implemented they become manifest in actions and have causative effects. Consequently

Maxwell is critical of approaches to research design that address the tasks of the study without attending also to the structure of research. His solution is a non-linear model in which the components (of research questions, methods, goals, conceptual framework, and validity) relate to one another, and interact in the design process.[249(pp. 69-91)] This iterative approach was adopted in the design of this study where options, for example, in methods of data collection were weighed against the methodology of the study and the validity of the data it would produce. A pivotal issue in the study design related to the generation of data from which to make both descriptive and explanatory inferences about the reliability and validity of the Synoptic Model. This cannot be resolved without considering the potential burden of the data collection method in terms of both the content, response effort and time required of participants. A two-part design was adopted that aimed to balance data requirements with acceptability to patients and overall project feasibility (Figure 3). We assumed that a self-completed questionnaire might have wider acceptability than an interview alone, and given sufficient responses, provide data to select a representative sub-sample for interview.
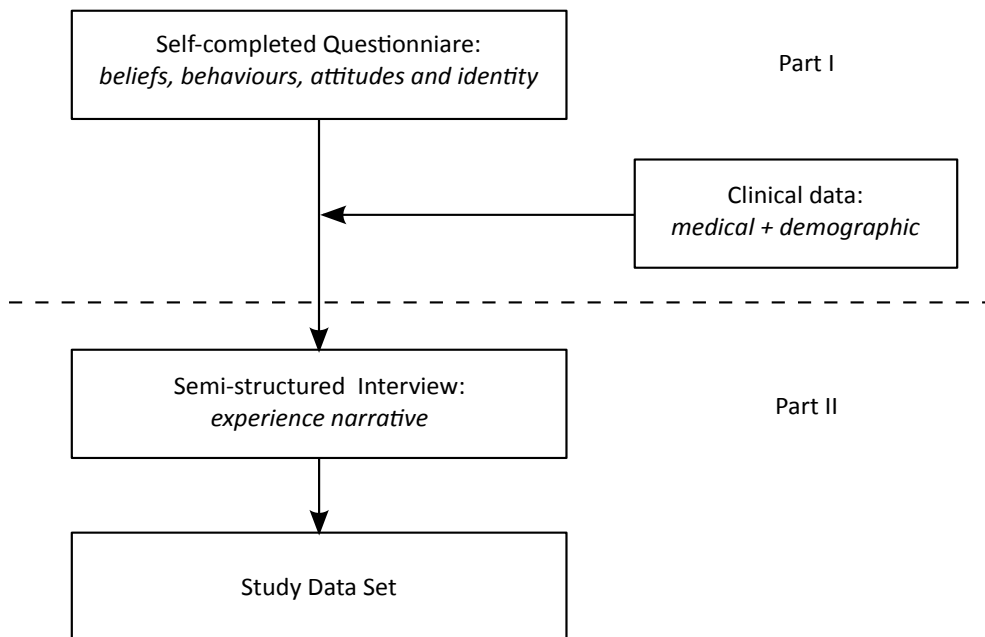
Figure 3: Two-part data collection scheme

At this stage in the design process, with sufficient information to explain how the study would work, a decision was taken to involve patients and their advocates with testing the prototype. Collaboration[250], co-production [251] and participation are strong themes in design and a request was made to have the prototype reviewed by Sheffield Palliative Care Studies Advisory Group, which consists of service users, carers and advocates of palliative and end-of-life care who provide feedback on the design and implementation of studies. A written overview of the study was submitted that explained the need for study, the study design, the recruitment process for patients, the time required of them, and the likely benefits of the study for patient care. In addition the Advisory Group asked if we had any specific questions that we would value their opinion on, and the following were submitted:

1. What sort information do you think would be helpful to people when deciding to take part in this study?

2. Do you think that people might have particular concerns about this study because it is about spirituality, and if so what do you think these concerns might be?

3. The questionnaire will be available in paper form and it will also be available online for people to complete if they use the internet. Do you think people might have particular questions about using an online questionnaire, and if so what might these be?

4. Should we offer the choice of an interview (a) in the person's own home, (b) over the telephone, or (c) over Skype?

The Advisory Group provided detailed feedback on the prototype design including points of clarification about the information on the study, comments on the timing of the approach to patients, and clear opinion on modes of interviewing that did not involve a researcher in the same room as the patient. In addition to practical matters relating to the study, the Advisory Group also emphasised that they felt that spirituality was a sensitive issue and that the study would be presented to patients at a time when faith was being tested and may change. These characteristics of the study were known and had been accounted for, but the feedback prompted a redrafting of patient information and a review of computer-based data collection methods and related electronic data systems. Primary data collection is a significant component of the study design and again requires trade offs in terms of the chosen technology. For example paper is highly effective technology, is an inexpensive and easily understood media for participants to use, but it limits the presentation of a questionnaire to a static layout, may introduce data errors through the potential for illegibility and typically requires the data to be converted to other forms for analysis, such as entering into a spread sheet. It has been

suggested that the latest tablet computers may approach the ease of paper with advantages of electronic data collection,[252] but this was not supported by the recruitment sites and concerns were raised by the Advisory Group about familiarity with digital technology in the likely demographic of patients participating in the study.

The implementation phase of the design process will now be described in detail as this contains the final design of the study, its methods and the process followed (see Figure 4). This phase is structured under the headings of data generation, data collection, data analysis and data interpretation, and follows the implementation sequence of the study. Specific information on research governance and ethics is included in the relevant sections.

Patient Study Invitation Pack:
- Introductory letter from responsible clinician
- Patient information sheet
- Consent Form
- Freepost Envelope for return

Palliative Care Outpatient Clinics

Palliative Care Community Services

Palliative Day Care Unit

Clinicians issue Pack to patients within inclusion criteria and outside of exclusion criteria:

Patients choosing to participate complete consent form & return to MC

Questionnaire Pack sent to patients:
- Letter explaining questionnaire
- Instructions to use online questionnaire
- Printed copy of questionnaire
- Freepost Envelope for return

or

Online questionnaire

Completed copy of questionnaire returned to MC

Patients identified for interview

Data set I compiled

Clinical data from patients' notes

Patients consented & interviewed

Interviews digitally recorded & transcibed

Data set II compiled
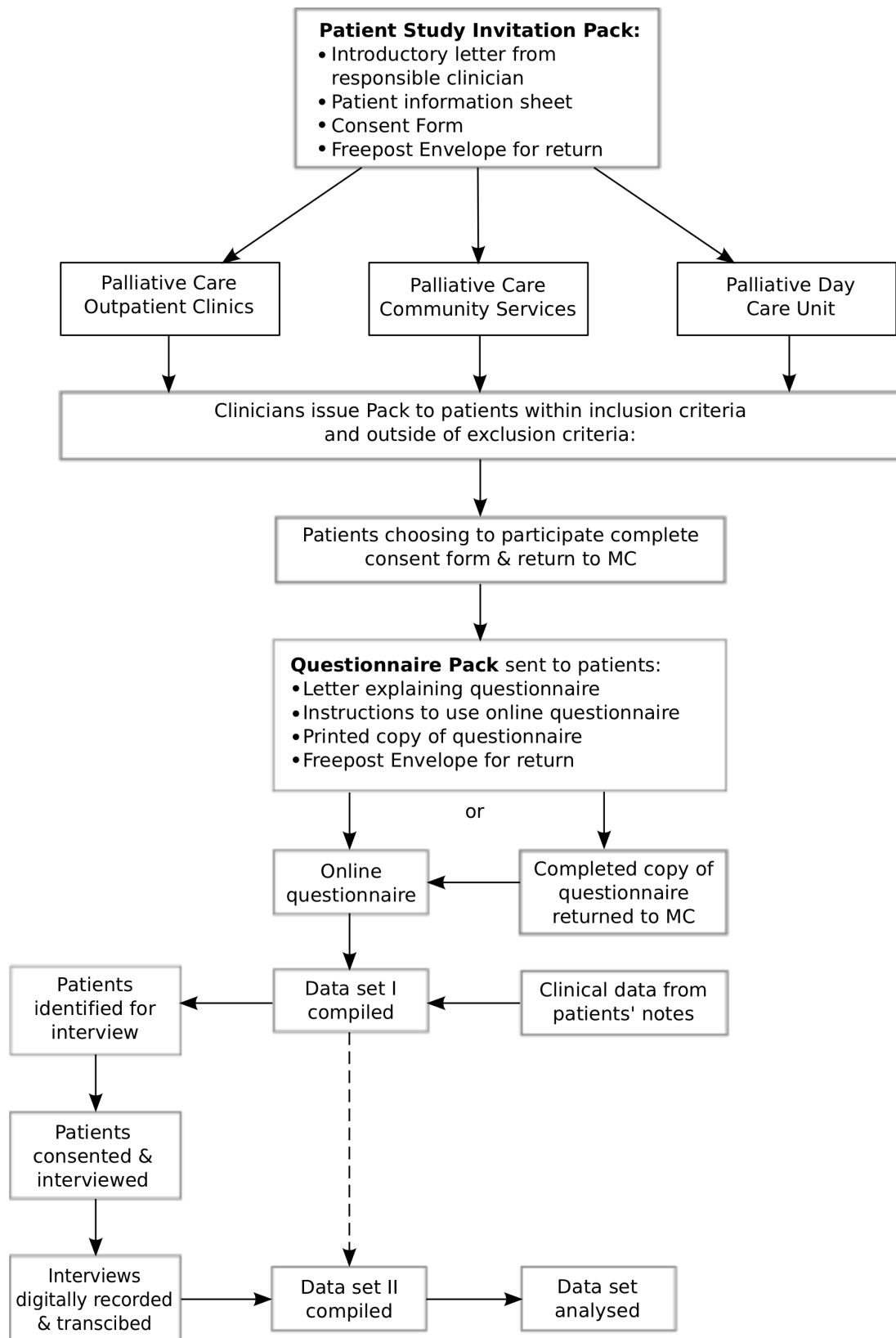
Data set analysed

Figure 4: The Research Study Process

Data Generation

The UK Departments of Health recognise that research is essential for improving health and wellbeing and at the same time they acknowledge that, "The public has a right to expect the highest scientific, ethical and financial standards, transparent decision-making processes, clear allocation of responsibilities and robust monitoring arrangements." [253(p.8)] Consequently a research study that involves research participants, identified because of their past or present use of an NHS service, must receive a favourable review from a Research Ethics Committee (REC) before it can proceed to ensure that it is ethical and worthwhile. The review must be proportionate to the complexity and risks of the proposed study, and at the time of designing this study a new Proportionate Review Service (PRS) was introduced by the National Research Ethics Service for research that presents 'no material ethical issues'. It was clear that this study was not of the order of risk typical of say a clinical trial, and no serious adverse events were considered possible by participating in the study, however the PRS exclude questionnaire and interview-based research that includes 'highly sensitive areas'. We considered that this study contained three significant ethical issues: the confidentiality of patient invited and those consenting to participate; the vulnerability of patients with advanced progressive disease, and the potential for distress that the subject matter may prompt. Each of these was addressed in the design and implementation of the study (see Box 1). It was our opinion that spirituality did not present such a risk, and the PRS concurred, we then proceeded to a full review and submitted the Study Protocol and fourteen other required documents including a favourable Independent Scientific Review by the University of Liverpool. A favourable opinion was issued (Rec Reference 12/WA/0313 (Appendix B), subject to minor amendments in the patient information leaflet and the consent forms. The

study was registered with Sheffield Teaching Hospitals NHS Foundation Trust (STH16428) and local applications were made to establish financial and information governance approval (Appendix C), and to comply with local study set-up and monitoring requirements of the three recruitment sites across Sheffield Teaching Hospitals and St Luke's Hospice Sheffield.

Participant Confidentiality

The invitation to participate in the study will be issued by the clinicians and only the details of those patients consenting to participate will be available to the researcher. The study staff will ensure that the participants' anonymity is maintained through their professional practice, training and systems of work. In particular, the participants will be identified only by a unique study number on the questionnaire (paper and online version) and in the study database. The exception to this will be the consent forms and the participant index that matches study numbers to patient details, both of which will be kept separately. All documents will be stored securely and only accessible to study staff and authorised personnel. The study will comply with the Data Protection Act.

Vulnerability of participants

People with advanced terminal disease typically experience a declining health status accompanied by troublesome symptoms that can result in frailty. The study has been designed to minimize the burden of participation through its two-stage approach and by using a succinct survey instrument. Patients who consent to participate in the interview will be re-assessed at the time of the interview by the investigator against the study criteria and the patient will be offered the choice to continue. Whilst the potential

burden of participating will be the primary consideration for patients we shall also hold the potential life-affirming benefits that patients may respond to including the time to reflect on their lives, the value placed in the illness experience and the opportunity to help others. [254, 255]

Potential Distress

There is a minor possibility that the subject matter of the interview might raise emotive issues for participants or prompt them to consider difficult aspects of their life. The researcher is an experienced healthcare chaplain and is suitably qualified to deal with any immediate distress and to advise participants about sources of support if this is necessary. In addition the researcher, with the permission of participants, will complete a *Note of Concern* (Appendix F) form for the care team if during the interview the participant discloses any significant problematic issues related to their wellbeing that the care team may not be aware of.

Box 1: Ethical Issues

It was determined that the population of community-dwelling palliative care service users local to the investigator (MC) had two principle advantages compared to recruiting elsewhere: firstly, the population was considered large enough to achieve a reasonable recruitment to the study; and secondly, the clinical staff and service managers were known to the investigator and therefore could easily be approached for support with the study. In discussion with palliative care clinicians and in response to the feedback form the Advisory Group it was considered that palliative care inpatients would not be included in the study population as the patients are typically highly symptomatic and dying can be imminent and

physiological [227]. A set of inclusion and exclusion criteria were proposed and agreed with palliative care clinicians (see Box 2).

Inclusion Criteria

Participants are eligible to enter the study if ALL of the following apply:

- Male or Female, aged 18 years or above.
- Diagnosed with advanced chronic disease that is not responsive to curative treatment.
- Attends either (1) a palliative care outpatient clinic at Sheffield Teaching Hospitals NHS Foundation Trust, (2) the Day-care Unit at St Luke's Hospice, Sheffield, and/or (3) is under the care of the Community Specialist Palliative Care Nursing Team at St Luke's Hospice, Sheffield.
- Participant is willing and has the capacity to give informed consent for participation in the study.

Exclusion Criteria

Participants may not enter the study if ANY one of the following apply:

- Inability to understand the consent procedure.
- Difficulties understanding written or spoken English.
- Considered by the clinician unsuitable to participate in the study.

Box 2: Inclusion and Exclusion Criteria

To ensure that patients invited to participate in the study remained unknown to the investigator, recruitment was restricted to the clinicians in the palliative care services. An information leaflet was prepared for

medical and nursing staff, and in addition a presentation on the study was delivered to the Clinical Nurse Specialists that provided the opportunity to address questions not covered in the leaflet. A Patient Study Information Pack was prepared for clinicians to issue to patients meeting the study criteria and included a patient information leaflet (Appendix D) whose content had been revised following comments from the Advisory Group. Patients choosing to participate in the study completed a consent form, returned to the investigator, and which triggered the issue of a Questionnaire Pack that included a printed copy of the questionnaire and instructions for its completion.

Data Collection: Part I

Part I of the data collection process used a self-completed questionnaire to achieve advantages for patients who could stay at home, avoid the need to schedule a meeting, and may enable more truthful responses without the influence of the investigator present. However, it is regarded that postal questionnaires achieve low response rates that are likely to introduce non-response bias, the questionnaire has to be self-explanatory and respondents may consult with others. In considering the alternatives of face-to-face or telephone administration of the questionnaire, a systematic review of questionnaire best practice reported that, "Findings from high-grade primary studies were equivocal, suggesting that no single mode of administration is superior in all respects or in all settings."[256(p.31)] We also considered the option of a self-completed online version of the questionnaire which might have advantages for some patients in terms of the time required for completion, instant return and a more intuitive presentation. However, there is little evidence of the effectiveness of this mode in healthcare despite the growing use of internet-based questionnaires in general, most typically for market surveys. For example,

an assessment of the equivalence between online and paper-based surveys with a comparable sample of businesses claimed a higher response rate for online surveys (28.47% versus 16.58% for mail) and almost identical response characteristics in terms of reliability, accuracy and response to open-ended questions. [256(p.31)] Similarly an evaluation of internet-based surveys in higher education reported that they were, "…a methodological alternative to a paper questionnaire, but not necessarily a more fruitful one." [257] Clearly samples of American students and business people are not comparable to the likely population of this study and a significant factor is access to the Internet. The Office for National Statistics report that in Great Britain 97% of households with children have an Internet connection, compared to 74% of single households with an adult aged 16 to 64, and 40% where the adult is aged 65 or over. [258] We therefore concluded that whilst there was unlikely to be an advantage in using an online survey it could be a preferred alternative for some patients and we therefore chose a mix-mode paper and online approach to the administration of the questionnaire. In addition online survey tools provide automatic data compilation and basic analytical functions and we decided to use the *FluidSurvey* system both for the online questionnaire and to import responses from completed paper questionnaires to provide a single data set. The privacy and security of online data was addressed as part of a compressive information governance protocol (see Box 3).

The content of the questionnaire was determined as part of the overall data set that the study was intended to generate to test the Synoptic Model. There are extant research instruments designed to measure global spirituality or specific constructs of spirituality some of which were identified in the review of literature for this study (see Chapter 3). A systematic review of spirituality measures in end of life care identified 24

instruments of which they rated nine that had content validity in an end-of-life population. The review identified three primary dimensions of spirituality measured: Spiritual Well-being, Spiritual Cognitive Behavioral Context and Spiritual Coping.[259] There are advantages in using either whole instruments or sub-scales of instruments that have demonstrable content validity, however we would question the rigour of the development of some of these measures, their sensitivity to wellbeing related to spirituality, as opposed to a conflated general wellbeing, their sensitivity to populations outside of America where many have been developed, and their underlying assumptions about spirituality. For the purposes of this study none of the extant instruments, even if combined, would enable data to be collected on all elements of the Synoptic Model, and it was therefore decided to consider other instruments that may provide valid and reliable data to test elements of the Model and be more sensitive to the broader expressions of spirituality that are represented in a UK population. We therefore made the trade-off of validity determined in the general population, rather than the specific palliative care population, to extend the range of candidate instruments to include those developed in UK or European populations. Typically this meant survey instruments aimed at understanding society and social change based on methods of comparative quantitative sociology. The *British Social Attitudes* survey, for example, has been running since 1983 and explores religion and religiosity in society, most often in the form of religious affiliation and attendance.[260] In addition, and in various years, the survey has included questions about beliefs in God, spiritual beliefs and spiritual experiences.[261] At the European level comparative sociology has produced a portfolio of ambitious projects that include religion such as the *European Social* Survey and the *Religious and Moral Pluralism (RAMP)* survey.[262] We concluded that the *European Values Survey*

(EVS)[263] contained items that would enable us to collect data on religion and spirituality in a survey form and which would assist us in selecting participants for a interview.

The final version of our questionnaire consists of twelve questions, of which eight are taken from the *EVS*. Five of these questions aim to measure a person's religious and/or spiritual identity and attitudes in a contextually valid manner [264] and use both categorical choices and an open text box to enable respondents to self-identify. Two questions measure beliefs, with one question specifically about God that uses a 10-point scale. A single question measures whether the respondent takes any time to pray, meditate or contemplate. In addition to the *EVS* items three questions ask respondents what they thought about answering the questions in the survey, and a single question was added to supplement the existing demographic data that could be obtained on ethic identity (See Appendix E). The same questions were imported into *FluidSurveys* to create an online version of the questionnaire and both were piloted with colleagues, which demonstrated that it could be completed in less than 20 minutes in either form.

Part I also included the collection of some basic medical and demographic data that could be obtained from the patients' healthcare records which therefore reduced the question burden. Patients consented for the investigator to access their medical records to obtain basic clinical and demographic data that is stored on the *Infoflex* information system operating across all palliative care services in Sheffield. This avoided the need to request and process paper-based notes but the data that could not be obtained digitally had to be collected on a simple Clinical Data Form.

Data security

Data will be in the form of paper documents and digital files. Paper documents will be kept by the investigator in a locked filing cabinet located in his office in a secured building at Sheffield Teaching Hospitals. Digital files will be stored on the investigator's Apple laptop computer and backed-up on the *Dropbox* service. The laptop is password protected and all Microsoft Office files (Excel and Word) will be password protected. The Macintosh Operating System provides a disk level encryption system (FileVault 2) that uses full disk, XTS-AES 128 encryption to keep data secure. *DropBox* transfers files over a secure channel using 256-bit SSL (Secure Sockets Layer) encryption to Amazon S3 servers, and encrypts the file as it is written to S3 using the AES-256 standard. *Dropbox* has received TRUSTe's Privacy Seal and complies with the U.S. - E.U. Safe Harbor Framework.

Data uploaded to the online analysis application *Dedoose* will be identified with the unique study number and no identifiable data (such as the patient's name or address) will be stored on this system. *Dedoose* transfers data over an encrypted SSL tunnel (SSL AES-128). All backups are encrypted with AES internally and the *Dedoose* Data Center is compliant with SAS 70 Type II and HIPAA (the USA Act that regulates the use and disclosure of Protected Health Information).

Anonymity of Participants

The survey and the interview schedule do not ask for any personally identifiable information, however it is possible that

participants may provide information by which they could be personally identified. Should this occur this will be removed from the survey database or the interview transcript. The online survey tool (*FluidSurveys*) does not request personal information, and neither the IP address or respondents location are captured. Sessional cookies (which are not shared or used to track behaviour) can be blocked for the survey.

Notification under the Data Protection Act 1998

The data processing for this study is included within the notification of the University of Liverpool: Data Protection Register number Z6390975.

Box 3: Information Governance Issues

Data Collection: Part II

Part II of the study used a semi-structured qualitative interview to collect data of patients' experience of the spiritual and how it related to the life story. The Advisory Group were of the clear opinion that the interviews should not be conducted over the telephone but conducted face-to-face with the investigator in the same room rather than online using a videoconferencing service such as *Skype*. The reason for this was not provided, however exploring the conceptually large, and what may be for some a personally engaging, subject of spirituality requires a level of rapport necessary to support in-depth and reflective accounts that may be difficult to achieve unless the investigator is present.[265] In face-to-face interviews the investigator is also more likely to notice and respond to visual clues and body language when present with the participant. For some patients this may provide reassurance and support if they disclose

emotive material, or confidence that they are being listened to when talking about doubts and beliefs. A critical issue therefore in this mode of data collection are the boundary issues[266] associated firstly with personal interactions over sensitive subjects, and secondly with being a clinician-researcher immersed in the context and practice that is the subject of the study. Boundary issues are recognised in the theory and practice of pastoral care and are the subject of key texts[267], training, and a professional *Code of Conduct*.[268] In addition the investigator received formal support through clinical and academic supervision. A key skill used to support the interview process was reflexivity, which in relation to this study meant the use of self as an investigator rather than a chaplain:

> Focusing on oneself as the interviewer can highlight our assumptions and values that may be subconsciously driving the interview. Reflexivity has been recommended as a means of ensuring that not only the data gathering, but also interpretation of the findings is qualified by this knowledge.[269]

The content of the interview was given structure by a set of questions developed within a realist methodology and in relation to the Synoptic Model. This meant devising and structuring interview questions to support a dialogical space, both in conversation with the investigator and also the self-reflective (interior) dialogue of the patient. The intention of the interview therefore is to provide the necessary conditions to explore spirituality from the experience of the patient and to capture the narrative account that may develop during the encounter. A range of questions were explored in relation to the Synoptic Model, but to limit the time required for the interview and maintain a subject focus a set of seven questions were chosen and sequenced (see Box 4).

B1	Does spirituality or religion help you to make sense of your life?
B2	Has your illness changed your spiritual or religious beliefs?
B3	Have you had any spiritual or religious experiences or insights since being ill?
B4	Do you have any spiritual or religious practices that you do by yourself?
B5	Do you have any spiritual or religious practices that you do with others?
B6	Have you had to change any of your spiritual or religious practices because of your illness?
B7	Is there any help or support that would you would like with your spirituality?

Box 4: Interview Questions

Patients who completed a questionnaire were contacted by the investigator and offered an interview in either the patient's home or an outpatient clinic. Interviews were digitally recorded using high quality 24-bit, 96 kHz analogue to digital conversion, and *Audacity* open-source software running on a laptop computer. There is little evidence of the impact of recordings on participants, but unlike the suggestion of one author to use unobtrusive equipment[270], we did not attempt to obscure our laptop and microphones but demonstrated the equipment to patients as part of the pre-amble to the interview so that they understood why we were using it. Immediately following the interviews field notes were taken to capture initial reflections on the interview, any peripheral information that situated the patient, and any concerns not initiated by the patient that might need reviewing with an academic or clinical supervisor. Recordings were transcribed verbatim into text documents and these were imported into a web-based data analysis application, *Dedoose*[271], which has been

developed to support the analysis of quantitative and qualitative data. Quantitative data from questionnaires and descriptive clinical data were also imported into *Dedoose* to create a full data set for the research sample.

Data Analysis

Quantitative data from the questionnaires will be subject to two forms of analysis: (a) descriptive statistics to summarise data and determine the sample characteristics, and (b) a basic form of exploratory data analysis which uses techniques of visual representation to gain insights into data and identify relationships and features within it.[272] Qualitative data will be subject to content analysis to derive an observer-independent account of the interview texts. In contrast to ordinary readings of a text, in which material may be selected to support a hypothesis, content analysis aims to be a systematic method to give equal treatment to all parts of the text, "…to support inferences that go beyond the unaided understanding of a text…".[273]
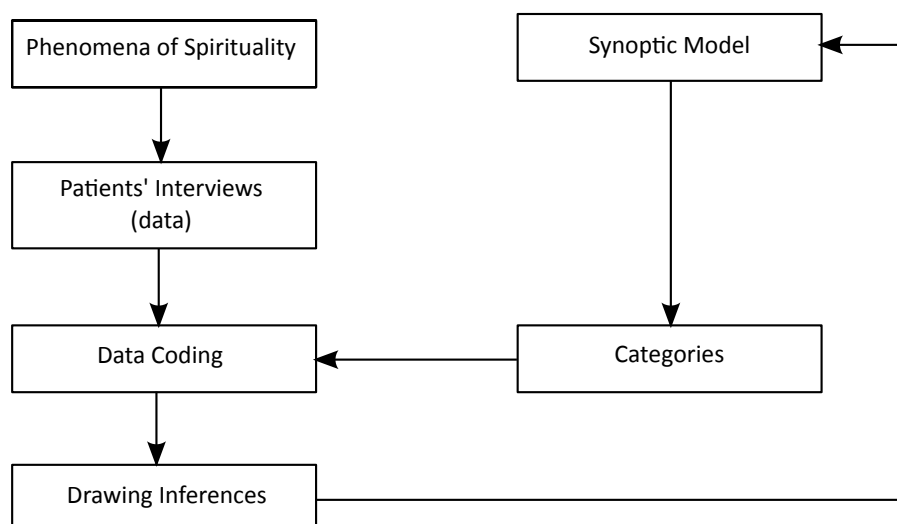
Figure 5: Deductive Content Analysis Process

The purpose of this study is to test the Synoptic Model and we therefore have an existing theoretical model of spirituality that predetermines the

variables of interest. This is the basis of Deductive Content Analysis (DCA) and it can be distinguished from inductive forms of content analysis[274(p.404)] in which information and insights are derived directly from the data and then compared to relevant theories.[275] The Synoptic Model provides a system of categories and their operational definitions that can be applied as codes to the transcribed interview texts that constitute the units of analysis (see Figure 5). The DCA process followed a close reading of transcripts and the attribution of codes to segments of text that contained information related to the category. Following completion of a first cycle of coding it was evident from the data that a number of sub-categories could be delineated and a remainder of uncoded text could be categorised as 'Discussing Spirituality' (see Table 7). All texts were subsequently subject to a second cycle of coding[276] to attribute these categories. However, we did not allow what Gläser & Laudel refer to as "inductive corrections" to resolve contradictions between the Synoptic Model and segments of data but noted these for a later stage when decisions could be grounded in all data and theory.[277] Finally, the consistency and reliability of coding was checked by an academic supervisor reviewing a sample of coded material.

Primary Categories	Sub-Categories
Behaviour and Practice	Prayer
Personal Experiences	Experiences of God Experiences of Health Services
Social Engagement	
Social Experiences	
Inness, dying and death	Treatment

Disease	
Values and Goals	
Ways of seeing & responding to the world	
Personal Beliefs	Belief in God
Discussing Spirituality	

Table 7: Primary & sub-categories for coding

Content Analysis is one of the research methods that is supported by the *Dedoose* application. Texts are imported to the application and then segments of text are coded by the investigator. The application automatically builds an index of codes, a compilation of excerpts and summary descriptive statistics. *Dedoose* also supports quantitative data that are imported to the system and connects quantitative and qualitative data by establishing a set of relationships, in this case based upon data relating to individual patients (see Figure 6). A major advantage of using a computer-based system is that it automatically organises data, provides a single place for it all to be stored securely, and enables data to be easily navigated and viewed, thus contributing to the rigour of the analysis. In the early years of what became known as Computer Assisted Qualitative Data Analysis (CAQDAS) there were debates about whether disadvantages of the software outweighed the advantages, particularly in terms of the time required to become familiar with software and input data, and whether the system imposed constraints on the method. Software has now become increasingly user-orientated and an almost ubiquitous tool of data analysis providing that, "The software is the loom that facilitates the knitting together of the tapestry, but the loom cannot determine the final picture on the tapestry."[278]
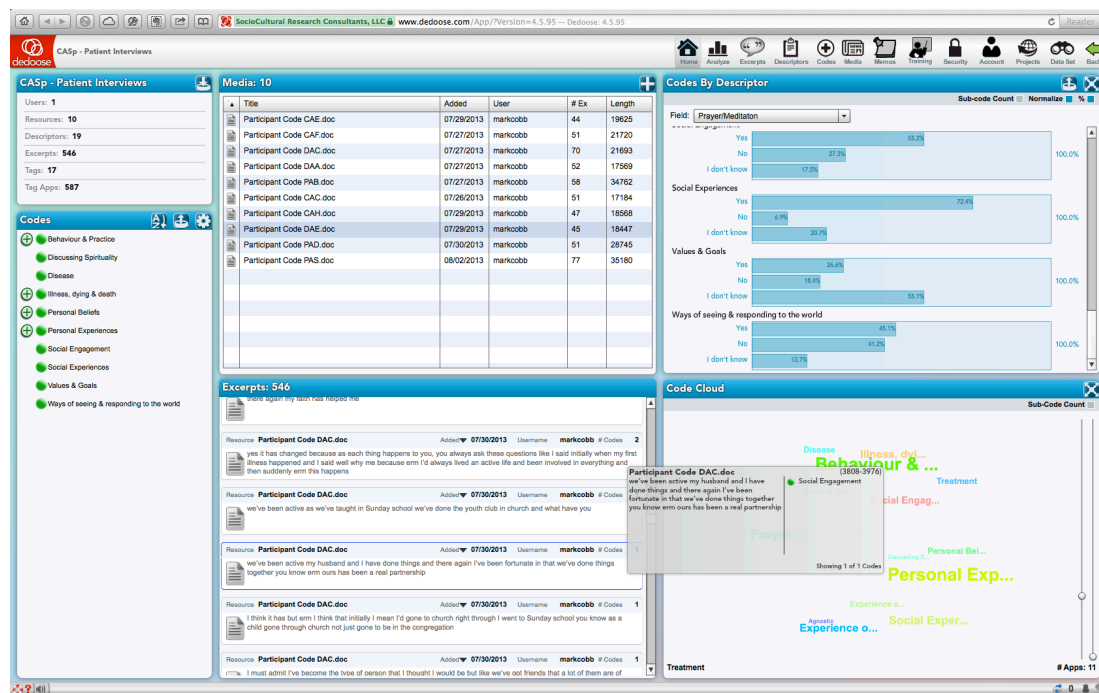
Figure 6: Screenshot of Dedoose

Qualitative content analysis is highly dependent on the interpretation and the selection of texts to build up the tapestry, and this requires practice in the art of understanding, or hermeneutics. Gadamer, a philosopher of hermeneutics, considers that the human capacity for communication must be understood as more than the ability to signal to one another, but to listen and attend to one another in order to reach an understanding. A concern with things that are not understood lies at the heart of Gadamder's explanation of hermeneutics, not just in terms of the incomprehensible, but the enigmatic human questions about life that the arts and humanities respond to. Gadamer therefore argues that:

> Herein consists the universal dimension of hermeneutics, a dimension which encompasses and supports all our reason and thought. It is for this reason that hermeneutics is not an ancillary discipline, serving merely to provide an important methodological framework for various other science. Rather, it extends into the

heart of philosophy, which is not only the study of logical thinking, and the method of inquiry, but a pursuit of the logic of dialogue.[279(p.70)]

Hermeneutics as an interpretative art between the text and the reader is therefore an important consideration in content analysis. Ricoeur's theory of interpretation reminds us that text is removed from the live discourse event (the interview in the case of this study) and that the interpreter is far from naïve but draws upon intuition, experiences, beliefs and prior knowledge in approaching an understanding.[280] Understanding without distortion is a primary aim of content analysis but we should acknowledge that whilst we seek to be faithful to the text and let it 'speak', all hermeneutics involves suspicion (Ricoeur)[281] in the sense of being critical of our interpretations and aware that they remain corrigible and incomplete.

In this study the analysis of the qualitative data is driven by a prescribed deductive content analysis process that provides an explicit framework within which to interpret the transcribed interview text. The codes used in the data analysis are derived from the Syntopic Model, which provides both functional and descriptive content to the elements of spirituality being studied, and supports interpretative correspondence between data and the phenomena's constructs. The attribution of coding through the two cycles of coding are subject to verification by academic supervisors to ensure robust procedural validity and a high level of consistency and reliability in the research findings.

Characteristics of the Sample

	Questionnaire	Interview
Age: n, mean, range	19, 64, 25 − 85	10, 78, 61 − 85
Female: n (%)	11 (58)	7 (70)
Ethnicity: n English/Welsh/Scottish/Northern Irish/British	16	8
Irish	1	0
White background not listed	1	1
Pakistani	1	1
Religion:n Christian	11	7
Muslim	1	1
None	7	2
Years since diagnosis: median, range	2, 0 − 25	8, 0 − 25
Years since referral to Palliative Care: median, range	2, 0 − 13	2, 0 − 7
Primary diagnosis of a cancer: n (%)	15 (80)	9 (90)
End stage/terminal disease: n (%)	11 (58)	7 (70)

Table 8: Characteristics of patients completing the questionnaire and interview

The sample of nineteen patients completing the questionnaire were typically over 60 years old, identifying themselves as white, and the majority were female. Cancer was the most common disease in the sample with most having a diagnosis of a malignant tumour that had metastasized. One patient had Chronic Obstructive Pulmonary Disease, and one had Cystic Fibrosis. Eleven patients had been referred to Palliative Care in the past 12 months with end-stage or terminal disease. Four patients died shortly after completing the questionnaire. (Table 8)

What are your beliefs?	a convinced atheist	a religious person	I don't know	not a religious person	Total
I don't know			1	1	2
I don't really know what to think		1		2	3
I don't think there is any sort of spirit or God	2	1			3
there is a personal God		8	1		9
there is some sort of spirit		1		1	2
Total	2	11	2	4	19

Table 9: Patient's Beliefs and Religious Identity

The majority of patients in the sample did not believe in a personal God (10) and also identified themselves as religious (11) and belonging to a religion (Christian (11), Islam (1)). There were two patients who identified themselves as "convinced atheists" in the sample and the remaining patients either identified themselves as not religious people (4) or didn't know (2). (Table 9) Three patients who did not belong to a religion reported that they had been a member of a religion, and two of them did not think there was any sort of spirit or God. Almost three-quarters of patients considered themselves spiritual to some degree, with the strongest interest reported by those who identified themselves as religious. (Table 10)

	How spiritual are you?	I don't know	not at all interested	not very interested	somewhat interested	very interested	Total
Are you religious?	a convinced atheist		1	1			2
	a religious person			3	3	5	11
	I don't know	2					2
	not a religious person	1	1	1	1		4
	Total	3	2	5	4	5	19

Table 10: Patient's Religious and Spiritual Identity

The importance of God in the lives of respondents was rated by them on a 10 point scale, where 1 represented "not at all important" and 10 represented "very important". The majority of patients (12) responded at 5 and above on the scale and these were more typically patients who had also described themselves as spiritual to some extent. (Table 11)

		How important is God in your life?					Total
		1	4	5	9	10	
How spiritual are you?	I don't know	1		1		1	3
	not at all interested	2					2
	not very interested	2		2	1		5
	somewhat interested	1			1	2	4
	very interested		1			4	5
	Total	6	1	3	2	7	19

Table 11: Spiritual Identity and Importance of God

Comfort and strength from religion was reported by ten patients, nine of whom also responded that religion was quite or very important in their lives. A large proportion of patients (14) reported that they took moments

of prayer, meditation or contemplation, and many of these identified themselves as religious (10) and rated God important in their life. (Table 12)

		How important is God in your life?					
		1	4	5	9	10	Total
Prayer or meditation?	I don't know			2			2
	No	3					3
	Yes	3	1	1	2	7	14
	Total	6	1	3	2	7	19

Table 12: Payer or Meditation and Importance of God

Finally, patients were asked three questions about their experience of completing the questionnaire. Nearly all patients found that it was not difficult (10) or not at all difficult (8) to answer the questions, and the majority responded that they were quite happy (13) and very happy (3) to talk about spiritual and religious matters. Most patients also responded that they would find it very acceptable (6) and quite acceptable (9) for spirituality to be assessed routinely as part of their care, although a small number didn't know (3) and one responded that it was not acceptable.

Characteristics of sub-sample of patients who were interviewed

Eleven of the fifteen surviving patients who had completed the questionnaire agreed to be interviewed, and one of these patients was admitted to hospital 24 hours prior to the interview and died. The sub-sample of ten patients interviewed was of a higher than average age compared to the main patient sample, all but one had a cancer, and seven patients were classified with terminal or end stage disease. (Table 8) Two of the patients identified themselves as not religious and one identified as an atheist. Eight of the patients reported belonging to a

religion (Christian (7), Islam (1)), five patients rated religion as very important in their life, and eight patients reported taking moments or prayer, meditation or contemplation. The names used throughout this study are pseudonyms which are intended to reflect something of the patient as a person rather than simply a source of data. (Table 13, Table 14)

	Age	Sex	Primary Diagnosis	Religious	Spiritual	Importance of God	Religion
Janet	65	F	Breast Cancer	a religious person	not very interested	9	C of E
Jospeh	85	M	Metastatic Prostate Cancer	a religious person	somewhat interested	9	Methodist
Patricia	71	F	Metastatic Breast Cancer	a convinced atheist	not very interested	1	
Michael	61	M	Metastatic Nasopharyngayl Cancer	not a religious person	not at all interested	1	
Frances	83	F	Malignant Neoplasm of Pelvis	a religious person	very interested	10	Christian
Helen	71	F	Osteosarcoma	a religious person	somewhat interested	10	Methodist
Barbara	66	F	Malignant Thyroid Gland	not a religious person	not very interested	5	C of E
Irene	80	F	Endometrial Cancer	a religious person	somewhat interested	10	Christian
Margaret	66	F	Intractable Degenerative Back Pain	a religious person	very interested	10	Pentecostal
Naseer	62	M	Multiple Myeloma	a religious person	very interested	10	Islam

Table 13: Characteristics of Patients Interviewed

The people interviewed

Janet retired early as a result of ill health from an academic support role in a medical faculty. She has a science background and remains interested in medical research. Janet lives on her own and is still able to drive although she does not know for how much longer. She was brought up by Christian parents but has never been involved in a church until recently. Pain is one of the symptoms of her disease, which was evident throughout the interview.

Joseph has been a life-long and active member of the Methodist Church but more recently has found it difficult to attend services and social functions. He lives with his wife who on the day of the interview was due to be discharged from hospital. They receive health and social care and have support from their son and daughter. Joseph found it difficult to find the words he wanted at times during the interview.

Patricia is a retired civil servant who has been actively involved in women's rights and related pressure groups. She lives on her own, has firm atheist views, is not religious and describes herself as very well read. Patricia was currently suffering from adverse effects of palliative chemotherapy and symptoms relating to her underlying disease.

Michael is a keen member of a local walking group and loves to spend as much time as possible outdoors. He was born in Eastern Europe but has lived most of his life in England. Michael took early retirement as a result of his illness and is taking part in a number of research studies. He lives with his wife and a family member who has mental health needs. Michael describes himself as not at all interested in spirituality and is not religious.

Frances is a member of her local church that she is able to attend because either her friend takes her or the church arranges transport. She has recovered from a stroke and still misses her husband who died over twenty years ago. Frances writes poems about her experiences and she shared some of them after the interview.

Helen is mid-way through a course of chemotherapy following surgery and radiotherapy. She recently had to decide whether to have a leg amputated. She is an active Methodist and with her husband attends the church that her daughter and grandchildren attend.

Barbara lives on her own and has a severe sight impairment. She has a son and grandchildren who are very important to her. Barbara was confirmed as a child in the Church of England and although she no longer attends church, and questions her beliefs, she does welcome occasional visits from a vicar that she knows.

Irene became a nurse at seventeen and this has been a major part of her life. She is Christian but is not able to get to church often these days because she is the main carer for her husband who has dementia and has suffered strokes.

Margaret used to be a successful businesswoman until a powerful conversion experience inspired her to establish a Pentecostal church and community centre. Margaret is now very restricted by her illness and belongs to a small Pentecostal house group.

Naseer is a British Pakistani and a devout Muslim. He lives with his

extended family and took early retirement as a result of his illness, but this gives him more time to explore his faith and observe the requirements of Islam.

Table 14: description of people interviewed

Results of the Content Analysis of Patients' Transcripts

The incidence of codes in each transcript is represented in tabular form with the dark cells indicating an incidence that exceeds the mean for the code across all the patients interviewed. (Table 15) It is evident that the code 'Disease' was the least frequently applied to the transcripts and 'Personal Experience' the most frequent. The full set of codes were applied to all transcripts except Janet and Naseer in which two codes and one code, respectively, were remaindered.

	Values & Goals	Behaviour & Practice	Social Engagement	Social Experiences	Illness, dying & death	Personal Experiences	Disease	Ways of seeing & responding to the world	Personal Beliefs	Total
CAC	4	11	11	0	5	10	0	4	2	47
CAE	1	4	6	5	7	12	1	7	3	46
CAF	4	2	7	1	11	12	5	9	2	53
CAH	4	1	10	6	2	15	1	5	5	49
DAA	2	8	8	6	8	10	2	2	9	55
DAC	4	7	9	15	8	12	1	8	10	74
DAE	8	12	3	2	5	6	2	2	6	46
PAB	5	5	5	9	7	13	4	7	5	60
PAD	7	4	12	2	10	7	2	6	5	55
PAS	0	21	5	6	12	15	3	7	8	77
Total	39	75	76	52	75	112	21	57	55	
Mean	4	8	8	5	8	11	2	6	6	

Table 15: Incidence of Codes

In what follows each category will be illustrated with excerpts from the transcripts that have been matched to the code. In many interviews patients responded to questions in the form of narratives and where necessary the length of the excerpt has been selected to preserve narrative coherence rather than a strictly coded meaning unit. Narratives are also central to the practice of healthcare chaplains and therefore this approach is also consistent with my professional experience and training.

Behaviour and Practice

Patients who identified themselves as some form of Christian and who rated God as important in their life spoke typically of attending, or

wanting to attend church if they were well enough. Illness had been the motivating factor for Janet to start attending church, and she spoke with the emotion of relief about this decision:

> … the only difference it has made is that I now go to church and that was because I need some help… I've been a very private person and I've been very private about it, or I don't talk about it. If somebody's asks me if I'm religious I'll say yes, I'll never deny it, erm, but I don't push it down other peoples throats, and now it feels like I've come out, but nobody knows, only close friends know, but if anyone else wants to know I'll tell them, but its no different except that I go to church now, I don't think anything else has changed in my life and I look forward to going.

Helen reads the Bible every day along with Bible reading notes, and Irene says that, "…we do read the Bible, I must admit not very often, but we do read it occasionally and we can quote it." Whereas Barbara has impaired sight and therefore relies more on the radio and television:

> … and anything like that Easter services that sort of thing, its not a sort of thing I do every week, erm, occasionally its on the radio and I put it on but its not a thing I do out of habit, you know, it's just sort of there, erm, but I like to hear the Easter hymns and the story, and I like Christmas carols.

Naseer is a devout Muslim and he was interviewed during Ramadan:

> … the second thing is that we read but we also try to understand the word of God which is our Quran, the Bible, and that is another thing that we as Muslims do a lot of, on a regular sort of basis. As

you know this is the month of Ramadan the 30 days when we fast and it's also called the month of the Quran, but it was revealed in err, Ramadan, and err, we do a lot on that err, reading it but not just, it's in Arabic, but we have got translations in English and our own languages, so we read a lot of that too and try to understand, so it's not just reading it in Arabic, not understanding, which all Muslims can read of course, Arabic, to read that Quran.

Behaviour and Practice: Prayer

It became evident during coding that there was distinctive aspect of Behaviour & Practice related to Prayer which accounted for 31 incidences, and therefore prayer was added as a secondary code to Behaviour and Practice on the second round of coding. Seven out of the ten patients interviewed spoke about prayer. Janet has prayed all her life and now prays, "… to have not so much pain {crying}…, if I'm in pain". She went on, "I just say the Lord's Prayer then I pray for people you know my friends and people that's got something wrong with them." Helen spoke about, "… sort of saying a quiet prayer talking to God." Barbara reflected that:

> I don't sit down every night at ten o'clock and pray, it's not that, it's, I think it's how you think and different things to think about, trying to sort things out in your mind erm, and as I say particularly when you're on your own, you know, you haven't somebody you can turn to and talk to, but I don't think it's a sort of thing you can talk about anyway.

Irene "wouldn't dream of going to sleep without saying my prayers and…
and you know all the things that's troubling you, you can say those in
your prayers can't you." She went on to describe her prayer routine:

> I always say the Lord's prayer, and then I always follow up with err,
> Lighten our darkness, we beseech thee, O Lord. I always say that,
> and then after that all my troubles, you know, what our problems
> are {laughing}… got anything that I would like the Lord to look at
> and help, help us in life, you know, yes.

As a practising Muslim Naseer spoke about his obligation to pray and he
distinguished between general prayer and the five set prayers:

> When I'm on my own and doing the prayer, and erm, because
> prayer is not just, I mean you can pray for anything anywhere, it
> can be outside, in the garden park, to do that, but the five prayers
> set are prayers that you should do very very slowly, concentrate
> with them, and concentrate on that is not just, your not just doing
> it, and to perform the prayer, you have to be ready to pray.

Personal Experiences

Personal experience was the category with the highest incidence of
coding and included spiritual experiences in general, experience of God
and experiences of the Health Service. These last two categories emerged
during the first round of coding and were added as secondary categories
and will be reported on separately. Patients spoke about the shock of their
diagnosis and some of them related this to their understanding of the
world. Helen said that:

It has been a very traumatic time and I have to admit that initially when they found the sarcoma I was shocked, and yes, I used the phrase that people say, 'why me ?', erm, I couldn't understand why me because I'd always been so active, and then suddenly, you know, this awful thing happened.

Patricia in her interview reflected on how her experience had changed the way she understands the world and she relates spirituality (as an atheist) to her feelings and her relationship to others:

I've tended to be one of those people who thinks everything is very straight forward A = B and leads to C, and it isn't like that you know, it doesn't work like that. One has to learn that as you grow older, some of it is, some of those things that distort that model are not of a practical or rational nature, I think that is all I can say… We can't explain our feelings through the practicality of A + B = C. I mean they are irrational, they are confusing, erm, and we live by them and we can't pretend that we don't, erm, so I suppose in that respect I accept the spiritual which affects the way I feel and other people feel and how we relate to each other.

Most patients did not consider that they had had any spiritual or religious experiences or insights since being ill, although this was expressed indirectly by patients as is evident in the previous excerpt from Patricia. In the following two excepts Joseph was struggling to express his sense of spiritual or religious experience, and Naseer relates his belief to his experience of coping:

I am not continually looking for things relating to spiritual or religious things or what ever, err, I just know that they do happen for me err, and it's difficult to put a finger on. (Jospeh)

I think believing in God, in one God, the true God, does help you through life err, life's hardship really, erm, and I think I've coped very well personally because of that belief, erm, and belief is just not for me to say I believe, and I'm much better and I'm coping. (Naseer)

Two patients spoke about their personal experience of place in relation to spirituality as distinct from the social experience of observing religious practice with others. Janet had started attending church since becoming ill and explained that, "…I get comfort when I go to church, and the support, and really it's from the vicar and the building, it's not so much from the other people there." When asked further about her experience of the church she replied, "…it's quiet and it's calm really… Yes, it's a calm place to be and that's really, that covers the spiritual.". Frances spoke about her experience of intermediate care in a nursing home where there was no chapel, and contrasted it to her time in day care at the hospice:

Well I think it's nice when they have a…, like they have at the [hospice], a chapel, where if you feel you want to go and sit on your own, you know, I think that's nice that, but that's what I missed at when I was at that [the nursing home].
Mark: What is it about the chapel at [the hospice], is it just that it is a quiet space?
Frances: Yes, a quiet space yes, it doesn't have to be elaborate thing.
Mark: No, do you think chapels like that are special spaces?

Frances: Yes

Mark: Why do you think that?

Frances: {laughing}… I don't really know, it is just nice to go but you feel a bit nearer, do you know what I mean, feel a bit nearer to believing just certain, you say your prayers or whatever you know.

Janet writes poetry and after finishing the interview she presented me with two poems one of which is entitled, *Chapel of Love*. It is a thirteen-line poem about the experience of entering an empty chapel and sensing a presence.

Personal Experience: God

Patients spoke directly of their personal experience of God without being asked specifically about this. Joseph and Frances talked about experiences of being guided by God, and Helen expressed this as a presence helping her to make decisions:

> I … felt as thought somebody was telling me what to do, I've always been a very indecisive person I you know I've sort of gone along with things a quiet person you know usually got on with things because people have said but I now find that you know, erm, I can feel that presence helping to make that decisions I've got to make, somebody telling me that you've got to do it.

Margaret talked extensively about the active role of God in her life who spoke to her and showed her what to do. Helen explained her experience when she was confronted with the decision about amputating a leg:

… you sort of say, 'well how do I make a decision like this?', you know, and that's where I think God become more important to me because I felt that he's helped me to make the decision. 'Tell me what to do because I don't know what's going to happen', erm, and I mean none of us do but I think that, err, you know He's been there to say to me, could I, yes it is important, its … if you like, yes I can feel the presence whereas before I just went through the motions, now I can feel and sense what is happening you know, so erm, my faith is very much stronger than it was, err erm, but err, and I feel that God is good to me, He's helped me through these difficult things that I've had to go through.

Naseer experienced feeling closer to God as a result of his practices as a Muslim. His experience of illness were not distinct from his experience of God because he believes that everything happens through God:

> … and same with the illness because I believe it's coming from God. I don't mind how what happens err, if that was the case you're going to think that, why, who wants to leave this world. Everyone would want to say 'I don't want to', but when the times comes, and we believe it's a set time and you can't change a second either way, and it can be anywhere, wherever, your destination or destiny is to die, you'll be taken there we believe, and so you can't say that the illness you have, or what country, or whatever the illness will catch you, so no I find myself I'm coping well, I'm happy whatever God has given me, and the illness, I say I'm happy to have it really, it's part of life.

Personal Experience: Health Service

The patients had a wealth of experience of using the NHS and often related experiences of using health services when answering the interview questions. For example Barbara, who identified herself as not a religious person and not very interested in spirituality, spoke about her disappointment at not being asked if she wanted to attend a religious service when she has been a hospital patient:

> …nobody comes round and says anything, you don't very often see anybody, erm, a priest or a vicar or anybody in church, unless they come to visit one particular person, but nobody ever comes and says, 'it's Sunday would you like to go the church or chapel?', or something, you could be taken in a wheelchair, I've never heard that said.

As a practising Muslim Naseer spoke about his experience of being on an Oncology ward, his need for a space to pray, and his concern about staff understanding his religious observance:

> But err, for Muslims there is a prayer area perhaps, in that I know every ward can't have it, but err, or they can pray in the locality where they are, erm, and I know the staff are very very busy, and time wise they haven't got that time really for a person like a religious person to say, 'can I have a space here, could you move this that?'. I would never ever say that to them, 'can you move this?', I just wanted to ask them if I was to be standing there and doing something they wouldn't mind me being there. 'Why have you come out of bed you should be in there, why you walking down there when the patients are here next to you, and there's two beds why would you close the curtain?'.

Social Engagement

Despite obvious restrictions on their mobility patients maintained some level of social engagement, including that which was not associated by the patient with spirituality or religion. Michael, who is visually impaired, is a member of a walking club, and he still joins them on walks if he feels well enough and if there is a guide available for him. Frances attends " … a meeting they have on Tuesday at, they call it TLC, and we just all talk together, and not really a religious group you know."

Patients spoke about changes to their social engagement with religious institutions since becoming ill. Joseph described the changes to his church attendance: "… we attended various functions at the church in addition to the, err, Sunday services there were several functions during the week which normally we attended, err, and err, but that's all had to stop." Barbara spoke about the lack of social engagement and the role of the church: "I think it would be nicer if the church was more important as it used to be, people and more of a community, whereas everybody just seems separate now they go their own way, they don't join in with things together." Helen is an active member of her church and she spoke about what happens when she is unable to attend church: "I'm lucky the minister comes and gives me sacrament, erm, at home during the period that I've not been able to go to church and have it, erm, I mean it's not like joining together in church when your all doing it together." Irene was unable to attend church as often as she used to, in part because she was also caring for her husband who had dementia and had also suffered strokes. She clearly missed the social aspects of the church and was keen to remain engaged: "I think yes, I think there is, I think I could be involved more from home with the church I really do." Naseer explained how giving up work following his illness had freed him up to attend the

Mosque regularly and how his religious observance was done either with his family or as a member of the congregation in the Mosque. Margaret spoke about her church as a 'family' and how it related to her biological family:

> So the friends I've got in my little house group are my family, church family. Apart from my physical family, because I don't have many physical persons, I've got my father and my son, so I'm not a big, I don't come from a big family, there's only me, I'm the only one, then I've got my son. We all live separately, but we live in triangle, so I've not got a big physical family to buoyed me up as other people might have, but my church family do, they're well all together, we're all known all together.

Helen had spent time in hospital and had discovered the hospital chapel as a place to engage with others:

> …. some people can be there in hospital a long time and I think it's good you don't feel totally shut off from being able to practice your prayers and share them with other people if necessary in in a place like the hospital you know.

Social Experiences

Experiences with others and shared experiences were coded as social experiences and were referred to by all patients. Michael spoke about the satisfaction he had of being part of a walking group:

> … its err, very nice people in a groups, your socialising with them, your walking and err, you see a lot of different places around

Sheffield you know so and that's err main part of enjoyment to be in a group of the walkers you know…

Patricia spoke about her experience of engaging with others who are also facing a terminal illness:

I suppose I've err got some solace from talking to other people in the similar situation to myself, erm, I, you know that knowing that life is limited by their illness erm, but that's, err, I don't think, I don't regard that as very spiritual it's just, you know, its nice to share experiences with people.

The death of her husband motivated Frances to seek out social support and find help with her loneliness and her bereavement:

… when my husband died I didn't know what to do with myself, and I was walking everywhere and… I went to the cathedral, and I went in there for a bit, and then I came out of the cathedral and I went, do you know Quaker House, I went passed there and I saw this notice in the window and it said bereaved families… And I went in and I said, 'my husband didn't die of cancer'. She says, 'that's alright you can come', but and I went to that meeting there and I think perhaps somebody guided me there and I was alright once I got in with people and … we all used to talk together and have a cup of tea and a chat yes that helped me a lot.

Helen spoke about the experience of being part of a supportive family and of the "great uplift" she experiences from her friends who are thinking about her and praying for her. It was evident that the experience of being part of a church was significant to her as was the involvement of her

family, and this was illustrated by the experience she had when her mother died in hospital recently:

> the doctor had been to see us and said, you know, they didn't think mum would be very long, erm with us, erm, was there anything, and we said, 'you know we'd like … our minister or our chaplain to come in'. And they said, 'well the chaplain is on the ward would you like him to come?.' And he came and it was nice because he shared that blessing with all of us, and we just felt as a family we were all there together and it was nice to be there with mum, erm, because it was what she would have wanted, you know, so I found that when I've needed this sort of extra, erm, boost if you like, erm, there's been somebody there…".

Illness, dying and death

Illness was an inevitable feature of patients' lives and it often played a part in their interview as a symptom would become apparent, most commonly that of pain. Half of the patients also spoke about treatment in relation to the illness and this emerged as a secondary code in this category. Patients often spoke in very matter of fact terms about getting ill, for example Janet said: "…it's something that happens {laughing}… it happens to a lot of people." But during most interviews there were times when the patients would weep as they reflected on the impact of terminal illness on their lives and what it meant to them. For example Joseph expressed that:

> …sometimes, you feel err, well not is it worth it, I wouldn't put it like that, but err, what, what more can I do, and err, there isn't a lot

more you can do when you've got cancer is there, its just one of those things, 'why not me?'.

Being ill was a new experience for Patricia, and as a result of her terminal diagnosis, or "death sentence" as she referred to it, she had clearly contemplated her limited existence:

> Awareness of one's own mortality is quite dramatic, and erm, I was told three years ago I'd got three years to live and I'm still here {laughing} erm… I have a cancer in my bones and, err, liver and things, erm, and that concentrates the mind on who you are and what you've done and what you would like to do before you go, but its it hasn't dominated my thinking, I accept that I'm going to die and I'm not frightened of death at all, I'm worried about the process of dying.

Frances also talked about her terminal condition in a very matter-of-fact way:

> …the doctor told me that they can't operate because of my lungs and my, you know, my asthma and breathing, and … they said I've only got a three month chance of, if I had an operation, but … it was at [my GPs] and she said, 'don't worry about it you've probably, your alright on your own, you can manage, and you might last three or four years without any trouble', so … that … that sort of helped me with her talking to me like that.

Naseer expressed his understanding of illness with reference to his religion and from a perspective that all people are mortal:

I'm not really afraid of what happens to me because we are all going to go from this world, erm, and if we leave the correct way then, you know way of being gone is being good to them humans, and religion is part of that illness it comes and if it doesn't go then we have to go, it's just not that illness is something one should be, well I don't personally think, but if I've got that severe cancer and I'm going to die, well so what if I didn't have an illness, I could have died crossing the road you know.

Patients would often talk about symptoms during the interview and the physical effects of illness, for example, Margaret explained:

I can be all right at ten o'clock, I can dressed, then I'm not, I get undressed and go to bed. I wait while the pain has got a little bit better, I get back up, I get dressed, and then just before kick off, I know for a fact I'm not safe to drive, if things are that bad, ermm, I shouldn't drive. I had a stroke, err, another stroke about fifteen months ago, so when things are really dicky, errm, I try not to do anything silly.

Illness, dying and death: treatment

Treatment emerged as a secondary category for patients who were still undergoing some form of treatment, much of which was palliative. Helen described:

I've had these two very serious operations, and what have you, and treatment and, err, radiotherapy, and now going through, erm, some more treatment because, erm, this nasty thing has now moved into my lungs, erm, I'm having chemotherapy for that.

Patricia explained how she was struggling at times remembering things. She had mentioned this to her consultant who had replied that, "… it was probably chemo brain," which had not impressed her:

> I mean something affecting your brain is bloody serious, erm, you know that you have other side effects you know sickness, nausea whatever, you know those are all.., we can all deal with those, we all understand those but I think when you feel that your memory isn't working properly and its frightening, its frightening… and I'm not sure they can say much, but they could at least give you hints that you may find this a problem.

Naseer was the only patient who spoke about treatment within the context of his belief in God:

> I can't do anything, God says that you do as much as you can to cope with it, and the first thing that we did, and everybody does, is to go to the doctor. So the means to treat, that is through the doctor, you can't do it yourself, or you might believe as much as you want to believe in God that he brought this upon you but, err, God will of course take it away if he wants to, but he's not going to take it away like he brought it, he's going to take it away by you helping yourself, by going to the doctor, getting the treatment, erm, but our belief is mainly with God… is not the medication, just medication on itself, but it's through God that that medication will work.

Values and Goals

> Well I think its right simple, I don't mean that I don't go over the
> top and swear and stamp my feet you know, I'm quite normal
> really, erm, but when it comes to the nitty gritty I think there's a
> right and a wrong.

In this excerpt Janet explains the moral values that she says have always
had a place in her life, and she says that, "… I believe that conscience is
religion as well, and that's the biggest effect it's had on my life, I have a
conscience and I bear that to religion." Helen also expresses a clear moral
orientation aligned to her religious belief:

> I think it helps you to see what is right, you know, its not a matter
> of following this that and the other, it's a matter of living your life
> as Jesus taught us to and hoping that, that is the right thing to do,
> you know, and people will pick this up.

Margaret embraced Pentecostal Christianity when she ran her own
business and as a result sold it in order to support her church. In this
excerpt she contrasts the value she originally placed on the business with
the value she now associates with being involved in the church:

> 2 shops, 2 businesses, everything material that I wanted or could
> get, ermm, apart from family, I'm talking about material things,
> there was nothing I couldn't go out and get, but the thing I couldn't
> buy was inner peace, and I knew it… the business that I thought
> was life, everything you know, turned out to be… squash it up and
> put it in a little box at the end. It was… it counted for nothing. The
> church family, the church life, the church doings if you like, is life.
> It's the thing that keeps me together. Err, and in my life probably

is… If the Lord is 100% of me, the church family, the church doings if you like, is about 95.

At the same time illness had gradually restricted Margaret's life, and therefore one of her goals was a simple and practical one but which remained beyond her grasp:

So the goal, the goal is if things can be sorted out, I might be able to be able to help me dad. Not be able to spring clean from top to bottom, but you know just be with him a bit more.

Michael identified himself as neither religious or spiritual and he did not speak of these things, however he did reflect on the time he had left and the value of this time:

Oh absolutely yes I try to use every single opportunity to go out to walk, err, to sit down in the garden in the sun because of the dreadful winter, so its now everyday and every minute counts… For me because I enjoy everything there, the greenery of the garden the flowers and things like that, oh yes it helps me that a lot because it's just, well… I'm still alive [282]… that's a good thing you know, yes.

Patricia provided the boldest expression of this sense of life's value in the face of impending death illustrated in these two excerpts:

I know it sounds ridiculous to say this, its like me telling you that your going to die is useful, but it concentrates the mind on who you are and I don't waste time like I used to and I'm much clearer about what I want to spend time doing in the next few years, if I

have a few years and I find that quite good. Awareness of one's own mortality is quite dramatic and, erm, I was told three years ago I'd got three years to live and I'm still here {laughter}, erm, I have a cancer in my bones and err liver and things, erm, and that concentrates the mind on who you are and what you've done and what you would like to do before you go…

I feel things don't matter as much as they used to, erm, I'm much more tolerant of things going wrong, or things not working out because in the end it doesn't matter, I'm not going to be here for very long I'm not.

Disease

The code for disease was the least applied in the analysis of the transcripts. Patients typically referred to disease at the start of their story about their illness experience and did not mention it again. Barbara, for example describes the impact of receiving a diagnosis of a cancer disease:

…when I first found out I'd got cancer I was very frightened I was very shocked, I…, it's something I'd never thought about, I was really amazed and then it went on, and it got worse, and you do come to a stage where you think you're never going to get better…

In the following excerpt Irene, a former nurse, talks about the recurrence of her disease after almost thirty years and the implications this had on her treatment options:

[The endocrinologist] …said no, go down and make an urgent appointment for a scan, which I did, and it came back of course

very quickly, and I'd got cancer back again after all those years. I could not believe it, but I really couldn't, I wasn't on the same wavelength… that it happened again, you know, and err, I was referred to Mr [P]. I went to Mr [P] and he was absolutely great but unfortunately it was in the pelvis, unfortunately I couldn't have any more treatment radiation, I couldn't have any more surgery because I had had the lot, so they put me on progesterone a hormone treatment and, err, my son went with me because with me being hard of hearing he didn't want me to miss anything you know, and [my husband] couldn't go, err, and it was him that said…, I was very held together you know.

Knowledge about the disease was clearly helpful to Naseer who found out about it from his doctors and from his own reading. In this excerpt he sets this knowledge within his understanding of illness:

Naseer: Well first of all the, for instance take the, my illness Myeloma, I heard the name Myeloma before but I didn't actually know what it was, what it entailed.

Mark: Ok

Naseer: And it helped me a lot by reading up, and also the consultant and the doctors explained to me what it was, so when I got the background of the illness, err, that made me understand it better, what it is and how I can respond to that particular one, erm, but then there is my thoughts on life that illnesses can come at any time to any person. So I wasn't shocked that Myeloma and cancer, erm, so I just took it as it came and, erm, coped with it that way.

Ways of seeing and responding to the world

The way people understand the world and respond to it was captured under this code. Patients talked in different ways that typically reflected their religious worldview and beliefs. Michael, who is not religious or interested in the spiritual, explains becoming ill as his "destiny":

> Michael: … I always been healthy and I was shocked quite honestly because this has happened, just err, well it just came out of the blue all of this, so, and it was very, same time, strange, same time, well felt that's my destiny and that's it.
>
> Mark: Right, and is that how you explain it: that it's your destiny?
>
> Michael: Well yes, I would say, well I can't do anything else about it and that's came to me for some reason, I don't know why, you know, I always had a healthy life did a lot of sport, physically fit, and my wife knows I've been running for nearly 15years.

Patricia, a convinced atheist, did not ask the question of why this illness was happening to her. She said, "No these things happen, I mean cancer is cancer and people die of it and it's caught me, no I don't, no I don't think about me in relation to that." However, as was evident throughout the interview, whilst she had clearly rejected religion, she also tried to account for aspects of the world that were beyond simple explanations:

> I think that when I realised, I was a child actually, that this religion thing meant absolutely nothing to me, erm, I've kind of grown from then in terms of taking account of the aspects of existence which are not rationale and not sensible and not, you know, you have to adapt to them and I think I've done that all of my adult life.

Religion provides Irene with not so much an understanding of the world but a belief that what happens has a purpose. In responding to a question about how she made sense of what has happened to her, she said:

> I don't know really, I just, I suppose I could say to you that I just look at things, and think things that happens, that they are there for a reason, they're there for a reason… I always say, um, God's good and whatever happens in life - and I've had some funny things happen in my life believe you me - err, and at the time these things have happened I've been cross, and probably bitter, but always there's been a reason for it, and eventually that reason has been apparent…

Naseer understands the world and what has happened to him within his Islamic belief-system. In this excerpt he explains the role of God in illness and death:

> …we are God's people, servants of God, and God can bring anything upon us. He gives us joy, he gives us happiness, he gives us death, he gives us life and takes death, so err, illness is the same thing, so I just take it like that, that is has come from God. There's no argument, there's no discussion in that...

> I'm not really afraid what happens to me because we are all going to go from this world, erm, and if we leave the correct way, then, you know, way of being honest and being good to them, humans, ermm, and religion is part of that illness, it comes and if it doesn't go then we have to go…

There is a similar theme in Margaret's worldview of God being in control and the need to maintain a "right" way in life. When asked about how she makes sense of her life, she replied:

> I don't have to worry about it. I'm not in charge. I've gone from doing everything my way. Sometimes I do, I come back to the beginning. He always brings me back to where I left it, and then we stand again on the right path, you know. I'm not always been brilliant at it, I've had a few misdemeanours, ermm nothing major, but things that have held me back a bit. Now I don't bother with that, I just believe Him. You know, I don't worry about what will be because I don't know what will be, I've not met anyone who can tell me, so I don't waste time worrying – I think about it – I don't worry about it because I don't need to.

Personal Beliefs

Patients primarily talked about religious forms of belief. When Michael was asked if he had any beliefs he drew upon to make sense of what had happened to him he related the question to religion: "No, I haven't got any beliefs, no I just, I just thought what's happened happened, and that's end of that because I'm not a religious person anyway." Patricia, who identifies herself as a convinced atheist, expressed a different form of belief:

> I do believe there is something beyond the, err, practicality of day to day existence, that there is some sort of element in our beings as humans, erm, one could call spiritual, erm, but whether I just take that for granted rather than calling upon it if you see what I mean?

An Islamic belief in the way God works through people was expressed by Naseer. In this excerpt he explains his belief about the actions of the medical staff:

> I think of the doctors and consultants, although they are not my religion, they are not Islam, they are not Muslims, but for them to treat you how they have treated me - and the treatment was successful - and the way they helped me and advised me and things, I believe that they are Muslims too in that sense, because God says that that everyone has to help another person, and although they weren't Muslim they still did so much for me, and they did it in a way that God sets the line, and you work on that line there.

Janet was very clear that she did not call upon any religious or spiritual beliefs to make sense of her life, and she also distinguished her personal beliefs from the beliefs of the church, saying that they did not matter as much as her "idea of living". Joseph was asked if his life-long Methodism had taught him any particular beliefs, to which he replied:

> It may well have done over the years, but I can't specifically point to an instance, but it may have, something over the years that you pick up, well, as you go along, whether you're a child or an adult, I don't know I can't give a straight answer to that really.

Personal Beliefs: God

Explicit references to a personal belief in God became a secondary code in the analysis of transcripts. Barbara, for example, had a belief in God but said that she didn't always know if there was God when there were

disasters reported on the news: "…it just makes you more doubtful about a God and yet its sort of a thing that's a comfort at times." Margaret considered that she never had a day:

> … when I think the Lord isn't there, or faith isn't there. I could say some days my faith isn't as good as yesterday, in which case it's my fault and not anybody else's. But we can always read a bit more, pray a bit more, have common sense a bit more, you know?

Illness had disrupted Helen's many years of active involvement in the church and prompted her to explore her life-long faith. She has realised that her belief in God has become more important to her since being ill:

> …yet my faith has changed in that, erm, it's not sort of: you read about God and you say your prayers and what have you, and that's it. I feel now that my faith is more ingrained in me, its there all of the time with me, you know. I can find myself sort of saying a quiet prayer talking to God, erm, sort of at any time of day you know, ironing and things like that, and suddenly something comes into my mind and I think, you know, so I think God has become more real to me, erm, I err, and I suppose I've got to the stage now where I'm thinking that yes God is going to see me through this you know, sort of the medical people can help with things, and my family are wonderful, but I know that God is going to be there for me when things get really bad, erm, so yes I do sort of cling on. He's become more of a real person to me as the months have gone on.

It was illness that had made Naseer take retirement and this has given him more time to study Islam and the belief in God expressed in the writing of the Quran:

I believe that we are, we are all, every human being is the same closeness to God, in a way that is well, God doesn't take one person away from him and put another one in his place or closer than the other one, but close in the sense that I understand what God meant when he wrote that, and to understand that then, you understand God more, so that is closer if it can be put that way, that you are close if I understand that word exactly means, then I know that God wanted it that way whereas before I didn't know that but I believe we are all close to God {laughing}…

Discussing Spirituality

A final code that emerged from the second round of coding was that of discussing spirituality. Six of the patients made some comment about the possibility of discussing spirituality within the health service. Janet, who described herself as a very private person, thought it could be difficult for healthcare staff:

I don't know because it's a very personal thing personal to them you don't know that their uncomfortable talking about spirituality so no I don't think they should, I think they should have normal awareness, but not to pass on to… It has to be a specialist because they could be atheist, well how are they going to talk somebody whose deeply religious, and it's not their job really, isn't their job, but there is a lot of support, cancer support services.

Patricia was critical of the health service as it had a tendency "to see everything as a physical problem". She reflected on her experience of attending outpatients where she says, "…all there interested in is your physical being":

I think sometimes that the health service is a little bit too practical and that occasionally it would be a good thing for them to allow for the possibility the patient has other problems than needing medication or operations or whatever, erm, and I think I'm afraid, I think that's the fault of the consultants you know I think they don't take account of what's going on with you…

Several patients had experienced speaking with a chaplain whilst in hospital and found this helpful. Helen thought it was important that people had the opportunity to talk to the chaplain on duty as she had, and Margaret had experienced the support of a chaplain during her inpatient stay: "… he was brilliant, and it's not what he did, he just sat. Ermm, and sometimes he just sat, he was profoundly silent, if you know what I mean?". A Muslim chaplain had visited Naseer during his inpatient stay, but he explained that he would have like anybody to talk to him about his religion:

…it's not just a Muslim that I would like, erm, but anybody, a social worker, anybody coming in. In hospital, when you're in hospital, you want somebody to be there. Well I personally thought that, not to stay there two hours, just for ten minutes. And it's very very helpful spiritually, yes, knowing that somebody has come especially for you…

Finally, Irene was evidently curious about the way the research project had been described in the patient information leaflet and the use of the word spiritual:

… when I read the thing [the information leaflet] I had, I said to my husband, 'I want to ask you something,' so he said, 'what's that?, I

said, 'in actual fact what does spirituality mean?', because you know the first thing you think about is religion, and it's not is it, it's not, and when you think about it… I've just been telling her next door {laughing}… when you think about it it's in more depth than that, it's a wider thing than that, and I was going to ask you what you thought about it when you came, if I've got the right attitude?

Chapter 7

Discussion

In this chapter the findings from the empirical study will be reviewed and each of the nine elements of the Synoptic Model will be evaluated against the findings. The reliability and validity of the findings will be considered against criteria specific to a realist approach to research, and the Synoptic Model will be compared to other similar models to identify the particular contribution of this study. A range of clinical implications will be outlined, including patient care and staff training, and finally the limitations of this study will be discussed.

Main Findings

This is the first known study of patients with advanced terminal disease based upon a Synoptic Model of spirituality. Results from both sets of data collected suggest that spirituality is experienced and expressed through the mental, personal and social lives of patients. This approach overcomes the tendency of much existing research in this field to focus on spirituality as individual cognitive or emotional dimensions, and it appears sensitive to the complex forms of spirituality manifest in much of contemporary society. Most patients participating in the study did not find it difficult to answer the questions, they were happy to talk about spiritual and religious matters, and considered it acceptable for spirituality to be assessed as a routine part of care.

The presentation of religion and spirituality by patients responding to the questionnaire was more nuanced than the 'either/or' dichotomy often

used to portray these variables and well beyond simplistic categories on patients' clerking forms. Belief in a personal God was indicated by just under half of the patients participating in the questionnaire, and nearly two-thirds of patients indicated that God was important in their life to some extent. Just over one-third of patients indicated that they did not belong to a religion although half of these used to be a member of a religion. One-quarter of patients indicated uncertainty or no interest about the spiritual, and three-quarters of patients responded that they took time for prayer or meditation. Patients identifying themselves as religious represented almost half the patients indicating that they were spiritual, and the majority of patients who prayed or meditated did not believe in a personal God. The spiritual and religious variety indicated by patients in this study expresses something of the wider spiritual milieu that has been described as, "… diverse, complex, multi-layered and contradictory".[283(p.26)] Pluralism of views and beliefs is a characteristic of contemporary European societies,[284] but whilst heterogeneity is an overall pattern there are clear strands and features in societies, such as the co-existence of progressive and conservative forms of religion,[32] religious diversity resulting from immigration, for example Islam in Britain,[285] the subjective experiences of the sacred without reference to conventional faiths,[29, 286] and the forms of spirituality or its rejection by people who identify themselves as non-religious or atheists.[8, 27]

The sub-sample of patients who proceeded to an interview remained diverse from a religious and spiritual perspective, although in comparison to the larger sample there was less diversity in diagnoses or disease progression: cancer was the most prevalent disease and over two-thirds of patients interviewed were classified in their clinical notes as having end-stage or terminal disease. In response to the interview questions patients

discussed multiple aspects of spirituality including their beliefs, practices and experiences. It was evident that for some patients spirituality provided an orientation to life and it was therefore used to interpret and make sense of illness and its consequences. Spirituality was also a resource for some patients in helping them to face their current situation and their mortality, both individually and with others. This was often in explicitly religious forms, but religion was also problematic for some patients because illness had disrupted their associational activities such as attendance at religious events, and the patient's social engagement with a faith community had become restricted.

Patients participating in interviews were typically living with symptoms of advanced disease, such as pain; many were receiving palliative treatments, such as radiotherapy and chemotherapy; and patients were involved in a range of health and social care services including hospice daycare, palliative care outpatients and domiciliary services. The Sheffield Palliative Care Studies Advisory Group, who was consulted about this study, considered that spirituality was a highly sensitive issue and they commented that the study would be presented to patients at a difficult time. Despite these concerns and sensitivities patients who consented to be interviewed were highly responsive to the questions, candid in their responses and willing to talk in depth about emotive subjects and experiences, such as 'why me?' and death. The combination of what is perceived as a sensitive subject in a vulnerable population can provoke over-caution in the systems that approve and support patient research, and avoidance by researchers who may resort to the use of proxies such as carers or clinicians. This study illustrates how these concerns can be addressed in a research design and provides evidence of how patients with advanced disease participate in studies of spirituality. Patricia, who

identified herself as a convinced atheist and was not very interested in theocentric spirituality said, "…I think it is very interesting that you are doing this survey, and I think it is very worth while, and I wish you luck."

The Synoptic Model

The deductive analysis of the patients' interviews suggests that the content of the Synoptic Model can be related to the spirituality of patients. All nine components of the model could be assigned across the patients' transcripts through coding, which resulted in a total of 562 excerpts. Sub-categories were identified on the second round of coding that captured more specific and defined aspects of the main category: the practice of prayer, the treatment of illness, belief in God, experience of God, and experience of the health service. A small remainder of transcript material was also assigned a post-hoc code of 'discussing spirituality' and resulted in an additional 25 excerpts in which patients expressed their thoughts and experiences of talking about their spirituality in general and in reference to the health service. In what follows the empirical findings will be used to support, supplement and question the nine primary categories derived from the Synoptic Model.

Values and Goals

This component of the model refers to people's future intentions and the moral claims and judgements that direct them. There were two distinct ways in which this related to patient's transcripts. Firstly, there were moral values expressed by patients in how they conducted their lives and from which they compared themselves to others. Some patients associated these moral values with their spiritual beliefs and the practices, or the tenets of their religious faith, which had a bearing on their lives. These social forms of morality are considered by moral foundation theorists to

promote cooperation and strengthen community[287] and it may be that this sense of belonging for patients remains important even though their physical connections and agency diminish. Secondly, two patients who were not religious made no reference to any beliefs or authoritative spiritual sources, but spoke about the value of being alive knowing that life is impermanent. This mortal awareness was also the inspiration for the goal of spending time wisely before death, making the most of opportunities and trying to do what mattered. This existential value may derive from the significance or meaning we find in living, which for those without beliefs in a transcendent reality does not imply that, "… that there are no purposes *in* life that are worth achieving, doing or having, so that life in reality must be just one damn thing after another that finally senselessly terminates in death."[288(p.157)]

Behaviour and Practice

Spirituality is primarily a matter of praxis, or a way of life directed towards a belief in a transcendent or ultimate reality. Patients who were atheist, or who did not express their understanding of life in religious terms, made no references to such a belief but did talk about behaviours and practices that helped them make sense of life or made it fulfilling. Nagel reflects that without God people can still have an attitude or aspiration, "… to live not merely the life of the creature one is, but in some sense to participate through it in the life of the universe as whole."[199(p.6)] If patients identified themselves as religious they typically spoke about behaviours and practices associated with religious observances, rituals and activities. Reading and studying sacred scriptures were often cited by patients along with prayer. The practice of prayer is common across many religions although the object and modes of prayers vary. Three-quarters of participants reported they took moments of prayer or meditation and it constituted a distinctive secondary code in the analysis of interviews.

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Prayer and meditation are the subject of a growing body of empirical enquiry[289] and systematic reviews,[290, 291] in part because patients report using them to cope with consequences of advanced disease, such as pain.[292] Prayer and meditation may also help patients who are more socially isolated to maintain a connection with the shared practices of a faith community as well as a transcendent reality or deity.

Social Engagement

Some behaviours and practices are directed towards social engagement and patients in the study spoke about associational activities they were involved in or social places that they visited. The social aspects of life were evidently the subject of significant change for most patients and typically in a detrimental way. The corollary of advancing disease is both increasing healthcare demands and more physical disruption that interfere with established patterns of social engagement. In two cases illness was seen as the opportunity to pursue meaningful social engagement as a result of retiring from work, however, the majority of patients talked about their receding social horizon. Patients who were religious tried to maintain associational activities although this often required adjustments to patterns and places, such as relocating to a closer church or relying on a minister of religion to visit. Sometimes the need for institutional healthcare provided unexpected opportunities for religiously or spiritually orientated social engagement, typically through attending a religious service in a hospital or hospice chapel during an inpatient stay. This may support the needs for people socialised in a religion, particularly those who have become disenfranchised rather than disaffiliated through illness.

Social Experiences

The experiential aspects of social engagement were often talked about in emotive terms and appeared related to the extent of loss and change in the patient's way of life resulting from their illness. Past social experiences were therefore a common motif as patients recalled times without illness when they felt more connected and socially supported. The emotional experience of solace and comfort were typical of the positive aspects mentioned by patients, and these could still be invoked through more distal social experiences such as through visits, and cards. Belonging was also an important social experience for patients that enabled engagement with a supportive community in which there were shared understandings. Faith communities were a feature of patients who were religious, and mosques, churches and chapels were talked about as both places of social experience and the locations of a social nexus. Belonging was also a way of creating social identity and collective meaning through being involved in an affective community or institution such as a daycare centre or a chapel congregation. In contrast, as patients became more disconnected, and their social experiences diminished, so they talked about their sense of identity becoming more diluted and nominal. 'Believing without belonging' has been an evocative theme in the sociology of religion and first coined by Davie to describe the latent religiosity without participation of Britain in the 1990s.[25] More recently this thesis has been questioned on the basis that belief and affiliation decline at the same rate.[27] In this study strength of belief was not measured, however there is some evidence that patients unable to participate in spiritual or religious events expressed more doubtful or ambiguous beliefs.

Illness, dying and death

What illness felt like to patients, how they experienced and made sense of it, and what if any meaning they found in it appeared to be at the intersection of their embodied, personal, social and spiritual self. However, rather than present a sharply analytic discourse, patients used everyday narratives to explain their illness, which some have called, "…the means by which the links between body, self and society are articulated."[293(p.281)] This connecting or cohering function of narrating illness meant that when patients talked about spirituality it was a part of their life story and became foregrounded or detailed as patients reflected on being ill. For example patients unprompted described the experience of living with a terminal condition and spoke about life with an acute awareness of their mortality. Illness for many patients also meant what were sometimes "gruelling" treatment regimes they endured to manage symptoms, and being presented with treatment options that caused patients to reflect spiritually on life with the burden of disease and the demands of treatment. It was evident in this study that spirituality informed and framed both the meaning of illness and the future possibilities that it implied. Significantly spirituality appeared to function in the clinical decision-making that involved patients, for example whether to have further surgery. The role of religion and spirituality in decision-making by patients with advanced disease[294] and by their doctors[295] is beginning to figure in research, but none of the patients in this study talked about spirituality being admitted into such discussions.

Personal Experiences

Patients shared significant personal experiences from their lives both since becoming ill and from their past. Two aspects of the way patients talked about their experience have particular relevance to spirituality and emerged from some of the disjunctions between the past, present and

future. Firstly, being terminally ill can place people in a state of liminality as they face existential uncertainty, the limits to an embodied mortal existence, and disruptions to their identity.[296] This may be particularly evident in the paradoxes and ambiguities of living while dying, for example in receiving treatment and preparing for death, that constitute the liminal experience of patients.[297] Secondly, some patients talked directly and explicitly about spiritual experiences and about the presence of God, whilst others used more symbolic, abstract or metaphoric language to designate the spiritual. Stanworth, for example, in her study of the ways in which patients in a hospice disclosed spiritual needs, identified a set of metaphors. "… that disclose, mediate and structure their reality.",[298(p.98)] including those related to temporality, marginality and liminality. All of these metaphors were present across the discourses of the patients interviewed. An unexpected finding, however, was experience in relation to place that was mentioned by some patients. This was typically a sacred building, such as a church or chapel, which represented a site of meaning or significant experience, such as feeling nearer to the sacred or a sense of peace. This experience of place was distinct from the environmental domain of spiritual wellbeing,[299] and might be important to patients because the liminal is represented and enacted in sacred places. This is in contrast to studies that report how sacred spaces within the geography of secular healthcare organisations are contested and undervalued.[300, 301]

Disease

The specialist knowledge and technical language of healthcare is about disease and trauma, and it maybe therefore unsurprising that disease was rarely spoken about in interviews with the exception of the diagnosis that becomes determinative of treatment, access to services and a life-limiting prognosis. The inherent tension between the patient's subjective

interpretation of disease and the equally legitimate diagnostic investigation of the doctor can be an alienating experience for patients whose bodies become the object of investigation and medical attention.[302] When patients in this study mentioned their disease it was generally because it symbolised the beginning of their illness story, but it rarely figured in anything else they spoke about. Good clinicians do their best to work with this tension and exercise bi-lingual skills, but perhaps a patient not having a grasp of the clinical language is more problematic than we recognise. Rose, for example, sharply argues this point following the news of her terminal diagnosis of ovarian cancer:

> Medicine and I have dismissed each other. We do not have enough command of each other's language for the exchange to be fruitful. It is as if, exiled for ever into a foreign tongue, you learn the language by picking up words and phrases, even sentences, but never proceed to grasp the underlying principles of grammar and syntax, which would give you the freedom to use the language creatively and critically.[303(p.95)]

One patient in this study echoed something of this incongruence when she spoke (with some anger) about a conversation she had had in clinic when her oncologist who had used the term "chemo-brain" without any introduction or subsequent explanation. The findings from this study suggest that the symptoms of disease are a more meaningful construct for patients and the evidence for this was not just in what they spoke about but in their physical presentation and behaviours during the interview that were recorded in contemporaneous field notes. Observational data also included equipment and aids used by patients to compensate for the functional impairments resulting from their disease, and in nearly all cases medication was close to hand. Even organising interviews provided

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evidence of the impact of disease on the lives of patients as these had to be arranged to avoid clinic and outpatient appointments.

Ways of seeing and responding to the world

The belief orientation of the patient was closely related to the ways in which experiences were interpreted and a response was determined, however what appeared to have prima facie similarity in what was being said by patients could refer to highly distinctive views and orientations. The notion of destiny, for example, was invoked by patients with theistic beliefs and those with no interest in religion, spirituality or a belief in God. One patient, for example, expressed that becoming ill was his destiny, that it had to be accepted and that he could do nothing about it. Another patient understood God as the creator and author of life from birth to death, and that his destiny including his illness was therefore predetermined by God. Both of these responses were related to the ways in which the patients talked about coping with a life-limiting condition and the ways in which they perceived and responded to healthcare. Patients also spoke about how illness had changed their understanding of and way of living in the world. The most dramatic case was the patient who had started attending church for the first time, other patients described how it had challenged them to explore their faith further and practise their spirituality in more committed ways.

Personal Beliefs

Four fifths of the patients interviewed had indicated that God was important in their lives to some extent, and theistic beliefs were often referred to by these patients. Religious beliefs were also cited by patients to illustrate their religious identity or to demonstrate their commitment to a faith tradition. Patients also spoke about the ways in which their belief or faith had become more doubtful or difficult, whilst others talked about

their faith becoming stronger or more "real" to them. It was apparent that patients used belief and faith as equivalent terms, but in philosophical discourse they are distinct: the former referring to a positive disposition or capacity for belief, and the latter referring to truth propositions.[304, 305] Perhaps what patients were expressing in interviews therefore were the fundamental commitments by which they orientate their lives and are practised in their living. Day, from her research experience is critical of questions about belief that present a simple dichotomy of believing in God or believing in nothing, and her approach is to consider belief orientations which she categorises as theocentric and anthropocentric: beliefs articulated primarily with reference to human beings or with reference to God.[57] There was evidence in this study of both these orientations and Day's approach also helps to explain people who appear to confound the religious-secular binary, such as those who identify with a religion but are disaffiliated from it.

Validity and Reliability

The data derived from the self-completed questionnaire and interviews with patients suggests that the Synoptic Model contains sufficient descriptive and functional content to plausibly represent (by analogy and not direct correspondence) the lived spirituality of palliative care patients. However, it is evident from the discussion that particular findings may warrant some revision of the theoretically based elements of the Model. The methodological orientation of this study does not justify the use of inductive corrections when data and theory have diverged, and for reasons explained in the review of the literature on this subject (Chapter 3) this study has aimed to preserve *a priori* theoretical premises. Consequently the argument of Gläser and Laudel is pertinent:

…we would contend that immediately abandoning theory whenever a conflict between data and theory arises is not a good way of resolving such a conflict. Theory, after all, often has emerged from prior data, which makes the contradiction between prior theory and current data actually a contradiction between interpretations of previous and current data.[279]

This caution requires that a promissory note be issued on the claims of the Model while the empirical data is subject to the assays of validity and reliability. These standard tests are not without problems from the realist perspective[306] when dealing with complex open human systems,[307] as distinct from that which may only exist independently of humans, and where not everything experienced is directly observable.[308] There are no accepted universal criteria of validity and reliability used in realist approaches because realists are not convinced by the generalisable, nor do they accept that validity is simply a property of research design and methods – so called procedural criteria. However, this does not imply that researchers in the realist tradition are unconcerned with threats to the validity of their enquiries, even though many address them more in abstract than practical terms. Healy and Perry are helpful therefore in proposing a set of six criteria that can be applied to research within the realist paradigm:

1. Ontological appropriateness
2. Contingent validity
3. Multiple perceptions
4. Methodological trustworthiness
5. Analytic generalization.
6. Construct validity[309]

The first criterion is to ensure that realist methodology is appropriate to that which is being investigated, a point argued in Chapter 5. Realists explore open systems that are contingent upon context, and therefore the second criterion is not about an ideal objective view but a contingent perspective on validity. In this study contingent factors have been addressed by accurately describing the population from which participants were drawn, an account of the patients' characteristics, and the inclusion of situational details in interview excerpts to provide context to coded units. Nagel considers that the pursuit of objectivity is a necessary but problematic method for understanding the world, because it depends upon detachment from the human and subjective perspective, but, he argues: "… here are things about the world and life and ourselves that cannot be adequately understood from a maximally objective standpoint, however much it may extend our understanding beyond the point from which we started." [310(p.7)] If maximal objectivity is unachievable then the third criterion follows and requires an epistemological awareness of other perspectives, interpretations and data. The interpretation of patient data therefore has been reviewed by, and discussed with, two academic supervisors who come from different clinical fields to the investigator. Different perspectives have also been considered in discussing the findings that have brought in arguments from the disciplines of sociology, anthropology, philosophy and religious studies.

The fourth criterion is a form of procedural validity based upon verification strategies used throughout the enquiry, "…so that reliability and validity are actively attained, rather than proclaimed by external reviewers on the completion of the project.".[311] In this study close attention has been paid to the entire research process from design to data

analysis to ensure rigorous and consistent procedures that maintain data quality, theoretical and methodological coherence, and allow for error checking. The ethics of the interview have been addressed previously, however procedurally the conduct of the interview also required carefully framing to maintain a focus on data collection. An interview contains some of the conditions necessary to establish a therapeutic relationship such as providing a safe space, building a rapport, and exercising reflexivity.[312] Therefore the interview followed a clear structure with established questions that would not support a therapeutic process or goals, and the investigator maintained self-awareness during interviews to avoid making a therapeutic connection.

Analytic generalisation is a form of external validity adopted from case study research[313(pp.43-44)] and has been described as, "the extraction of a more abstract level of ideas from a set of case study findings – ideas that nevertheless can pertain to newer situations other than the case(s) in the original case study." [314(p.325)] This approach is clearly distinct from statistical generalisation dependent upon random sampling, but it remains an ambiguous technique, which may explain why qualitative researchers sometimes infer generalised findings without justification.[315] In this study the direction of validation is from the theory to the phenomena with the aim of testing the Synoptic Model. The Model is already at an abstract level, and the test is therefore not one of discovering an empirical warrant for generalisation but the extent to which the Model's theoretical propositions are plausible in a relevant population. This requires assessment of the validity of the test, but tests are not discussed in Healy and Perry's proposal, which appear to assume inductive methods. Finally, construct validity is another verification strategy employed in other methodologies and refers to how accurately the data from a study

captures what is intended to be measured. As this is a theory-driven study the specification and operationalization of constructs are provided by the Synoptic Model, but because constructs cannot be directly observed the reliability of the empirical data is critical. This returns us to different methods of data capture used in this study and the verification procedures adopted to analyse and interpret the data.

Healy and Perry's criteria do not explicitly address studies that test theories, but a comprehensive review of the criteria promoted by leading philosophers of science identified a hierarchy of twelve criteria for the purpose of evaluating a health theory based on a realist ontology.[316] There is some overlap of these criteria with what has already been discussed, but two criteria remain distinct. Firstly, there is the testability of theory which requires that it can be operationalized and survive being replicated; and secondly there is empirical adequacy which requires congruence between the theoretical claims and the findings. Research with open systems cannot achieve the controlled environment of experimental research but it remains important that the conditions, circumstances and relevant parameters under which the theory is expected to hold are specified, and this is set out in inclusion and exclusion of this study. It would be outside the scope of the current Synoptic Model to conduct a test, for example, with healthy first-year nursing students, but further tests within the specified population could be conducted, and ideally these would take place in different locations and with different investigators.

Repeating the test within its specified scope would expose the Synoptic Model to more opportunities of being falsified: for example there may be factors unique to this sample, the Sheffield context, or in relation to the

particular investigator, whose effects would not impact on a study elsewhere. Conversely if findings from other investigators or contexts were confirmatory this would increase confidence that the Model can be generalised to a broader palliative care population. Accumulating findings beyond a particular study sample is a recognised approach to increase validity, and whilst this can be a goal of further research on the Model, the aim of this study was not to generate findings that can be generalised but to test the descriptive and explanatory properties of the Model. The importance of theory can be under-emphasised in social sciences and without theory there cannot be generalisation:

> If the theory under test is falsified, we have evidence that the theory requires modification. If the theory escapes falsification, we gain confidence in the utility of the theory. As a theory escapes falsification in multiple tests, we begin to have confidence that the theory will hold in diverse situations. It is in this way that we produce general knowledge. No single study, however, can produce general knowledge in the absence of theory.[317(p.247)]

The Synoptic Model Compared

The findings of this study have been discussed with reference to their validity, reliability and limitations. This first-stage study provides sufficient warrant to infer that the findings from this sample are congruent with the theoretical claims of the Synoptic Model, subject to revising the specification of the 'Disease' element to that of 'Symptoms of Disease'. The final consideration is how the Model compares to current knowledge and understanding in this field. The dearth of extant models makes direct comparison problematic, however Koenig et al, present a set of general theoretical models of causal relationships, based upon an extensive

review of research findings.[318] Koenig's work is significant, not only because of his prolific evidence-based output, but because of his sustained critique of the ways in which definitions and measures of spirituality have been developed for a pluralistic healthcare context.[119] In summary, Koenig argues that researchers use definitions of spirituality that are too vague and confuse spirituality for an outcome of health rather than a source of health. Consequently, he argues, researchers confound spirituality and religion with positive psychological and social traits (such as hope and connectedness), thereby contaminating the measures:

> Research that documents an association between spirituality defined this way and positive mental health, is meaningless since constructs measured with the same or similar items will always be correlated with one another. Of particular concern is that defining spirituality as positivehuman traits or good mental health completely eliminates the possibility of identifying circumstances in which spiritual awareness or the spiritual quest is associated with turmoil, unhappiness, and perhaps mental and physical morbidity.
> 119(p.350)

The Causal Models[a] of Koenig et al explain how Western and Eastern types of religion and spirituality, and how secular humanist beliefs, affect physical health. In all three models what is referred to as the 'Source' distinguishes the models and drives the pathways that end in physical health. For example, in their Eastern version, the 'Source' could refer to the Buddha, which gives rise to practices and commitments of Buddhism that lead into psychological, social and behavioural pathways and which in turn affect cardiovascular, immune and endocrine functions.[318(p.591)]

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[a] This is a title of convenience applied in this Thesis and not one used by Koenig et al

These highly detailed Causal Models are an attempt to describe
naturalistic pathways that can be subject to measurement, and whilst
there are evident similarities with the Synoptic Model, such as the role of
beliefs and behaviour, Koenig et al have described sequential linear
models that do not include feedback mechanisms. The Synoptic Model
allows for a more dynamic account of spirituality in which, for example,
the experience of illness may impact upon beliefs. It also aims to have
clinical utility within a context of patients with life-limiting conditions and
therefore has to account for declining disease trajectories and mortality.
The Causal Models are built from a critical review and synthesis of
existing research but the causal inferences embedded in the pathways are
largely dependent upon correlational studies that cannot warrant the
inferences. In addition the higher specificity of the Causal Models, evident
in the requirement for three versions of the Models, may be necessary for
outcomes research purposes, whereas the Synoptic Model functions in the
same way for any belief system and may be sufficient for clinical
purposes.

A simple Conceptual Model of the sources of spiritual wellbeing in
patients with advanced cancer has been developed and tested by Lo et
al.[319] The researchers recruited a large sample of 747 patients over a
period of six years and subjected them to a battery of measures aimed to
test the Model. The researchers give scant explanation about how their
model was developed other than explaining it was based on the findings
of the study, and proposing three predictors of spiritual wellbeing: values
and belief systems, self-worth and identity, and social relatedness, none of
which are specified. The data is subject to structural equation modelling
to test the predictors and to confirm the Model. Whilst it is an elegant
exercise in mathematics, the data on spiritual wellbeing is measured using

the 12-item Functional Assessment of Chronic Illness Therapy – Spiritual Well-being Scale (FACIT-Sp-12),[142] which is one of Koenig's exemplars of a contaminated measure.[119(pp.351-352)] Aware of this caveat, the Conceptual Model has similarities with the Synoptic Model in its inclusion of social, psychological and belief factors, and it also provides an account of the way in which advanced disease can impact upon spiritual wellbeing. The study measured common symptoms of cancer and the structural equation model includes physical burden as a latent factor statistically related to physical symptoms, pain interferences and symptom severity. This may be a more valid and reliable approach to what in the Synoptic Model was originally described as disease, and is more consistent with what patients manifested in this study.

The term 'spiritual wellbeing', when used in research papers, is a construct that emerged from America in the early 1980s in association with an instrument to measure it.[107] The only known attempt to develop a specific measure of spiritual wellbeing for palliative care is that of the European Organisation for Research and Treatment of Cancer (EORTC). The 36-item instrument (EORTC QLQ-SWB36) is in its final field-testing phase of development and is constructed from issues identified in the literature and grouped into three dimensions of personal relationships with self and others, existential issues, and religious and/or spiritual beliefs and practices.[320] The EORTC group have chosen to take a functional rather than a substantive approach to measuring spiritual wellbeing. The concern here is not with the content and orientation of a person's spirituality but exploring, "…the function served by an individual's set of beliefs and activities or how people's behaviours and activities relate to fundamental questions of existence. [110(p.860)] The EORTC instrument is significant because of its cross-cultural development and its

twin aims to be: (1) a clinical tool to initiate an exploratory discussion of spirituality, and (2) a reliable measure of the efficacy of spiritual care interventions. However, the instrument is also susceptible to Koenig's critique of contaminated measures both in the literature it draws from and in the way items have been constructed. The Synoptic Model clearly lacks at this stage cross-cultural testing, and in EORTC terms, combines the function and substance of spirituality, which explains why the Synoptic Model includes elements related to 'values and goals', and 'ways of seeing and responding to the world'.

The EORTC was set up to support international cooperation in clinical research and therefore standardized measures are a necessary tool to ensure comparability. At a global level, and with an interest in comparing populations, the World Health Organization (WHO) develops instruments that monitor and assess key health trends, including the effect of health on quality of life. The WHO concept of quality of life (WHOQOL) has six domains (physical, psychological, social, spiritual, environmental, and level of independence) and the assessment instrument has four out of 100 items that address spirituality.[321] Subsequently a 32-item instrument has been developed, the WHOQOL-Spirituality, Religiousness and Personal Beliefs (SRPB) instrument which is the subject of field testing.[322] O'Connell and Skevington have used this instrument as the basis of an international study of 285 participants from a heterogeneous sample to test the best fit model for spiritual quality of life, for example whether it is a superordinate construct or a component of the psychological or social domain.[299]

Statistical analysis, including exploratory and confirmatory factor analysis, was used to compare the hypothesised models, and demonstrated that

spiritual quality of life made an equal and distinctive contribution to overall quality of life relative to the other five domains. The WHO study also attempted to address Koenig's critique as the instrument includes measures of hope and peace. The confirmed model contains seven SRPB facets (beliefs, connection, meaning of life, wholeness, spiritual strength, awe, and faith). Hope and peace were more strongly associated with the spiritual domain than the psychological domain, and this prevented their inclusion in the final analysis:

> On the evidence of the present data, hope and peace contained both spiritual and psychological properties. Which way these two issues are rated may depend upon interpretations that respondents bring to the evaluation, and the context or setting of administration. 299(p.743)

The WHO study is another example of a cross-cultural approach to understanding the distinctive role of spirituality and may support the argument that one model can apply across diverse belief systems. The Synoptic Model does not aim to measure quality of life but it includes similar domains to the WHOQOL model with one exception, the latter has an environmental domain, which includes facets such as safety, the physical environment and transport. It may be that some of these facets are manifest in the personal and social elements of the Synoptic Model, however the experience of place reported by patients in this study remains distinctive and does not find an equivalent in the current WHOQOL. The study by O'Connell and Skevington of the WHOQOL also confirms the theoretical position of the Synoptic Model that spirituality is an indivisible but distinct expression and experience of the person.

The Synoptic Model is not directly comparable with any other known model for two significant reasons: firstly its specificity to palliative care, and secondly its aim of understanding patients rather than measuring an outcome. However, there are family resemblances given that all the models are within a defined field of study and are seeking to articulate plausible accounts of spirituality in relation to the health and wellbeing of patients. Consequently the Synoptic Model makes its own unique contribution to this field most critically in providing a strong theoretical basis for spirituality rather than relying on either a consensus view, or a broad synthesis of findings that has relied upon measures and constructs often known for their longevity rather than their rigour. The Synoptic Model must itself be empirically responsible, and there is further development and testing required to refine its content and specification, but the conceptual apparatus of the Model has already added to wider critical discussions in palliative care about research in this field.[b,323]

Implications for clinical practice

Clinical care lies at the very heart of palliative care and concerns the optimal management of distressing physical and psychological symptoms of the patient and relief of social, spiritual and existential problems of patients and their family caregivers in order to improve their quality of life. Clinical care is provided at home, in nursing homes, in hospices and hospitals and includes especially vulnerable groups and situations, e.g. at the end of life.[81]

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[b] The model was included in a paper by Professor Carlo Leget about fundamental research questions in spiritual care delivered to the 13th European Association for Palliative Care Congress, Prague, 2013.

A primary motivation for this study was to develop knowledge that can be in the service of palliative care and has epistemological and practical value. To this aim a model is a visual artefact that can span actual and perceived boundaries between the contexts of scholarship and clinical practice. The Synoptic Model can therefore function as a 'boundary object' that embodies knowledge that is recognisable to both the scholarly and clinical communities and enables their interaction and the development of shared understanding.[324] The Synoptic Model provides empirically supported theoretical knowledge of spirituality that can be utilised in the context of palliative care and which has implications for clinical practice in terms of patient care, education and development, assessment and research.

Patient Care

Spirituality is woven into the fabric of palliative care and referenced in authoritative statements and guidelines that describe and define the nature and purpose of palliative care. In the UK, for example, the NICE guidelines on *Improving Supportive and Palliative Care for Adults with Cancer* recommend that "Assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as at diagnosis… at relapse; and when death is approaching).", and devote a whole chapter to the subject of spiritual support services.[325] However, what most of these key documents fail to provide is any conceptual framework for spirituality and this lacuna may result in under-specified services and vague or ad hoc approaches to spirituality in the clinical practice of patient care.

The Synoptic Model expands and explains what spirituality may mean and how it can operate in the life of a patient. It illustrates the ways in

which spirituality is enmeshed and entangled in a person's inner and outer lives, and accounts for how spirituality is both a worldview and way of living. The relevance of this synopsis to patient care is evident form the data collected and analysed in this study and challenges approaches that compartmentalise spirituality in conceptual and practical terms. For example, beliefs are not just states of mind but embodied and performed through a person's behaviours and decisions. Similarly the ways in which patients make sense of their lives is a dialogue with the reality of the world they know and experience including, for some, a divine being or God. Patients interviewed for this study implied that palliative care services rarely venture into this territory and show few signs of understanding or being interested in patients' spirituality in this extensive form. Consequently patients have low or no expectations that palliative care services can address or support their spiritual needs, and this in turn questions the quality of palliative care in relation to achieving its holistic aims.

There are many contextual factors that determine the quality of patient care, and in relation to spiritual care key issues in a palliative care service include the extent to which spirituality is regarded as important and legitimate, how it is operationalized, who is responsible for addressing it, the pathways or practical mechanisms that are intended to address spirituality, and the resources available. Even where these necessary conditions exist there may need to be improvements to the quality and effectiveness of spiritual care. At an operational level, in contrast to the aspirational level, this may not be a self-evident problem, and where it is, there may not be a clear solution. Interventions to achieve improvements need to be relevant to clinical practice, congruent with the imperatives of

clinicians, and result in demonstrable benefits for patients and clinicians.[326]

The issue here is not the place of spirituality in palliative care, but the structure and effectiveness of clinical care in addressing spirituality needs. This study contributes empirical data and conceptual clarity to this debate, firstly, by adding to the slim body of research that gives direct voice to palliative care patients, secondly, by proposing a theoretical model of spirituality that expands the knowledge available to palliative care practitioners and services, and thirdly by articulating how spirituality is experienced and expressed in the lives of patients and shapes the ways in which they face their illness and dying. The Synoptic Model is not a service or clinical model, however it does represent the elements of spirituality to be addressed in palliative care and therefore asks questions of current service provisions and clinical practices.

What is perhaps most evident from the Synoptic Model is that spirituality, whatever a person's metaphysical commitments, is embodied, personal and social, and it is therefore congruent with the humanistic ethos and conventions of palliative care. Spirituality articulated in this way can expand and deepen the practice of palliative care, and in particular has the potential to enhance the patient-centred ethos of clinical services. Spirituality is an indivisible part of the person, and even when clinicians intentionally exclude or are insensitive to this aspect of the patient, this study demonstrates how palliative care can affect the spiritual interests of patients.

It was evident from this study that most of the participating patients were very articulate about their spirituality, and equally clear when it was not

part of their lives. The patient is an expert in their own lived experience of spirituality and a respectful, informed and intentional enquiry by clinicians is likely to be regarded as an affirmative action that can establish a level of trust sufficient to enable a patient to share something of their spirituality. This is not an argument for clinicians to become metaphysical investigators but to express interest in and to seek understanding of aspects of patients that will shape their living and dying.

Education and Development

Meeting the spiritual needs of patients is widely recognised as a core competency in palliative care,[95, 327] and it has been the subject of detailed level-descriptors within a stepped-care model of generic to expert levels of practice.[328] An example from the UK *Specialty Training Curriculum For Palliative Medicine* includes the following statement of learning:

> To have the knowledge and skills to elicit spiritual concerns, recognise and respond to spiritual distress, and demonstrate respect for differing religious beliefs and practice, and accommodation of these in patient care. [329(p.48)]

The evidence of how such statements are adopted, implemented and evaluated remains scant in the undergraduate level[330, 331] or the specialty training level in medicine,[332] or in nurse training.[333] It is equally unclear what underlying assumptions and theoretical foundations underpin the term 'spirituality' used in many of these programmes. The Synoptic Model could therefore serve a pedagogical function in the training of clinicians by providing descriptive and functional content to spirituality in relation to patients living with advanced disease. When the Model is illustrated with case studies, such as the narratives of the patient interviewed for this study, it also provides a framework to explain how spirituality is manifest

in the lives of patients, the impact of their illness, and the ways in which palliative care can engage with and provide opportunities to address the spiritual needs of patients.

What is distinctive about the Synoptic Model is the way in which it integrates the multiple aspects of spirituality within a dynamic system and challenges reductive notions often confined to religious-secular binaries and invariant beliefs and practice. The consequences of understanding spirituality as a complex enmeshed human capacity means that clinicians need to attend to the particularity of each patient's situation and how it might change. This does not require a new course or a new training tool but the integration of spirituality across existing modes of learning and development. For example in nursing the synoptic approach to spirituality could be mapped onto the person-centred nursing framework developed by McCormack and McCance.[334] Speciality training in palliative medicine could offer placements with palliative care chaplains who already provide student placements, and spiritual issues identified in this study could be used as examples in the Advanced Communication Skills Training Programme for cancer multidisciplinary teams.

Palliative care is the organising principle for multidisciplinary teamwork[335] and when this is effective spirituality moves out of a uni-disciplinary task and becomes the responsibility and concern of the team. The Synoptic Model supports a systemic view of spirituality and explains why good spiritual care is rarely achieved by the isolated efforts of a particular clinician but requires complementary perspectives and efforts of the team. Collaboration of team members around spirituality requires intentional development work and shared learning that can enable coherent approaches to spiritual care and a necessary level of trust

between team members on what is both a professional and personal subject. The Synoptic Model offers a theoretical base from which a rational for this approach can be developed, and when a team is functioning at the highest level of cooperation, the transdisciplinary, it is likely to create the best possible conditions to address spirituality in its complexity and as part of the whole person.[336]

Assessment

The Synoptic Model has one further implication for clinical practice: the assessment of spiritual needs. The data from this study suggests that patients would find it acceptable for spirituality to be assessed routinely as part of their care, and the Model also provides content areas that could be developed into valid and reliable components of an assessment. Whilst there are limitations to any assessment method the UK's *National Cancer Action Team* states there should be an on-going holistic assessment of patients' needs along the patient journey, and suggests that an assessment tool can provide the following benefits:

- It ensures that the patient's individual needs are the focus, not those which the healthcare professional undertaking the assessment thinks are the patient's needs.
- Used well, it provides a structure to the assessment conversation, enabling the patient's concerns to be prioritized.
- It ensures all areas of assessment are covered and not forgotten, or avoided.
- It becomes familiar to the patient and can be administered by several different healthcare professionals involved in their care.[337(p.12)]

This study used a semi-structured method to explore the spirituality of patients based upon items from an extant survey instrument. In most cases these acted as prompts to initiate subject areas and provided patients with target questions that they could address. The data demonstrates how patients respond to focussed questions about spirituality and suggests that direct rather than oblique approaches to this subject may help clinician-patient interactions. Possible reasons for this may be that clear communication goals minimise ambiguity and anxiety about the purpose of the discussion, normalise and validate the subject under discussion, and gives confidence to patients that they will be listened to. Patients in this study reported that they had been given no clear indication that clinicians were interested in spirituality, and patients therefore neither disclosed nor initiated such discussion. This communication barrier might be overcome by the use of an assessment tool, however, further research into effective communication strategies with patients about spirituality is needed in similar ways that theory and research have been developed to address unmet communication needs of patients.[338, 339] In addition this study suggests that specific research on the semantics of spirituality and patient-centred linguistics would be beneficial to improving clinician-patient dialogue.

The majority of instruments developed for use with patients are measures of constructs of spirituality for the purpose of research, some of which were identified in the literature review (Chapter 3). One of the few practical clinical tools developed to enable clinicians to gain an understanding of a patient's spirituality is known by the acronym *FICA*.[340] The goal of *FICA* is an aide-memoire for taking a 'spiritual history', which has been described as, "a set of questions designed to invite patients to share their religious or spiritual beliefs to help identify spiritual issues."

[341(p.165)] As the acronym suggests *FICA* has four basic questions: whether the patient has a faith or considers themselves spiritual or religious, its importance or influence in the patient's life, whether the patient is part of a spiritual or religious community, and how the patient would like the spiritual history to be addressed by the healthcare provider.

The average interview in this study took approximately 40 minutes, and even a well-resourced palliative care team is unlikely to be able to devote this time to a patient assessment, whereas *FICA* is possibly more achievable. The implication is that a first-stage screening tool, such as *FICA* could be used for all patients, and then a more in-depth spiritual assessment could be undertaken where indicated by a healthcare chaplain.[95] However, what this study reports is that spirituality in the lives of patients is pervasive and dynamic, and the Synoptic Model supports the integration of assessment across all the domains and disciplines of palliative care with on-going opportunities to raise and address spiritual needs. It may be that in high functioning multi-disciplinary teams this is standard practice, but at a more realistic level communication prompts and tools, such as *FICA*, combined with a multidisciplinary assessment framework following the Synoptic Model, could enhance the ways in which clinicians understand and respond to the spiritual needs of patients.

Research

Good clinical practice needs supporting by the best available evidence, and whilst this study needs replicating in different settings and testing with larger numbers of patients, it also has implications for other research in this field. The primary issue identified in many of the studies reviewed was their lack of theory coupled with an uncritical use of instruments that have been used in prior studies. In addition many of the instruments have

been developed in America and even when they are theoretically robust there may still need to be additional work to evaluate their validity and reliability for UK populations.

In considering how the research agenda should develop in this field more work needs to be done on the methodology and the methods for studies aiming to generate knowledge about spirituality. This is another issue that would benefit from inter-disciplinary understanding and debate. The humanities and the sciences have lessons to learn from each other, and questions to ask of one other, in relation to the study of spirituality. Finally, there are traditions that have their own forms of knowledge and understanding about spirituality that could contribute to the research agenda rather than just regarded as an object of study.

Limitations of the Study

The number of patients recruited for the questionnaire and interview were low and did not reach the forecasted figures based upon: the number of palliative care outpatients seen by the services involved, the estimated recruitment rates of clinicians, the relatively low response burden of the questionnaire, and the positive user-feedback and pilot results. The reasons for this include lower numbers of patients than expected invited to participate in the study, which suggested that clinicians might have been selecting patients on their own criteria in addition to those of the study. There was some evidence of this from discussions with clinicians from one particular service in response to which a study information sheet was issued clarifying the recruitment criteria.
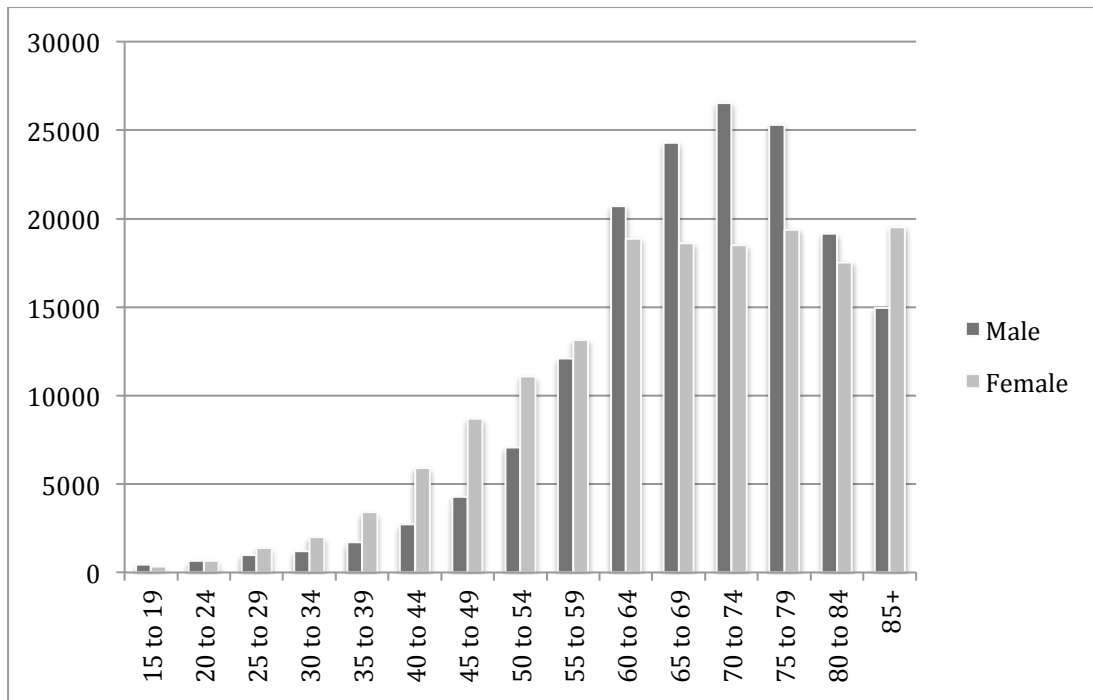
Figure 7: Cancer Cases by Age and Sex, UK Population, 2010[342]

A number of other studies were running at the same time that could have caused conflicts for clinicians in terms of achieving recruitment targets relating to portfolio and commercial studies. Patients invited to take part in this study may also have prioritised other studies, however a number of patients who talked about studies they were already involved with commented that they were happy to assist in any research provided it might benefit patient care. A further issue related to the population this study recruited from: patients with advanced chronic disease not responsive to curative treatment. Whilst these were all community-dwelling individuals, the level of support and specialist domiciliary care available means that many patients with advanced disease can remain at home until death and therefore clinicians were often selecting patients they considered well enough to participate. Despite this three out of nineteen patients died within a week of completing a questionnaire and one patient died within 24 hours of confirming arrangements for an interview.

Low response rates can introduce bias in studies typically where non-response is associated with outcomes but for this study the low sample sizes may bias the confirmation of the Synoptic Model and limit the generalization of the inferences made.
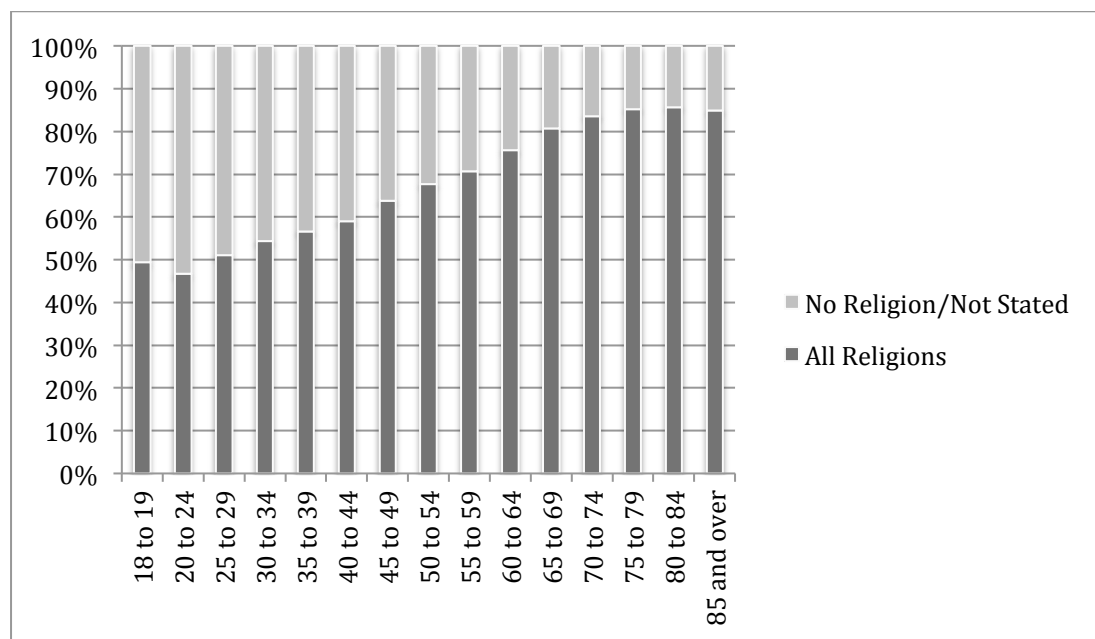

Figure 8: Religion by Age, Sheffield, 2011[343]

It is also possible that the study attracted people who were keen to make their views known, for example strongly positive or negative experiences of spirituality, although this was not evident form the data. Bender, for example, comments in her ethnographic study of spirituality in Cambridge, Massachusetts, that the interview far from being a neutral space can be the place, "… for spiritual practitioners to dialogically express the authority of their experiences in relation to a (secular) social science or science."[56(p.68)] There were two transcripts that contained significant amounts of testimonial narrative about faith and spiritual observances, but this seems a valid stance for people who are confident in their beliefs and whose belief systems are fundamental to their understanding of the world.

Whilst the specific characteristics of those who did not respond are unknown there are two known features of the population recruited from and to which the study sample can be compared, both of which relate to age. Firstly, cancer is an age-related disease with 63% of cancers diagnosed in people aged 65 and over.[342] (Figure 7) Cancer is also the primary diagnosis for the majority of patients receiving palliative care, and it is inevitable therefore that in the population targeted for this study the majority of people will be in this age group. The one exception was the young participant who had Cystic Fibrosis.

Secondly, age is a highly significant variable in relation to people's religious identity.[25] The 2011 Census included the voluntary question, 'What is your religion?' and the data for Sheffield demonstrate this variable clearly. (Figure 8) The questionnaire sample had a mean age of 64 years, and the interview sub-sample 78 years. In this age group approximately eight out of ten people report a religious identity in Sheffield, which is the same as the proportion reported in the interview sub-sample, but higher than the two out of three who reported a religious identity in the questionnaire sample. It seems reasonable to conclude therefore that the study sample was not unusual in either its religious or age profile when compared to the wider palliative care population in the UK.

The questionnaire used in this study adopts items from the *European Values Study* (EVS) that was developed by social and political scientists to understand beliefs, values and attitudes in the European context. Religion is a subject of the *EVS* and is limited to pre-determined categorical answers with the exception of the question of belonging to a religion that

requires the participant to provide the name. The *EVS* was originally designed for completion by an interviewer using response cards, which was not the method followed in this study. An advantage of having an interviewer present is the ability to answer queries and guide the participant's route through the questionnaire. However, a pilot of the questionnaire revealed no problems in navigating the questionnaire, clinicians involved in recruiting patients had no reports from patients of any difficulties, and patients did not indicate any difficulties in answering the questions. The question and response categories have accumulated face validity over the large samples and on-going phases of the *EVS*, and although they have not been validated with this specific population there is no reason why the constructs of religion used in the English *EVS* would be different for people with advanced disease.

The data derived from interviews included descriptive content by patients that it would be possible to verify through observation. Patients also provided accounts of meaning, values, beliefs and experiences that cannot be directly assessed by the investigator, and therefore it is necessary to rely on the patients' interpretive account. Coding relied on manifest content and a process of inference from the transcripts. Validity of interpretation rests on three critical relationships: that between the researcher and the participant, the researcher and the data, and the researcher and the reader.[344] The research design did not include any mechanism for the validation of findings by patients to limit the burden of participation in populations with advanced disease. Future methods to develop the Model, and in particular any clinical tools based upon it, would benefit from opportunities to disseminate findings to patients and more rigorous methods to test the construct validity.

Deductive content analysis depends upon stabilizing forms of data that have been generated in a specific time and place through the inter-personal dynamic of a human encounter. It is necessarily reductive, employs a particular hermeneutical approach, and asks specific questions of the data not directly asked of the person who provided the data. Atkinson, for example, reflects on two modes of reading his notes from an ethnographic study of surgery: the first mode is the analytical mode of disaggregating the text into fragments which can then be re-organised around themes; the second mode of analysis pays attention to the structure of the narrative and the rhetorical devices of its performance.[345] Alternative methods of analysis could be used to test the theory depending on the sample size, such as narrative analysis or factor analysis, and these could provide different approaches to validate or falsify the theory.

This study used the first available web-based application for research that generates quantitative and qualitative data. Computer-based tools have been available for decades and some authors suggest they introduce their own limitations into research. Gilbert, for example, considers that there are three levels of limitations to be overcome in using data analysis software: the tactile-digital divide from handling data on screen as opposed to manually on paper, near-sightedness that comes from the fine-grained view that software provides and which enables elaborate coding, and poor metacognitive awareness so that a user does not reflect on how the software might manipulate data or errors that can be introduced.[346] Most of the commentary concerns the application of software tools to grounded theory and the experience of new users learning to operate the software. More significantly, none of the current software enables a researcher to bypass the analytical method, but they do bring efficiency

and structure to the process and good data management, storage and retrieval.[347, 348] Web-based applications also support online collaboration by researchers who are not co-located. Limitations of digital tools appear overstated and until Artificial Intelligence, and semantic comprehension appear as functions in software and web-based applications, data analysis remains an intellectual exercise for the researcher.

Chapter 8
Conclusion

The aim of this study has been to make the spirituality of patients more intelligible to clinicians and therefore better integrated into the clinical processes that determine the care and support of people with advanced life-limiting conditions. At its simplest this has been a project of paying attention, firstly to the extant literature on the subject, and secondly to patients in palliative care. This exercise has been revelatory in both fields of enquiry but in different ways: much of the published research has lacked not only an explicit theoretical base and an organic understanding of spirituality, but the voice of the patient, using a proxy as substitute; patients who participated in interviews spoke eloquently about what spirituality meant to them, how it related to living with terminal illness, and the inattention of the healthcare system to this aspect of their lives. This contrast can be partly explained as an artefact of the research and publishing processes which inevitably cannot deal with the abundant data of real-world phenomena and must purposively choose to neglect, reduce and simplify. However, a fundamental argument in this thesis is that some of this filtering and limiting has rested upon assumptions and uncritical approaches to spirituality that have often gone unquestioned, particularly it seems in palliative care. This may have maintained an implied consensus and understanding of spirituality but it comes at a price, and that is a disservice to the complex and nuanced patterns of the lived spirituality of patients and the inhibited development of knowledge and practice in this field.

The strategy adopted in this study has been that of modelling, not of the statistical form that derives factors from the mathematical analysis of data and models causal influences using structural equations, but of the theoretical form that is an exercise in a priori reasoning to model an account that structures and describes a feature of the world whose representations can be evaluated and confirmed to a reasonable level of empirical adequacy. In this case the feature is that of spirituality in the lives of palliative care patients and the modelling process, despite the use of abstraction, has enabled a simple representation and elaboration of the complex nature of spirituality. The complexity arises because it is spirituality expressed and experienced through the embodied nature of human beings living with the consequences of irreversible decline. Consequently the model provides an integrated synopsis of the different perspectives and dimensions that constitute spirituality as a whole.

The Synoptic Model helps us think about spirituality in palliative care and to understand how it may be a feature of a patient's life. As a systematic approach the Synoptic Model contains both the general principles and fundamental properties of spirituality that have no direct isomorphic empirical equivalents but can provide the theoretical substrate for developing real-world applications, such as methods to assess the spiritual needs of patients, identify positive resources and recognise problematic aspects of spirituality that may need addressing. The Synoptic Model avoids the criticism levelled at other research methodologies for their selective inattention and superficial reductionisms because it does not collapse spirituality or explain it entirely through any one dimension and it takes a realist approach to the metaphysical commitments that some forms of spirituality entail. However, a model is not a biographical narrative of spirituality, and comprehending the model is not equivalent

to understanding the spirituality of a patient. The model is abstract and cannot warrant personal inferences but in its application it can point to the possible aspects of life in which spirituality can be manifest. Any attempt at understanding and interpreting the spirituality of another may be subject to personal bias and blind spots and therefore the Synoptic Model may ensure a more holistic approach and avoid the mistake of assuming that the part represents the whole.

A final conclusion comes from reflections on this research journey and the ways in which this study has provoked discussion about spirituality with patients, palliative care professionals, and academics. It seems that many people keep a respectful distance from the subject that inhibits what can often be lively, insightful and profound conversations. From a patient perspective this inhibition can be a very isolating experience and one that can devalue this aspect of their lives and neglect what can often be simple measures of support. From a clinical perspective this disengagement maintains spirituality in a mundane and anodyne form that rarely exhibits any of the breadth and depth that can make it so meaningful and inspiring to people. It can only be hoped that whatever other contribution this study makes it has made spirituality more comprehensible, legible and approachable to the many people who have made this journey possible.

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Studies included in the Literature Review

Author(s)	Date	Publication	Population	Sample	Measures (full or subcales)
Alcorn SR, Balboni MJ, Prigerson HG et al.	2010	J Palliat Med	Patients with diagnosis of an advanced, incurable cancer; active receipt of palliative radiation therapy (USA)	68	Fetzer Multidimensional Measure of Religiousness/Spiritualit, Religious Coping (RCOPE: Pargament et al)
Buxton F.	2007	Br J Nurs	Terminally ill patients (UK)	7	n/a
Chantal Chao CS, Chen CH, Yen M.	2002	J Nurs Res	Terminally ill patients of a hospice ward of a teaching hospital (Taiwan)	6	n/a
Fegg MJ, Brandstätter M, Kramer M et al.	2010	J Pain Symptom Manage	Palliative Care patients (Germany)	100	Schedule for Meaning in Life Evaluation (SMiLE)
Grant E, Murray SA, Kendall M et al.	2004	Palliat Support Care	Patients with a range of advanced malignant and nonmalignant illnesses (UK)	20	n/a
Hanson LC, Dobbs D, Usher BM et al.	2008	J Palliat Med	Patients wiht a prognosis <1 year (USA)	38	a validated two-item screen for depressive symptoms
van Laarhoven HWM, Schilderman J, Vissers KC, Verhagen CA, Prins J.	2010	J Pain Symptom Manage	Palliative cancer patients who were no longer receiving anti-tumor treatments and were facing death. (The Netherlands)	68	Images of God Scale; COPE-Easy abbreviated version (Carver et al 1989)
Hart A, Kohlwes RJ, Deyo R, Rhodes LA, Boweb DJ.	2003	Am J Hosp Palliat Care	Terminally ill patientsenrolled in hospice programs (USA)	16	n/a
Hebert RS, Jenckes MW, Ford DE, O'Connor DR, Cooper LA.	2001	J Gen Intern Med	Patients hospitalized with a life-threatening illness (USA)	22	n/a
Hermann CP.	2001	Oncol Nurs Forum	Terminally ill hospice outpatients (USA)	19	n/a

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Author	Year	Journal	Population	N	Measures
Hermann CP.	2007	Oncol Nurs Forum	Patients in inpatient and outpatients hospices (USA)	100	Spiritual Needs Inventory (SNI: Hermann), Cantril Ladder of QoL
Hills J, Paice J, Cameron J, Shott S.	2005	J Palliat Med	Patients referred to the Palliative Care Consult Service with a lifethreatening diagnosis requiring aggressive symptom management and end of life care planning (USA)	31	Brief Religious Coping Scale (RCOPE: Pargament et al), Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being (FACIT-Sp), FICA (Puchalski), National Comprehensive Cancer Network Distress Management Assessment Tool, Profile of Mood States—Short Form (POMS-SF).
Hui et al	2011	Am J Hosp Palliat Med	Palliative care inpatients (USA)	113	Edmonton Symptom Assessment scale (ESAS), 7-item MD Anderson chaplains' clinical assessment tool of Sp distress
Ireland J.	2010	Br J Nurs	Woman with breast cancer (UK)	1	n/a
Kawa M, Kayama M, Maeyama E et al.	2003	Support Care Cancer	Patients with cancer who were inpatients at palliative care units (Japan)	11	n/a
Kernohan W, Waldron M, McAfee C, Cochrane B, Hasson F.	2007	Palliat Med	Patients admitted to the inpatient unit or attending day hospice sessions (UK)	62	n/a
Kub JE, Nolan MT, Hughes MT et al.	2003	Appl Nurs Res	Patients diagnosed with amyotrophic lateral sclerosis, advanced cancer, or congestive heart failure (USA)	114	n/a

Authors	Year	Journal	Population	N	Instruments
Mako C, Galek K, Poppito SR.	2006	J Palliat Med	Patients with advanced cancer admitted to a palliative care hospital (USA)	57	Non-validated scales to measure: physical pain, spiritual pain, religiosity, severity of illness and level of depression
McGrath P.	2004	Support Care Cancer	Hospice patients with a terminal cancer diagnosis with less than 6 months to live (Australia)	14	n/a
Miller B.	2005	J Sex Res	People living with AIDS (America)	1	n/a
Mishra S, Bhatnagar S, Philip FA et al.	2010	Am J Hosp Palliat Care	Patients with advanced cancer admitted to the a Pain and Palliative Care Unit (India)	100	n/a
Mok E, Wong F, Wong D.	2010	J Adv Nur	Patients with incurable cancer and referred to the inpatient palliative care service (Hong Kong)	15	n/a
Mundle, RG	2011	Palliat Support Care	Hospice patients (Canada)	2	n/a
Murphy PL, Albert SM, Weber CM, Del Bene ML, Rowland LP.	2000	Neurology	Patients with Amyotrophic lateral sclerosis ALS (USA)	46	Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-Sp), preferences and use of technology, Beck Depression Inventory, Beck Hopelessness Scale, Attachment to Life, Revised Collett-Lester Fear of Death Scale.
Murray SA, Kendall M, Boyd K, Worth A, Benton TF.	2004	Palliat Med	People dying of lung cancer or heart failure (UK)	40	n/a
Norum J, Risberg TSolberg E.	2000	Support Care Cancer	Hospitalised patients with advanced cancer, no present therapy and only palliation (Norway)	20	n/a

Author	Year	Journal	Population	N	Measure
Osse BH, Vernooij-Dassen MJ, Schade E et al.	2002	Patient Educ Couns	Cancer patients with metastasised disease (The Netherlands)	40	97 item "checklist" of items covering range of dimensions including spiritual
Park C.	2008	Palliat Support Care	Patients with severe congestive heart failure who were ineligible for transplantation (USA)	111	Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-Sp) subscales, longevity estimate scale (Sulmasy et al), Clinical indices, Subjective functioning indices, Depressive symptoms CESD (Radlof), Satisfaction with Life Scale (Diener et al)
Penman J, Oliver M, Harrington A.	2009	Aust J Adv Nurs	Palliative care clients diagnosed with a life-limiting condition (Australia)	4	n/a
Scobie G, Caddell C.	2005	Internet J Pain, Symptom Control and Pall Care	Advanced terminally ill patients within 2 specialized care hospices (UK)	120	McGill Quality of Life Questionnaire – Scottish Version (MQOL-SV),
Stanworth R.	2004	Oxford University Press	Hospice patients (UK)	25	n/a
Stephenson P, Draucker C, Martsolf D.	2003	J Hosp Palliat Nurs	Hospice patients (USA)	6	n/a
Sulmasy D.	2006	J Am Med Assoc	Patient with metastatic pancreatic cance	1	n/a
Tamura K, Kikui K, Watanabe M.	2006	Palliat Support Care	Cancer Patients admitted to general hospital (USA)	2	n/a
True G, Phipps EJ, Braitman LE et al.	2005	Ann Behav Med	Patients diagnosed with advanced lung cancer or colon (USA)	68	Fetzer (adapted) + Daily Spiritual Experience Scale (Underwood & Teresi 2002)
Vallurupalli et al	2012	J Support Oncol	Patients with advanced cancer receiving palliative radio-therapy (USA)	69	Fetzer + RCOPE + Koening Religious Coping Index

Watts JH.	2008	Iln Crises Loss	Patient with multiple myeloma (UK)	1	n/a
Winkelman et al	2011	J Palliat Med	Cancer patients receiving palliative radiotherapy (USA)	69	Fetzer Multidimensional Measure of Religiousness/Spirituality
Yardley S, Walshe C, Parr A.	2009	Palliat Med	Hospice Inpatients, outpatients or day care patients (UK)	20	n/a

Appendix B

Ethical Approval

NIS©HR

Gwasanaeth
Moeseg
Ymchwil

RES
Research
Ethics
Service

Dyfed Powys Research Ethics Committee
Postal address: PO Box 108
Building 1
St David's Park
Carmarthen SA31 3WY
(for sat nav SA31 3HB)

Telephone : 01267 225045
Fax : 01267 225226
E-mail : sue.byng@wales.nhs.uk
Website : www.nres.nhs.uk

Revd Mark Cobb
Senior Chaplain & Clinical Director of Professional Services
Sheffield Teaching Hospitals NHS Foundation Trust
Directorate of Professional Services
Royal Hallamshire Hospital, Glossop Road
Sheffield
S10 2JF

4 October 2012

Dear Revd Cobb

Study title:	**A study of palliative care patients to investigate how spirituality operates in their lives.**
REC reference:	**12/WA/0313**
Protocol number:	**STH16428**

The Proportionate Review Sub-committee of the Dyfed Powys Research Ethics Committee reviewed the above application on 03 October 2012.

Ethical opinion

With regard to potential for distress Reverend Cobb explained that it was the decision of the patient and if they agreed a 'cause for concern' slip would be completed and passed to the clinician.

With regard to confidentiality Reverend Cobb explained that patients medical records were being accessed because it would be helpful knowing the primary diagnosis and medication beforehand and it was felt that asking patients at the interview could be distressing for them.

Reverend Cobb took on board the Committee's comments with regard to anonymity being assured but not necessarily guaranteed if direct quotes were used and audio recordings were played to others.

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

GIG
NHS
WALES
Bwrdd Iechyd
Addysgu Powys
Powys Teaching
Health Board

Ariennir gan
Lywodraeth Cymru
Funded by
Welsh Government

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

The Information Sheet
- alter 'compensation' to 'paid' or 'pay' to avoid participants thinking you are making amends for something that could go wrong.
- add a telephone contact number should anyone wanted to ask questions.
The Consent Forms - remove the yes and no boxes and only have an initial box.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved were:

Document	Version	Date
Covering Letter		27 September 2012
Interview Schedules	5	14 December 2011
Investigator CV	1	27 June 2012
Letter of invitation to participant	1	29 August 2012
Flow Chart	3	31 May 2012
Academic Supervisor's 1 CV		01 August 2012
Academic Supervisor 2 CV		27 June 2012
Participant Consent Form	2	29 August 2012
Participant Consent Form: Interview	2	29 August 2012
Participant Information Sheet	1	01 September 2012
Protocol	0.7	29 August 2012
Questionnaire	5	14 December 2011

REC application	3.4	28 September 2012
Peer review letter		18 June 2012

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/WA/0313	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Sue By

Mr Owen Hughes
Chair

Enclosures:	*List of names and professions of members who took part in the review*
	"After ethical review – guidance for researchers"
Copy to:	*Anna Leesley, Clinical Research Office*

Appendix C

NHS Project Authorisation

17 October 2012

Revd Mark Cobb
Clinical Director Professional Services
Clinical Directorate of Professional Services
14 Claremont Crescent
Sheffield

Dear Revd Cobb

Project Authorisation
NHS Permission for Research to commence

STH ref:	STH16428
NIHR CSP ref:	Not applicable

REC ref:	12/WA/0313	
MHRA ref:	**CTA no.:** Not applicable	**EudraCT no.:** Not applicable

Study title: A study of palliative care patients to investigate how spirituality operates in their lives

Chief Investigator: Revd M Cobb, Sheffield Teaching Hospitals
Principal Investigator: Revd M Cobb, Sheffield Teaching Hospitals

Sponsor: Sheffield Teaching Hospitals
Funder: Unfunded
URMS ref: Not applicable

The Research Department has received the required documentation as listed below:

1. **Sponsorship Agreement**   Not applicable
    Clinical Trial Agreement   Not applicable
    Material Transfer Agreement   Not applicable
    Funding Award Letter   Not applicable

2. **Monitoring Arrangements**   Not applicable

3. **STH registration document**   R & D Form
    M Cobb 26 Sep 12

4. **Evidence of favourable scientific review**   University of Liverpool

5. **Protocol – final version**   Version 0.7 29 Aug 12

6. **Participant Information sheet**   Version 2 04 Oct 12

7. **Consent form**   Version 3 04 Oct 12
    Consent form- Interview   Version 3 04 Oct 12
8. **Letter of indemnity arrangements**   NHS indemnity
    Insurance Certificate

9. **ARSAC certificate / IRMER assessment**   Not applicable

10. **Ethical review- Letter of approval from NHS REC**   Dyfed Powys REC
    04 Oct 12

11. **Site Specific Assessment**   SSI Form
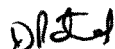   STH R&D 16 Oct 12

Ref: STH16428/AL   1

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STH16499\STH16428\section 5\pSH_Permission for research Letter16428.doc
Chairman: David Stone OBE • Chief Executive: Andrew Cash OBE

smoke-free
hospitals 238

12. Clinical Trial Authorisation from MHRA	Not applicable

13. Evidence of hosting approvals STH Finance Form
- STH Principal Investigator M Cobb 10 Oct 12
- Clinical Director S Pownall 11 Oct 12
- Research Finance D Patel 17 Oct 12
- Data Protection Officer P Wilson 12 Oct 12

14. Honorary Contract/Letter of Access Not applicable

15. Associated documents
Interview schedule Version 5 14 Dec 11
Letter of invitation to participant Version 1 29 Aug 12
Questionnaire Version 5 14 Dec 11

This project has been reviewed by the Research Department. NHS permission for the above research to commence has been granted on the basis described in the application form, protocol and supporting documentation on the understanding that the study is conducted in accordance with the Research Governance Framework, GCP and Sheffield Teaching Hospitals policies and procedures.

Yours sincerely

Professor S Heller
Director of R&D, Sheffield Teaching Hospitals NHS Foundation Trust
Telephone +44 (0) 114 2265934
Fax +44 (0) 114 2265937

Ref: STH16428/AL 2

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Appendix D

Patient Information

An invitation to take part in a research study

We would like to invite you to take part in a research study. Please read the following information carefully. Feel free to talk to others about the study if you wish and take your time deciding whether or not you wish to take part.

What is the study about?

We want to understand better the ways in which patients experience and express their spirituality to try and improve the care we provide. Palliative care has always been interested in the various ways that illness affects peoples' lives. This means that in addition to treating physical symptoms we also want to support people with their social, psychological and spiritual needs. Spirituality is about the ways in which people seek purpose and meaning in their lives. Some people do this through a religion or faith, whilst for others it is something more individual and private.

Why have I been invited to take part?
You have been invited to take part in this study because you are receiving palliative care and not for any other reason. We hope to recruit around 100 patients to take part. It does not matter for the purpose of this study whether you think of yourself as religious, spiritual, agnostic or atheist because we want to know about the different ways that people think about spirituality.

Who is organising the study?

This study is being organised and run by the Academic Palliative and Supportive Care Studies Group at the University of Liverpool in collaboration with Sheffield Teaching Hospitals NHS Foundation Trust and St Luke's Hospice.

Do I have to take part?

No, it is up to you whether or not you want to take part. Deciding not to take part will not affect the care you receive from your doctor or nurse now or in the future.

If I take part, what will happen to me?
If you agree to take part, we will ask you to sign a consent form. You will then be sent a short questionnaire to complete and return to us in a pre-paid envelope that we will provide. We will also give you the option of completing the questionnaire online if you prefer instead of filling in a paper copy.

We may also invite you to take part in a single interview to talk about what spirituality means to you. If you complete a questionnaire you are not committed to take part in an interview, we will write to you separately about the interview and it will be up to you whether or not you want to do an interview. If you choose to do an interview we will ask you to sign a consent form for the interview.

What happens next?
If you have understood what this study is about and would like to take part in it then you will need to complete the Consent Form and return it to us in the pre-paid envelope provided.

What else will I need to know?
If you agree to take part in the study we will collect some information from your medical records about your diagnosis. Only the researcher or your clinical staff will be allowed to collect this information.

What will happen if I don't want to carry on with the study?
You can leave the study at any time without giving a reason. This will not affect the care you receive now or in the future. If you do decide to leave the study we will use the information we have collected up to that time, unless you tell us otherwise, and we will not collect any more.

2

Are there any disadvantages or risks in taking part?

If you take part you will have to find a small amount of time to answer a short questionnaire. If you are invited to take part in an interview you will need to find time to meet with the researcher for about 45 minutes. There are no risks in taking part in this study.

What are the possible benefits of taking part?

By taking part in this study you will contribute to improving our understanding of the needs of patients and this may help us provide better care and support. This could be of benefit to you and other .patients in the future, but we cannot promise the study will be of any help to you.

Will I be compensated for taking part in the study?

No, there is no compensation for participating in this study.

Has the study been approved?

All research is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been approved by the *N* Research Ethics Committee. The study has also received feedback from the Palliative Care Studies Advisory Group based in Sheffield, that consists of service users, carers, and advocates.

Will my taking part in this study be kept confidential?

Yes, all the personal information collected about you during the research will be kept strictly confidential and stored in accordance with the Data Protection Act. Only staff on the research team at the University of Liverpool will be able to see the information collected about you. A copy of your consent forms for this study will be added to your medical records.

What will happen to the findings of the study?

Once the research study is completed we hope to have a better understanding of what spirituality means to patients and we will write this up for publication in scientific journals and presentation at scientific conferences. No patients will be identified in any report, publication or presentation and all the results will be anonymous.

3

What if I am unclear about the study and what to ask more questions?

Please don't hesitate to ask if anything is unclear or if you would like more information. You can talk to your doctor or nurse, or contact Mark Cobb, who is the researcher:

By post:

     Mark Cobb
     Directorate of Professional Services
     Royal Hallamshire Hospital
     Glossop Road
     Sheffield
     S10 2JF

By email: Mark.Cobb@sth.nhs.uk

Thank you for reading this leaflet and considering taking part in the study

Appendix E

Patients' Questionnaire

Understanding Spirituality Questionnaire

We have some questions that we would like to ask you. For each question there is a choice of answers. Please choose the answer that is closest to what you think.

There are no right or wrong answers. Simply tick the box next to the answer you have chosen, or write an answer in the box next to the question where it asks.

People usually take no more than 20 minutes to complete these questions.

We would now like to know what you thought about answering the questions in this survey.

10. How difficult did you find it to answer these questions?

☐ very difficult
☐ quite difficult
☐ not difficult
☐ not at all difficult
☐ I don't know

11. How happy were you talking about spiritual and religious matters?

☐ very happy
☐ quite happy
☐ not happy
☐ not at all happy
☐ I don't know

12. How acceptable would you find it for spirituality to be assessed routinely as part of your care?

☐ very acceptable
☐ quite acceptable
☐ not acceptable
☐ not at all acceptable
☐ I don't know

If you have any other comments you would like to make about completing this questionnaire please write them in this box:

Thank you for completing this questionnaire.

Please fold it in two and return it in the pre-paid envelope that came with the questionnaire.

1. What is your ethnic group?

Tick one option that best describes your ethnic group or background like this: ✔

White:
- ☐ English / Welsh / Scottish / Northern Irish / British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ A White background not listed

Mixed / Multiple ethnic groups:
- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ A Mixed / Multiple ethnic background not listed

Asian / Asian British:
- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ An Asian background not listed

Black / African / Caribbean / Black British:
- ☐ African
- ☐ Caribbean
- ☐ A Black / African / Caribbean background not listed

Other ethnic group:
- ☐ Arab
- ☐ An ethic group not listed

2. Which of these statements comes closest to your beliefs?

- ☐ there is a personal God
- ☐ there is some sort of spirit
- ☐ I don't really know what to think
- ☐ I don't think there is any sort of spirit or God
- ☐ I don't know

3. Whether or not you go to a place of worship or not (such as a church), would you say you are:

- ☐ a religious person
- ☐ not a religious person
- ☐ a convinced atheist
- ☐ I don't know

Now continue with Question 4 on the opposite page.

4. Whether or not you think of yourself as a religious person, how spiritual would you say you are, that is how strongly are you interested in the sacred or supernatural?

- ☐ very interested
- ☐ somewhat interested
- ☐ not very interested
- ☐ not at all interested
- ☐ I don't know

5. On a scale of 1 to 10 how important is God in your life, where 1 means not at all important and 10 means very important? (circle a number to answer this question)

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

not at all important   very important

6. How important in your life is religion?

- ☐ very important
- ☐ quite important
- ☐ not important
- ☐ I don't know

7. Do you belong to a religion?

- ☐ Yes - please write what it is in this box: [____]
- ☐ No ←
  If you answered No, were you ever a member of a religion?
  - ☐ Yes – please write what it was in this box: [____]
  - ☐ No

8. Do you find you get comfort and strength from religion or not?

- ☐ Yes
- ☐ No
- ☐ I don't know

9. Do you take moments of prayer, mediation or contemplation or something like that?

- ☐ Yes
- ☐ No
- ☐ I don't know

Now continue with Question 10 on the back page.

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Appendix F

Note of Concern

Study: **Understanding the spiritual needs of patients**
NOTE OF CONCERN FOR HEALTHCARE TEAM

The following person consented to be interviewed as part of a research study. During the interview the person disclosed concerns that the researcher considered should be brought to the attention of the healthcare team with the consent of the patient.

Title (e.g. Miss, Mr, Dr etc.)	
First name(s)	
Last name/Surname	
Address	
Phone number	

Summary of concerns:

Consent of Patient

I agree that this note of concern can be shared with my healthcare team.

_____   _____   _____
Name of Participant   Date   Signature

Researcher: Mark Cobb, Clinical Directorate of Professional Services, Royal Hallamshire Hospital, Glossop Road, Sheffield. S10 2JF. Tel: 0114 271 3327. Email: mark.cobb@sth.nhs.uk

Publication:

Cobb M, Dowrick C, Lloyd-Williams M. What can we learn about the spiritual needs of palliative care patients from the research literature? *Journal of Pain and Symptom Management* 2012;43:1105-19

Publication:

Cobb M. Belief. In: Cobb M, Puchalski C, Rumbold B, eds. *Oxford Textbook of Spirituality in Healthcare*. Oxford: Oxford University Press; 2012

Appendix I

Publication:

Cobb M, Dowrick C, Lloyd-Williams M. A Conceptual Model of Spirituality in Palliative Care. 7th World Research Congress of the European Association for Palliative Care (EAPC). *Palliative Medicine* 2012;26(4) 542-543

Appendix J

Publication:

Cobb M, Dowrick C, Lloyd-Williams M. Understanding spirituality: a synoptic view. *BMJ Supportive & Palliative Care* 2012;2:339-43