An exploration of the perceptions and practice of community nursing staff within two care settings in relation to spiritual distress at the end of life.

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by

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Dedications and personal thanks

Dedicated to my Father, Brian Leonard Laker, who sadly died whilst this thesis was being written. Much loved, greatly missed and a constant source of encouragement and inspiration throughout my life.

I'd also like to warmly thank all those who encouraged me to persevere with this study, and not to give up, particularly my wife Carol and our children Benjamin, Harriet, Zachary, Gabriella and Olivia.

In addition, I'd like to sincerely thank my Supervisors Dr Harshad Kaval and Prof Doug MacInnes, for their ongoing wisdom, insight, advice and encouragement. Without their help, this thesis would not have been written.

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List of abbreviations

KCHFT: Kent Community Health Foundation Trust

PH: Pilgrim's Hospices

EOL: End of Life

QOL: Quality of Life

MDT: Multi-Disciplinary Team

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1 Chapter 1: Thesis overview

1.1 Chapter layout

This thesis is structured as follows:

Chapter 1 describes the thesis framework, outlines the principal motivation for the study and sets the study within the context of community nursing. This chapter also lists the central research questions upon which the study is based.

Chapter 2 describes the research design, methodology and theoretical framework for the study, incorporating my journey towards defining and clarifying my own ontology and epistemology as a researcher. The chapter also clarifies why a qualitative methodology was used for the study.

Chapter 3 includes a literature review focusing upon definitions of spiritual distress and situates this within the wider context of present difficulties in defining spirituality, spiritual care and spiritual needs within a health-related context. I also offer my own definition of spiritual distress, based upon current literature and my own experience within community nursing. This chapter also seeks to identify some of the many variables that may influence the experience of spiritual distress in EOL patients within a community setting, examines suffering and distress at the EOL and identifies issues pertaining to ambiguity in terminology, obtaining a spiritual history and challenges related to assessment tools and their use.

Chapter 4 examines the research methods employed for the study, describes my own background, beliefs and likely biases as a researcher, outlines the analytical framework utilised for data analysis (thematic analysis) and considers rigour within qualitative research.

Chapter 5 is a data chapter which focuses on coding and thematic analysis of interview transcript data and relates this to the specific research questions of the study.

Chapter 6 is a discussion chapter which attempts to relate key findings to the research questions integral to the study and the earlier literature review.

Chapter 7 contains a summary of the study, implications for community nursing practice, a conclusion and suggestions for future research.

This is followed by a Bibliography and relevant appendices.

1.2 Abstract

High quality end of life (EOL) care requires a range of holistic approaches. Patients approaching the end of their lives frequently experience a variety of debilitating and distressing symptoms (e.g. nausea, breathlessness, or pain). Patients may also experience spiritual distress: a multi-faceted form of existential anxiety which can include fear, regret, loss of connection, loss of hope, and loss of meaning.

Spiritual distress within EOL care appears to be influenced by a lack of international consensus regarding definition, uncertainty regarding assessment tools and their use, and variation in specific interventions used to help relieve such distress. This conceptual ambiguity appears to directly influence patient care, both in the identification and assessment of spiritual distress and in relation to specific interventions utilised to alleviate such distress.

The assessment of spiritual distress in a community context is also problematic: most published studies to date are based within acute hospital settings. None would appear to describe how spiritual distress is perceived/experienced by community nurses within different care settings or attempt to evaluate spiritual distress as experienced by patients dying within their own homes. Likewise, literature describing the use of assessment tools within a community setting, specific interventions to alleviate such distress, and how practitioners perceive the effectiveness of such interventions appears scarce.

This study explores the perceptions of twenty-one community nurses (11 hospice, 10 NHS) regarding spiritual distress, as observed in EOL community-based patients. An initial literature review first attempts to situate spiritual distress within the wider backdrop of spirituality, spiritual care and spiritual needs. A qualitative investigative study was then undertaken using semi-structured interviews. Textual data were subsequently transcribed and analysed using thematic analysis, as described by Braun and Clarke (2006).

The study's findings suggest that spiritual distress is a challenging phenomenon for practitioners to effectively manage within community nursing. Ambiguity associated with such distress would also appear to directly influence the quality and delivery of nursing care for EOL patients within both care settings.

1.3 Content and rationale of this study: why and so what?

This study has arisen from my experience as a Community Nurse in the southeast of England. Part of my role involved caring for patients designated EOL. The experience raised important questions, relating both to the lack of definition surrounding the term itself but also the way in which patients were often treated using a cocktail of drugs administered sub-cutaneously via a battery-operated syringe driver. Current practice commonly utilises opioids (e.g. Morphine Sulphate) to alleviate pain, anti-emetics (e.g. Cyclizine) to help alleviate nausea or vomiting, anti-cholinergics (e.g. Glycopyrroium Bromide) to reduce troublesome secretions and appropriate sedation (e.g. Midazolam) to help relieve anxiety. These drugs can be used in any combination according to the patient's specific needs and administered in varying dosages. The McKinley T34 syringe driver is described in Appendix 4. Alongside such physical symptoms, I observed that patients frequently struggled with anxiety/distress which was existential in nature. For example, 'distress' can become evident pertaining to loss of hope, unresolved relational strain, fear of the future and/or fear of death. Little attempt was made to assess such anxieties or to address them other than via sedation, a clinical practice highlighted by Claessens et al. (2008). Work by Caldeira and Timmins (2017) allowed me to identify more accurately the phenomenon I was observing and introduced me to the term 'spiritual distress'. Their paper also provided the motivation for my undertaking a more extensive literature search to ascertain if specific research has been undertaken on this subject, within a community setting.

My reasons for studying this topic were therefore:

1. The topic directly relates to a key aspect of the care currently administered to EOL patients in a community setting. It also raised concerns for me personally regarding current community nursing practice.
2. Spiritual distress in EOL community-based patients appears to be a phenomenon which has received little attention in either UK or other nursing-based literature: my hypothesis is that spiritual distress may affect a significant percentage of such patients and yet appears to lack standardised protocols for its alleviation. This study therefore attempts to address what appears to be a gap in current nursing literature.

3. A greater understanding of this phenomenon and how it is currently managed would allow care to be reviewed and improved, should deficiencies in care be evident.
4. The study addresses a current aspect of nursing care which may directly influence the QOL of community-based patients who are likely to be in the last days/weeks of life.

1.4 How is the term situated within community nursing?

A literature search revealed that the term 'spiritual distress' appears to have minimal usage within community nursing settings (3.13). In my experience the term also carries considerable ambiguity amongst community nursing staff, as do the more generic terms 'spirituality', 'spiritual care' and 'spiritual needs'.

Central to this study was an attempt to elucidate if the language, thinking and practice of community nursing refers to the concept of spiritual distress when caring for EOL patients. It was therefore important to gain an understanding of the perceptions of community nursing practitioners. This has similarities to nursing discussions regarding the experience of physical pain and its alleviation. Essential to effective pain management is the acceptance on the part of the practitioner that pain is personal, subjective and real. As McCaffery (1965) stated in her now historic definition of pain: 'pain is whatever the experiencing person says it is, existing whenever and wherever the person says it does' (McCaffery, 1968, p.68). It seems appropriate to apply the same reasoning to spiritual distress, a phenomenon also referred to in related literature as spiritual pain (see 3.11).

1.5 Research Questions

This study explores perceptions of community nursing staff within two different care settings regarding the phenomenon of spiritual distress, as observed in EOL community-based patients. The study seeks to address the following research questions:

1. How are the terms spirituality, spiritual care and spiritual needs perceived by community nurses within the different care settings?
2. How is spiritual distress perceived by community nurses within the different care settings?
3. How is spiritual distress identified by community nurses in the different care settings?

4. What specific interventions (forms of practice) are utilised by community nurses in the different care settings to help alleviate spiritual distress?
5. Is there any commonality of practice between the different care settings?

Three key terms are ‘perception’, ‘definition’ and ‘conceptualise’. These are defined below.

The term ‘perception’ originates from the Latin ‘percipere’: (to seize or understand) and refers to *‘the ability to see, hear, or become aware of something through the senses’ or ‘the way in which something is regarded, understood or interpreted’* (Dictionary: Google UK).

This study therefore aims to identify how spiritual distress is understood or interpreted by community nursing staff within the two practice contexts, as practitioner understanding is likely to directly influence those interventions utilised by participants.

The term ‘definition’ originates from the Latin definire (‘set bounds to’) and refers to: ‘*an exact statement or description of the nature, scope, or meaning of something’* (Dictionary: Google UK) or *‘the act of making something distinct, or clear’* (Dictionary.com).

The study also aims to ascertain participant descriptions of the nature and meaning of spiritual distress, as encountered in EOL patients within a community setting.

The origin of the term ‘conceptualise’ is unclear, but the term refers either to *‘forming an idea or theory in the mind*’ (Cambridge online dictionary) or ‘*creating mentally’* (the freedictionary.com).

1.6 Data collection

This exploratory study utilised twenty-one face to face semi-structured interviews with a range of practitioners from two different community-based EOL contexts as an attempt to analyse current policy and practice. Interviews were conducted face to face, in a suitable room at the participants workplace. Semi-structured, in depth interviews are frequently used by health professionals (Whiting, 2008). Such interviews should be ‘personal and intimate encounters in which ‘open, direct, verbal questions are used to elicit detailed narratives and stories’ (DiCicco-Bloom and Crabtree, 2006). Semi-structured interviews are conducted conversationally with a single interviewee, and utilise a blend of closed and open questions, often accompanied by additional questions which aim to explore specific participant comments in greater depth.

Approximately sixty minutes is deemed to be a reasonable maximum length of such interviews, to minimise fatigue of both interviewer and participant (Adams, 2015). For this study, the average interview length was 40 minutes. This could be considered a relatively short time for interviews but reflected both the workplace demands of the participants, the framework used for questions, and participants frequently struggling to articulate answers to some questions, particularly those which focused upon attempts to elucidate definitions of key concepts such as spirituality and spiritual care. This time frame is also apparent in a range of other qualitative studies which utilise semi-structured interviewing (e.g., Campbell et al., 2016; Dong et al., 2016; Husband, 2020).

Each of the participants were also interviewed at their own workplace, as part of a busy and pressured shift. In this context, a significantly longer timeframe for interviews would have been unrealistic. I was also very grateful that participants allowed me an hour of their time during a typically demanding working day. Critical reflection of the interview data (see section 4.11) also found that the interview data obtained provided a rich and broad source of information.

Data collection occurred within two clinical contexts:

- Kent Community Health Foundation Trust (KCHFT).
- Pilgrim's Hospices, Kent.

The study did not involve contact with either patients or their families. Instead, it focused upon the perceptions of community staff towards the phenomenon of spiritual distress, as encountered in their care of EOL patients.

As the hospices utilised for data collection all have inpatient, day hospital and specialist community nursing teams, the term community nursing staff describes both hospice and NHS participants.

1.7 Other Intended Research Outcomes

These include:

- To produce research which informs current practice (i.e. 'actionable intelligence').
- To produce research findings which are comprehensible to practitioners.

- To produce research findings which are applicable to the community-based contexts utilised within the study.
- To produce research findings which may facilitate change in practice within these contexts.
- To provide recommendations for nursing education and ongoing professional practice which may help improve nursing care within EOL community-based care.

My intention is that this research will have value to patients, participants, nurses within both community settings and wider society.

2 Chapter 2: Research Design

This chapter describes my rationale for adopting a qualitative methodology, examines key definitions and clarifies my own ontological and epistemic positions. The chapter also seeks to differentiate between ‘methodology’ and ‘methods’ and identifies some key axiological perspectives which underpin the study. The chapter also demonstrates my own rationale concerning the decision to utilise thematic analysis as described by Braun and Clark (2006) as the primary method of data analysis employed for the study.

2.1 Rationale for adopting a qualitative methodology

A consideration of the primary research questions, the nature of the phenomenon (spiritual distress) and the practitioner experience this research was attempting to evaluate resulted in the study utilising a qualitative methodology in conjunction with qualitative methods of data collection.

Qualitative research describes a research approach employed within a range of paradigms and frameworks and which appears in a wide range of published studies (Mason, 2002). Qualitative research also utilises a range of ontological and epistemological underpinnings and assumptions. Qualitative approaches are particularly valuable when exploring complex situations in the natural setting where specific variables remain unidentified. Qualitative methods are therefore concerned with exploring the experiences of individual participants using inductive methodologies (i.e. seeking to create new knowledge rather than testing the validity of a pre-existing hypothesis), so attempting to make sense of or interpret a specific phenomenon. The use of such qualitative methodologies enables the study of individuals in their natural surroundings, employing methods of data collection and analysis that are flexible and which allow the exploration of those issues relevant to participants and their context (Ritchie et al., 2014). Spiritual distress is one such phenomenon. A summary of some common characteristics of qualitative research is shown below.

<u>Common characteristics of qualitative research</u>

- Aims and objectives that are directed at providing an in-depth and interpretive understanding of the social world of research participants by learning about the sense they make of their social and material circumstances, their experiences, perspectives and histories.

- The use of non-standardised, adaptable methods of data generation that are sensitive to the social context of the study and can be adapted for each participant or case to allow the exploration of emergent issues.
- Data that are detailed, rich and complex (again, the precise depth and complexity of data may vary between studies).
- Analysis that retains complexity and nuance and respects the uniqueness of each participant or case as well as recurrent, cross-cutting themes.
- Openness to emergent categories and theories at the analysis and interpretation stage.
- Outputs that include detailed descriptions of the phenomena being researched, grounded in the perspectives and accounts of participants.
- A reflexive approach, where the role and perspective of the researcher in the research process is acknowledged. For some researchers, reflexivity also means reporting their professional experiences of the field.

(Ritchie et al., 2014, p.4).

Denzin and Lincoln (2011) propose that despite the ‘inherent diversity’ evident within qualitative research, it can be described as:

> a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including fieldnotes, interviews, conversations, photographs, recordings and memos to self…. qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them (Denzin and Lincoln, 2011, p.3).

Qualitative research therefore values both the phenomenon under study and the individual interpretations applied to that phenomenon by study participants. The context in which the phenomenon is experienced, and the inductive nature of qualitative research are also both important, as highlighted below:

> In general, when we speak about qualitative research, we mean social research in which the researcher relies on text data rather than numerical data, analyses those data in their textual form rather than converting them to numbers for analysis, aims to understand the meaning of human action and asks open questions about phenomena as they occur in context rather than setting out to test predetermined hypotheses (Carter and Little, 2007, p.1316).

I believe this description captures the essential heart of the qualitative approach. Specific reasons underpinning my rationale for choosing this approach included:

- To attempt to gain a detailed understanding of underlying beliefs and motivations of practitioners.
- To understand how practitioners make 'sense' of spiritual distress. What is the process, influences or contextual factors?
- The use of textual data.
- Data collection which utilised semi-structured interviews.
- The use of a small number of participants (n =21) selected purposively (non-randomly) from two specific EOL contexts.
- An interpretive approach to data analysis.
- A central aim of attempting to develop an initial understanding of spiritual distress which seeks to identify and explain the behaviour, beliefs or actions of participants within EOL community contexts.

(Adapted from Hennink et al., 2011, p.16)

2.2 Paradigms

The term Paradigm originates from the Greek 'paradigma'; a pattern or scheme for understanding a phenomenon (Dictionary.com). Paradigms are 'models or frameworks for observation and understanding which shape both what we see and how we understand it' (Babbie, 2007, p.32). Paradigms are therefore 'perspectives or ways of looking at reality, providing frames of reference which researchers utilise to organise both their observation and reasoning' (Babbie, 2007, p.31). Each branch of scientific enquiry is therefore based upon a paradigm: ‘a set of theoretical perspectives or assumptions upon which the individual researcher bases their research questions and research methods’ (Bowling, 2014, p.132). As Muncey (2007) states:

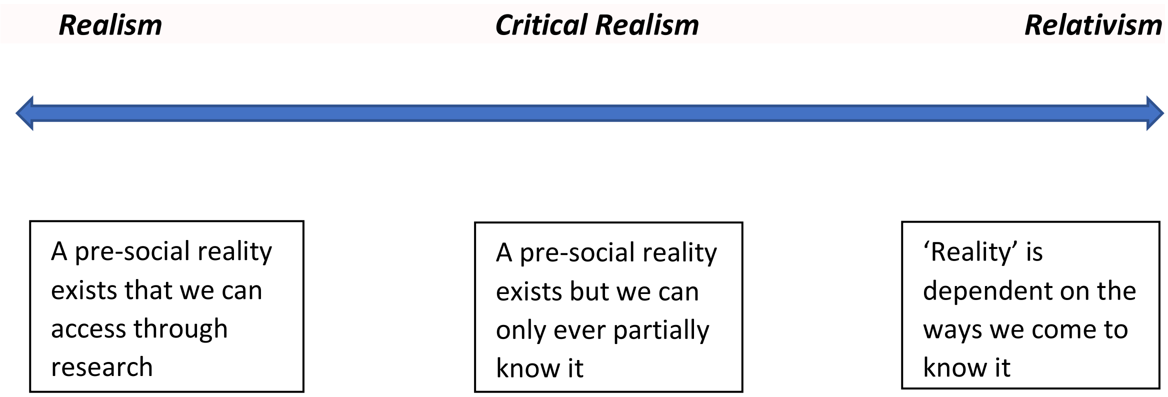
> To cope with the enormity of the complexity of reality, a scientist must reduce the problem to a workable scale because a consideration of all variables would be unmanageable. Therefore, even in the objective world of science, the scientist brings their own belief system into the study. No paradigm explains all the facts. Indeed, many paradigms can theoretically account for the same set of data. A new and radical theory is never just an addition or an increment to existing knowledge. Rules are changed, revision is required to existing assumptions and new thinking must be applied to existing facts and observations (Muncey, 2007, p.17).

In effect, the paradigm provides a repository for the individual researcher’s ontological, epistemological and methodological assumptions. The term ‘paradigm’ can also be referred to as a ‘theoretical framework’, ‘theoretical perspective’, ‘sociological perspective’ or ‘sociological theory’ (Gilbert and Stoneman, 2014). As Morgan (2014) states: ‘Paradigms are thus social worlds where research communities exert a powerful influence over the beliefs we consider to be ‘meaningful’ and the actions we accept as ‘appropriate’’ (Morgan, 2014, p.1049). Evident is that paradigms ‘may have powerful effects on both cognition and behaviour’ (Koltko-Rivera, 2004, p.3). Ross (2012) describes how two particular paradigms effectively dominate the research arena: ‘the positivist or quantitative paradigm which adopts a hard science approach and the naturalist or qualitative paradigm that is considered softer and less scientific’ (Ross, 2012, p.34). For this study, I have attempted to utilise two principal paradigms: critical realism and post-positivism. Each can be positioned upon a specific continuum, as described in sections 2.4 and 2.7 below. The terms Ontology and Epistemology are also integral to discussions regarding the nature of knowledge. Both are considered below.

2.3 Ontology

Ontology seeks to answer the question 'What is reality?' (i.e. what can be said to really exist or be?). This is crucial, because whatever assumptions we make in attempting to answer this question will significantly affect how we approach any process of scientific investigation. There are many variations, in terms of ontological position, ranging along a continuum from the view that 'reality' is entirely independent of human ways of knowing about it (realism); described as 'mind independent truth' (Tebes, 2005) to the view that reality is entirely dependent upon human interpretation and knowledge (relativism). In the centre of this continuum is my own position, critical realism. The continuum is illustrated in Fig 1 below.

Fig 1: The Ontology Continuum (Braun and Clarke, 2013, p.26)



Ontological 'realism' is the view that the world around us possesses intrinsic reality and is replete with new learning/information which awaits discovery and has an existence separate to the individual researcher. For the realist, an experimental approach then becomes key to the discovery process. As Maxwell states: 'the idea that there is a real world with which we interact, and to which our concepts and theories refer, has proved to be a resilient and powerful one that has attracted increased philosophical attention following the demise of positivism' (Maxwell, 2012, p.150). The realist position assumes that the world around us is accessible by rationale scientific investigation and method alone, an assumption which fails to satisfy my own view of the world. Ontology therefore determines whether we believe reality exists entirely separately from human practices and understandings - including the research we conduct to find such things out – or whether we believe it cannot be separated from human practices, and so knowledge will always reflect our own perspective. Realism (or Empiricism) assumes a world which is knowable and comprehensible through research, that truth is ‘out there’ and can be accessed by the appropriate use of research methods. At its most extreme, realism has been referred to as a ‘correspondence theory of truth’ (Madill et al., 2000, p.3), meaning that what one observes is assumed to mirror completely and truthfully what is there. Realism differentiates between epistemological assumptions (i.e. referring to ‘knowledge’) and ontological assumptions (i.e. referring to ‘being’), acknowledging that epistemological data cannot be apprehended directly because it is processed through a range of variables such as the individual researcher, language, culture, and research methods (Wong et al., 2013; Wiltshire and Ronkainen, 2021). Realism also incorporates the idea that ‘there is a state of the matter which is what it is, regardless of how we view it, choose to view it or are somehow manipulated into viewing it’ (Archer, 2007, p. 195).

Numerous other principles also characterise realist approaches. These include:

- Realist approaches recognise the inherent value in both qualitative and quantitative methods, using the approach of ‘critical methodological pluralism’ (Danermark et al., 2019).
- Realism, contrary to the qualitative paradigm, values the concept of validity, although it requires amending for some aspects of qualitative research (Maxwell, 2012).
- Causal explanation is central to realist approaches and demarcates from empiricist research focused on predicting observable phenomena (Clark et al., 2007).

In contrast, Relativism argues for the existence of multiple, constructed realities, rather than a single, pre-social reality or mind-independent truth, and assumes it is impossible to get beyond these constructions (Cromby and Nightingale, 1999). Situated between these two positions is critical realism, a position that also invokes a real and knowable world, which effectively sits ‘behind’ the subjective and socially located knowledge accessible by an individual researcher (Madill et al., 2000). Critical realism assumes that ‘authentic’, distinct reality exists and can be known, at least in part.

Realism contrasts markedly with what might be termed post-modernism, where reality is regarded as a constructed account and knowledge is constructed subjectively by people and groups. In this approach, discursive analysis leads to the interactive construction of knowledge (Bowling, 2014, p.131). Social constructionism expresses the view that scientific knowledge and biological discourses about the body, health and illness are produced through subjective, historically determined human interests, and are subject to change and reinterpretation (Gabe et al., 2004, p.130). A basic premise of social constructionism is that reality is a product of definitional practices and the task of social research is to explain the processes involved in the production of the knowledge pertaining to this reality (McDonnell, 2013, p. 115).

Evident is that it becomes very difficult to decide in any unequivocal way the ontological status of what people believe to be real; relativity therefore characterises this genre of research (McDonnell, 2013). Von Glaserfeld (1995) describes constructivism 'not as a pedagogic theory but rather as an epistemological statement' (Von Glasersfeld, 1995, p.1). Put another way, constructivism is viewed 'as an ideology committed to a specific world view' (Meyer, 2009, pp. 332-3). Meyer (2009) is highly critical of von Glaserfield, stating that the distinction between meaning, understanding and knowledge is obscured in constructivism, making it virtually impossible to identify what constitutes knowledge in the everyday. Meyer (2009) suggests that crucial constructivist ideas are very similar to the mind set prevalent in late medieval Europe. In the Heliocentric Revolution, Galileo helped to establish that the 'goodness' of a piece of knowledge was to be judged by how well it corresponded to the 'real' thing (i.e. in this case, that the earth orbited the Sun, and not vice versa), eventually becoming a martyr to this cause within the Inquisition. Galileo highlighted the distinction between meaning and knowledge. Put another way, 'what is meaningful in the most profound sense may not be knowledge - that is - it can be meaningful and wrong' (Meyer, 2009, p.337).

As Meyer (2009) states:

> Constructivism is not merely unable to distinguish knowledge from superstition. For a constructivist there is no difference between knowledge and superstition. This is not a post epistemology. Constructivists have just undone Galileo and returned to the world

> view of the Middle Ages with theology replaced by a psychologism (Meyer, 2009, p.338).

If everything in the head of the individual constitutes knowledge, as von Glaserfield suggests, then 'fallacy, error, hallucination and frank psychotic ideation' must also constitute knowledge, as these are also present in the heads of individuals (Meyer, 2009, p.338). The problem is one of where does the power to determine the rationality and 'truth' of such aspects of knowledge lay? For example, the sectioning of patients under the mental health act who are manifesting delusional behaviour clearly involves a series of authoritative assumptions concerning both the nature of knowledge and the power of medicine alongside the law, to effectively define what is deemed acceptable knowledge within a given context and culture.

My initial approach to this study was therefore one of a firm ontological realism combined with an equally firm empirical epistemology, though I had previously been unaware of this descriptive terminology. However, as the study progressed, I found myself instead adopting a critical realist ontology combined with a post-positivist epistemology. These terms are further described below.

2.4 Critical Realism: my own position

Akin to realism is Critical realism, a form of realism which succinctly summarises my own ontological position. My attraction to Critical realism comes both from its humility but also what I would describe as the inclusion of 'mystery'.

As Fletcher (2017) states:

> One of the most important tenants of Critical realism is that ontology (i.e. what is real, the nature of reality) is not reducible to epistemology (i.e. our knowledge of reality). Human knowledge captures only a small part of a deeper and vaster reality. In this respect, Critical realism deviates from both positivism and constructionism (Fletcher, 2017, p.182).

Fletcher's view exactly captures my own 'sense of things'. Put another way, I believe that a deeper and vaster reality surrounds us which is replete with mystery. A useful definition of mystery is that widely attributed to Covington (Anon, undated) namely: ‘not the absence of meaning, but rather the presence of more meaning than we can comprehend’. Much knowledge can be accessed and appropriated using the scientific method alone. However, I believe there is also profound reality (‘meaning’) surrounding us which impacts upon daily life, and which cannot be accessed in this way; particularly so within the realm of subjective knowledge, which is integral to the nature of being human.

In this thesis, I hope to describe the meaning(s) assigned by participants to the phenomenon of spiritual distress and its alleviation. Such acquisition of meaning would appear to utilise symbolic interactionism: namely, how individuals ascribe meaning to the everyday and how specific things, events or people come to occupy significance in everyday or professional life. Symbolic interactionist theory assumes that people create perceptions of each other and of social settings (such as EOL care), which then significantly influence their actions within those settings. In effect, how people think about themselves and others is then based upon their interactions (Neuman, 2011).

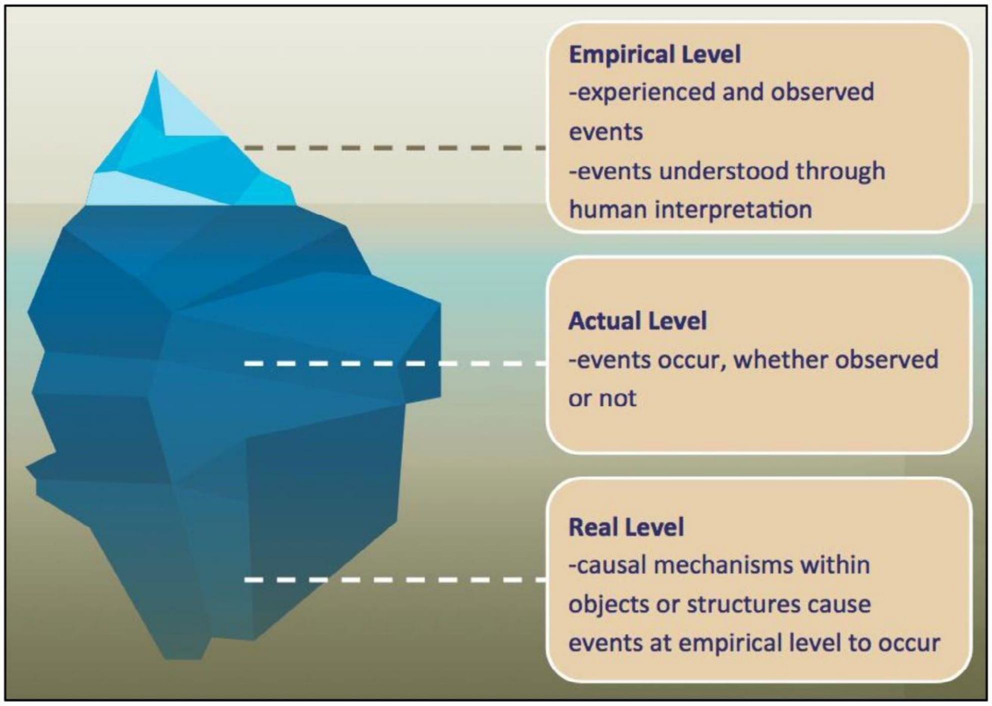
Bhaskar (1998) critiqued the positivist paradigm for promoting ‘the epistemic fallacy’ (Bhaskar, 1989, p.27), a limitation of ‘reality’ to what can be empirically known by the use of scientific experimentation alone. As Fletcher (2017) further states:

> The same critique applies to constructionist perspectives that view reality as entirely constructed through and within human knowledge or discourse. Despite the seeming opposition between the constructionist and positivist perspectives, each reduces reality to human knowledge, whether that knowledge acts as lens or container for reality (Fletcher, 2017, p.182).

In critical realism reality is stratified into different ontological levels, as described by Bhaskar (1998). Bhaskar’s stratified ontology (Bhasker 1975, 1978, 1989) provides a useful realist framework with its differentiation of observable phenomena into three overlapping domains: the ‘empirical’ (i.e. things that exist and are captured in data by the researcher), the ‘actual’ (i.e. things that exist but which may not be captured in data or observed by the researcher) and the ‘real’ (i.e. causal powers and potential mechanisms that are not observable but have the power to produce events). Fletcher (2017) uses the metaphor of an Iceberg (Fig 2 below) to illustrate this process of stratification. The first is the 'empirical' level, which is the realm of events as we experience them. At this level, events or objects can be measured empirically and are often explained through 'common sense', but these events are always mediated through the filter of human experience and interpretation. This is the transitive level of reality, where social ideas, meanings, decisions and actions occur – but, importantly, these can be causal. The middle level consists of the 'actual'. At this level there is no filter of human experience. Events occur, whether (or not) we experience or interpret them, and these occurrences are often different from what is observed at the empirical level. Finally, the third level is the 'real'. At this level causal structures, or 'causal mechanisms' exist. These are the inherent properties in an object or structure [or situation] that act as causal forces to produce events (i.e. those appearing at the empirical level).

Fig 2: Iceberg Metaphor for Critical Realist Ontology

Taken from (Fletcher, 2017, p.183).



Thus, critical realism attempts to explain social phenomena through reference to causal mechanisms and the effects which they mediate throughout the three-layered ‘iceberg’ of reality. Using a different metaphor, that of a tree, Walsh and Evans (2014) describe the ‘real’ (the roots) as ‘hidden, but necessary preconditions for the actual and empirical’, the ‘actual’ (the trunk) as ‘what is known but cannot always be seen’ and the ‘empirical’ (the branches) as ‘what can be observed’ (Walsh and Evans, 2014, p.2). Critical realism is also referred to as ‘subtle realism’ (Blaikie, 2007). Ritchie et al. (2014) summarise how ontologically:

> this means we see reality as something that exists independently of those who observe it, but it is only accessible though the perceptions and interpretations of individuals. We recognise the critical importance of participants’ own interpretations of the issues researched and believe that their varying vantage points will yield different types of understanding. Our position is that external reality is itself diverse and multifaceted and it is the aim of research to capture that reality in all its complexity and depth (Ritchie et al., 2014, p.23).

I believe spiritual distress profoundly illustrates such a ‘reality’, possessing both ‘complexity and depth’, particularly so for individual patients who are approaching death. Critical realism also fits closely with my own Christian theology, which celebrates the intrinsic ‘otherness’ of creation, integral to which is a profound interconnectedness and interdependence, vastly more complex than that accessible by purely scientific means alone and much of which awaits further discovery. I also believe God delights to create, and that our creativity and hunger to discover new knowledge as researchers is a practical outworking of a quality effectively hard-wired within us; in effect, mirroring a key aspect of our creator’s nature and personhood. The opening chapter of both Genesis and John’s gospel provide a useful summary of my own theological position, namely:

> In the beginning God created the heavens and the earth. Now the earth was formless and empty, darkness was over the surface of the deep, and the Spirit of God was hovering over the waters (Genesis 1:1) (The Holy Bible/The Message Remix, 2005, p.1).

> In the beginning was the Word, and the Word was with God, and the Word was God. He was with God in the beginning. Through him all things were made; without him nothing was made that has been made (John 1: 1-3) (The Holy Bible/The Message Remix, 2005, p.1353).

This perspective is likely to impact the way that I collect and interpret data during the study and effectively underpins my critical realist position. I believe that God is the creator and yet is separate from His creation (unlike in pantheism, where the creation is seen effectively as an extension of His personhood). A Christian understanding further emphasises that the God who creates can also be personally known and delights to gift humankind with the desire for discovery and a hunger for transcendent reality. As Fletcher identifies:

> Critical realism treats the world as theory-laden, but not theory-determined. Critical realism does not deny that there is a real social world we can attempt to understand or access through philosophy and social science, but some knowledge can be closer to reality than other knowledge (Fletcher, 2017, p.182).

Key, however, is whether this 'real social world' exists as a separate entity, rather than being purely a social construction. It is this type of knowledge; knowledge that Fletcher describes as 'closer to reality', which this study is attempting to elucidate: namely, what are the lived experiences of community nurses in relation to the phenomenon of spiritual distress, when caring for EOL community-based patients and what meaning(s) do they create from those experiences? Spiritual distress is a phenomenon which manifests because of several possible causal mechanisms (see chapter 3). As Bhaskar states, 'unlike the natural world, social structures are in fact activity-dependent'. In other words, causal mechanisms 'exist only in virtue of the activities they govern and cannot be empirically identified independently of them' (Bhaskar, 1979, p.48). Fletcher then helpfully adds:

> This means that causal mechanisms are social products that can ultimately be understood through – and indeed, that *exist within* phenomena at the empirical level (e.g. human actions and ideas that are generated by these mechanisms), making these phenomena relevant for scientific investigation (Fletcher, 2017, p.182).

Using this perspective, spiritual distress can be investigated as a phenomenon at the 'empirical level' whilst attempting to identify its causal mechanisms and those specific interventions employed by community nursing staff to reduce the level of distress experienced by individual patients. This is congruent with the central assertion of critical realism; namely, the deeper layers of ontology possess reality because their effects can be observed.

Whilst not my own view, this clearly may be contested using the argument that if something appears to excerpt no psychological effect upon individuals, it is therefore not observable or 'real'. As a consequence, it is important that researchers seek to identify these deeper layers 'as comprehensively as possible, whilst acknowledging that they remain generative, rather than definitive mechanisms' (Walsh and Evans, 2014, p.e4). Put another way, critical realism accepts the possibility that structures may exist that cannot be seen, regardless of the perspective of the individual participant or researcher (Ryan, 2019, p.4): this is 'mystery'.

One difficulty with critical realism is applying the methodology to the nursing context, in such a way that the theoretical position impacts upon patient care. Unless the right questions are asked about the reality that researchers are attempting to explore or describe, or for which explanations are being sought, knowledge of that reality is likely to remain superficial. Thus, the ontological and epistemological underpinnings of any chosen research method(s) are crucial. Critical realism views unobservable structures as possessing reality because their effects can be experienced or observed.

Within the context of healthcare, Bhaskar's ontological levels (the empirical: what can be observed; the actual: what is known but cannot always be seen; the real: hidden, but necessary precondition(s) for the actual and empirical) relate to a variety of experiences, including that of cancer induced pain at EOL. At the empirical level, pain related to cancer is commonly experienced by EOL patients' and observed by practitioners. Such pain can be measured relatively objectively using a pain scale, providing the patient is able and willing to communicate. Cancer related pain may be caused by tumour infiltration, nerve compression, nerve invasion or a combination of these. This form of pain can also be influenced by anxiety and the release of adrenaline (causing increased muscular tension); collectively representing the actual ontological level. Walsh and Evans (2004) suggest that the deepest level is the real;

the point where generative mechanisms operate; in this case to cause pain. Adrenaline can therefore enhance the pain experience, but adrenaline release is also sensitive to numerous other stimuli, both internal and environmental. In addition, interpersonal and relational factors and cognitive and affective disposition may also influence individual response to threat. Thus, a series of generative and overlapping mechanisms operate at the 'real' level, ultimately impacting the patient's pain experience at the 'empirical' level.

For thousands of years, pain has been experienced without such technical insights and understandings (meanings) may have been very different (i.e. before cancer was understood as a process of cellular deregulation). 'Macro level phenomena, such as organisational structures, the built environment, social relations and individual psychology can therefore be seen to influence micro phenomena such as physiological, anatomical and cellular activities, but are not reducible to them' (Walsh and Evans, 2014, p.e3). As mentioned earlier, Bhaskar (1997) refers to this observation as 'emergence': surface phenomena are influenced by and have their foundation in hidden sub structures but cannot be completely explained by them. This example illustrates that knowledge of these stratified layers of reality is always partial, incomplete and eminently revisable in the light of new research. The element of mystery also remains, because generative mechanisms may never be fully explainable, and our interpretive framework effectively filters information as we receive and respond to these mechanisms. As Easton states, 'we may always be surmising about the nature of the real' (Easton, 2010, p. 128). Again, a partial knowledge of reality and its layers fits well with my own position.

Critical realism has been criticised based upon alleged bias, particularly because the application of values in any given situation involves the researcher making specific judgements (Hammersley, 2009). However, all research endeavours could be described as inherently axiological, whether this is acknowledged or not; clearly, such judgements need to be as informed as possible. Attempting to ascertaining 'generative mechanisms' is therefore crucial (Walsh and Evans, 2014).

Interpretivists challenge how a 'layered ontology' can be identified with any certainty, stating that any reality is provisional and contestable and our knowledge of it therefore only partial and subjective (Deforge and Shaw, 2012; Walsh and Evans, 2014). In contrast, critical realists argue that the deeper layers of ontology are real because their effects are real and observable; it is therefore crucial that researchers seek out such mechanisms as comprehensively as possible, whilst acknowledging that they remain generative, rather than definitive. Only then can change in effects at the empirical level be addressed in practice (Walsh and Evans, 2012, p.e4).

Both critiques are evident in nursing literature, in which a critical realist framework for research has been comprehensively discussed for over two decades (Porter and Ryan, 1996; Angus and Clark, 2012; Deforge and Shaw, 2012; Musto and Rodney, 2016). As Walsh and Evans (2012) aptly identify, this discussion has included critical realism’s challenge to the dominance of the evidence paradigm (Nairn, 2012), its pattern of interaction with interpretivist research methods (Porter, 2007) and its appropriateness for researching the complexity of health and illness (Harwood and Clark, 2012).

My ministerial experience and Christian world view provide a significantly different perspective regarding spirituality, spiritual distress and the experience of death and dying compared to atheism, agnosticism, scientific reductionism or existentialism. I also accept the Biblical account of humankind possessing a tri-partite nature of body, soul and spirit, in contrast to authors such as Paley (2008a) who situate their reflections within an atheistic writing frame, which denies the existence of any spiritual component to humankind and the existence of spirituality per se. Critical realism therefore encompasses more than one perspective, whilst recognising that causal structures may exist that cannot be seen, regardless of one’s perspective. In this way, critical realism values modified objectivity.

In summary, the evaluation of research using a critical realist perspective therefore provides:

> a clear and logical process to produce evidence to inform policy and practice, based on what works, for whom and in what circumstances. It focuses on the practical application of findings, rather than the enquiry for the sake of science. It takes a realist approach to the evaluation of sociological interventions, programmes and initiatives, and seeks to inform the knowledge of stakeholders, practitioners, policymakers, the public and leaders involved in sociologic interventions and services. It examines the

> available evidence – perhaps through critical appraisal – to explain ‘what works for whom and why (Ryan, 2019, p. 5).

Pawson and Tilley (1997) identify the ‘co-production of implementable findings’ as central to realist enquiry, which resonates with my own desire for this study to produce ‘actionable intelligence’ or ‘knowledge’ (Kelly and Cordeiro, 2020) which informs and impacts current nursing practice.

Critical realism therefore ‘offers a radical alternative to positivism (the goal is not generalizable laws); to interpretivism (the goal is not solely to appreciate the lived experience of social actors); and to post-modernism (there are truths, and knowledge is more than an undetermined, socially-constructed linguistic system)’ (Jones, 2011, p. 202-3).

As Jones (2011) further asserts, Critical realism also ‘affirms the existence of an independent reality that can be studied scientifically, aiming to develop deeper levels of explanation as causal necessity, rather than regularity alone’ (Ibid).

2.5 Epistemology

Akin to ontology, epistemology seeks to answer the related question how can I ‘know’ reality? (i.e., if something really exists, how can I know that?). Understanding what constitutes knowledge therefore determines how meaningful knowledge can be generated and also what that knowledge then represents (Braun and Clark, 2013). This is important, because whatever assumptions we make as researchers about what can be known will affect our approach to scientific enquiry and the selection of those research methods we deem appropriate. If my assumption is that I can know and discover the objective world around me, replete with new learning/information using my senses, then my epistemological approach is one of empiricism, which is closely aligned with positivism. At the beginning of post-graduate study, empiricism very much summarised my own epistemological position. Epistemology can also be realist or relativist. A realist epistemological position assumes that it is possible to obtain ‘the truth’ through valid knowledge production; ‘a relativist epistemological position states that theoretically, knowledge is always perspectival and therefore a singular, absolute truth is impossible’ (Braun and Clarke, 2013, p.29).

Central to epistemology are the terms ‘induction’ and ‘deduction’: both relate to how new knowledge is acquired. Induction assumes this acquisition is essentially a ‘bottom-up’ process through which patterns are derived from observations of the world surrounding the researcher. In contrast, deduction assumes that the acquisition of new knowledge is instead a ‘top-down’ process, whereby hypotheses (proposed explanations based on limited evidence) are then tested against observations (Miles et al., 2014). Other authors describe hypotheses as ‘very much part of the epistemology of positivism… closed statements which one can decide to be true or not true’ (Hennink et al., 2011, p.42). They suggest that the deductive approach conflicts with the central foundations of qualitative research, which focuses instead upon understanding lived experiences and behaviour and attempting to ‘hear’ the voices of people (participants). Other authors, such as Blaikie (2007) suggest that it is a misleading oversimplification to depict qualitative research as purely an inductive process, arguing that ‘pure’ induction or deduction are figments of the theoretical imagination, rather than research approaches ‘grounded in reality’. Ritchie et al. (2014) also suggest that researchers cannot approach the process of data generation or interpretation with a blank mind, stating:

> Even if they [researchers] are not testing a hypothesis, the kind of data they have generated, the questions they have asked and the analytical categories they have employed will have been influenced by assumptions deductively derived from previous work in their field. Similarly, deductive researchers setting out to test a hypothesis will have drawn on a body of theory which in turn has been inductively derived from prior observations (Ritchie et al., 2014, p.6).

This could be described as Abductive reasoning, a form of inference which begins with observation or a series of observations and then seeks to find the simplest and most likely explanation for those observations. Abduction therefore describes a process of inference to the best or most likely explanation, and its conclusions consequently contain an element of uncertainty or doubt. This is associated with moving between everyday concepts and meanings, lay accounts and social science explanations (Mason, 2002).

This exploratory study will attempt to utilise an inductive approach, as the study is attempting to explore perceptions of participants to an observed phenomenon. In this sense, it is not seeking to test a specific hypothesis.

2.6 Positivism and epistemology

Positivism involves the description of phenomena using precise, unbiased recording of observations, using either verbal descriptions or sets of measurements. Positivism therefore assumes a straightforward, direct relationship between the world and our perception of it and 'advocates the application of the natural sciences to the study of social reality and beyond' (Bryman, 2012). Positivism effectively separates observation, the observer and that which is observed and assumes that research can be conducted 'free' of the researcher's influence and biases (Watson et al., 2008). Positivism is closely aligned with empiricism, an approach to the study of reality that suggests that only knowledge gained through experience and the senses is credible or acceptable (Bryman, 2012). The central foundation of empiricism is its emphasis upon learning through experience and the pivotal role of the senses of the researcher to create or discover knowledge through objective observation of the world around us.

As Schwandt (2007) states:

> on a daily basis, most of us probably behave as garden-variety empirical realists – that is, we act as if the objects in the world (things, events, structures, people, meanings, etc.) exist as independent in some way from our experience with them. We also regard society, institutions, feelings, intelligence, poverty, disability and so on as being just as real as the toes on our feet and the sun in the sky (Schwandt, 2007, p.256).

Positivism assumes a 'straightforward' relationship between the world and our perception of it, separates the practice of observation, the observer and that which is observed and requires demonstration of reality through unbiased, objective data collection using established scientific methods; such methods seek to control variables and remove, as far as possible, sources of contamination and/or bias (Braun and Clarke, 2013, p.29). Positivism assumes that the truth is 'out there' awaiting discovery and that research can be conducted 'free' of the researcher's influence (Watson et al., 2008).

A summary of my own understanding of positivism is shown in Fig 3 below.

Fig 3: Positivism: The scientific method

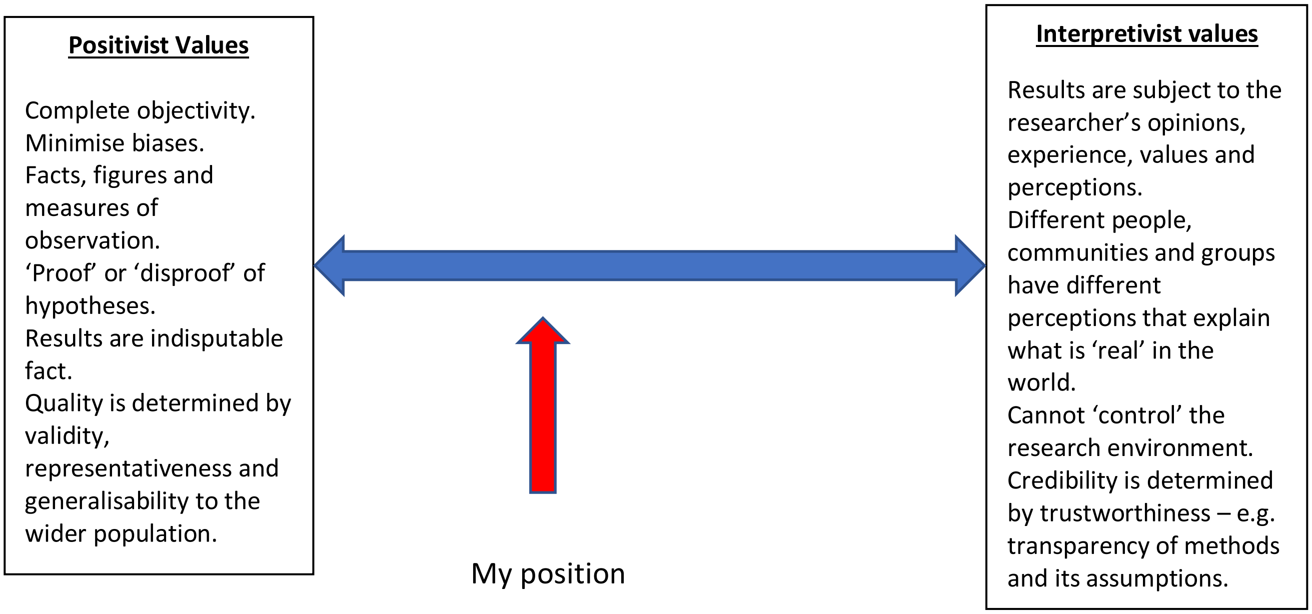
Adapted from Polgar and Thomas (2013, p.5).

Positivism was profoundly challenged in the second half of the twentieth century, as scientific advance contributed both new methods by which the world could be explored and new explanations of observed phenomena. For example, quantum theory and relativity both challenged the mechanistic, clockwork like view of reality previously held. In contrast, modern theories of physical reality are less defined and more probabilistic, with the observers no longer viewed as outside, external or separate from the phenomena they are studying (Polgar and Thomas, 2013, p.7).

2.7 Post-Positivism: my own position

Within qualitative research, very few researchers would adopt a purely positivist stance to research, particularly as 'qualitative inquiry is rife with ambiguity' (Patton, 2002, p.242). Instead, a less defined stance known as post-positivism is common, as proposed by Popper (1959). The post-positivist position believes the search for truth to be largely achievable, but also acknowledges that researchers are influenced by their contexts and that facts are theoretically influenced, rather than representing purely neutral reflections of the truth (Clark, 1998; Guba and Lincoln, 2005). Post-positivism represents my own epistemological position. This differs markedly from constructionist approaches and epistemologies, as the stance commits researchers to a position that retains belief in and aims to know that singular truth or truths which exist separately from the researcher, using methods which seek to limit or remove subjective influences on knowledge acquisition, as far as this is practically possible. Post-positivism is not a progression of positivism; neither is it 'anti-positivism'. Instead, it represents an alternative approach to enquiry which seeks to 'resolve the polarity of interpretivism and positivism, accepting some of their strengths and avoiding their limitations' (Howell, 2015). Post-positivism also 'allows for the complexities and individuality of patient care, builds on knowledge as the context of evidence-based practice changes, and helps to develop usable and transferable knowledge for those delivering care, not only researchers and academics' (Ryan, 2019, p.1). Ryan (2019) also identifies a continuum of post-positivism, as shown in Fig 4 below.

Fig 4: The Post-Positivist continuum (Ryan, 2019, p.3)



Positivist Values

Complete objectivity.
Minimise biases.
Facts, figures and measures of observation.
'Proof' or 'disproof' of hypotheses.
Results are indisputable fact.
Quality is determined by validity, representativeness and generalisability to the wider population.

Interpretivist values

Results are subject to the researcher's opinions, experience, values and perceptions.
Different people, communities and groups have different perceptions that explain what is 'real' in the world.
Cannot 'control' the research environment.
Credibility is determined by trustworthiness – e.g. transparency of methods and its assumptions.

Post-positivism also argues that 'facts' can be fallible (i.e. proven to be incorrect, as illustrated by Copernicus's assertion that the sun was at the centre of the solar system, and not the earth, as was confirmed by subsequent scientific discovery). In this sense, post-positivism places value upon objectivity, but also accepts that this can never be completely achieved (Danermark et al., 2019). This 'modified objectivity' assumes that it is impossible to completely remove all bias caused by the influence of social 'objects' such as people, places and communities; hence, it focuses upon removing those factors that can be controlled and accepting those that cannot (Ryan, 2019, p.2). For example, it may be impossible for an individual researcher to approach a situation free of their own background, values and assumptions, but it is vital that the researcher is aware of these biases and how they might influence the research process. Post-positivism therefore incorporates an openness to viewing our perception of reality as always incomplete, recognising that further research and reflection will bring new understanding which may both challenge and change existing knowledge. This is not a constructionist approach, where new knowledge is assumed to be co-constructed between participant and researcher. Indeed, what differentiates post-positivism from interpretivism is epistemology. Whilst interpretivism asserts that there are multiple realities originating from the different individuals within a given context, post-positivism argues that there is only one reality, but different individuals may perceive this differently.

Within interpretivism, reality is therefore defined by the person experiencing it, and so is changeable (Ryan, 2019). In contrast, within post-positivism, reality remains unchanged, whereas the individual's perspective of that reality may not. Post-positivism therefore asserts that findings, whether presented objectively or subjectively, are simply different ways of presenting a single reality (e.g. spiritual distress) that exists whether we observe it or not. Individual practitioners may therefore perceive such realities differently. Further, 'there may also be components of reality which are not experienced or observable in their pure form, such as social structures' (Ryan, 2019, p.22). Rather, new knowledge is discovered, albeit with humility and a recognition that knowledge always bequeaths new areas of ignorance. As Ryan (2019, p.23) states, 'The problem with using positivism in research involving biological, psychological, human or social factors is that 'we are simply not that simple' – it explains what we see, but not why, how or when'. For example, we cannot ever be certain that antibiotic or anticoagulant medications will act in the same way or be equally as effective for every patient in every circumstance. Post-positivists, however, argue that knowledge, though fallible, should be based on the best evidence available at the time of enquiry. This 'modified objectivity' assumes that we can never remove all bias by completely controlling or removing the external influence of 'social objects' such as people, places and communities.

Instead, post-positivism focuses on removing the factors we can control and accepting those we cannot. For example, researchers may never be able to approach a situation free of their own backgrounds, values and assumptions (i.e. biases), but can be aware of such biases and how these might influence the research context, either positively or negatively. Such awareness could be considered as reflexivity and therefore aligned with interpretivism (Bryman, 2008).

However, 'modified objectivity' can be differentiated from interpretivist subjectivity by its postpositivist approach to epistemology. Interpretivism asserts there are multiple realities, each stemming from those involved within a given context (i.e. relativism). In contrast, post-positivists argue there is only one reality, but each person has their own perspective of it, which may or may not differ (realism). Within interpretivism, reality is therefore defined by the person experiencing it, and so is changeable (Ryan, 2017, p.4). In post-positivism, reality does not change but the individual's perspective of it may do. However, as new insights regarding reality are discovered, new perspectives may also develop. Post-positivism also excludes the positivist epistemological perspectives of naïve realism, logical realism, rationalism or foundationalism (Ryan, 2017, p.4). Furthermore, components of reality may exist which are not experienced or observable in their 'pure form', such as social structures.

The aim of developing usable and transferable knowledge ('actionable intelligence') which may help inform and change practice is a key aim of this study.

In summary, my own position reflects my assumptions regarding the nature of knowledge (i.e. knowledge is separate from the researcher, and therefore can be accessed using specific research methods) and how such knowledge can be known (i.e. specific research methods will help to access part of this knowledge, but there is always more to obtain, particularly when attempting to elucidate subjective data such as the perceptions of participants regarding specific phenomena (e.g. spiritual distress)). One such research method is the use of semi-structured interviews, as described in 4.8. This form of interview was the primary method utilised to access participant data. The study therefore combines a critical realist ontology with a post-positivist epistemology.

2.8 'Methods' and 'methodology'

Giddings and Grant (2007) suggest that a 'lack of explicitness about paradigmatic positioning' often creates 'a lack of clear understanding of just what is mixed: methods or methodologies'

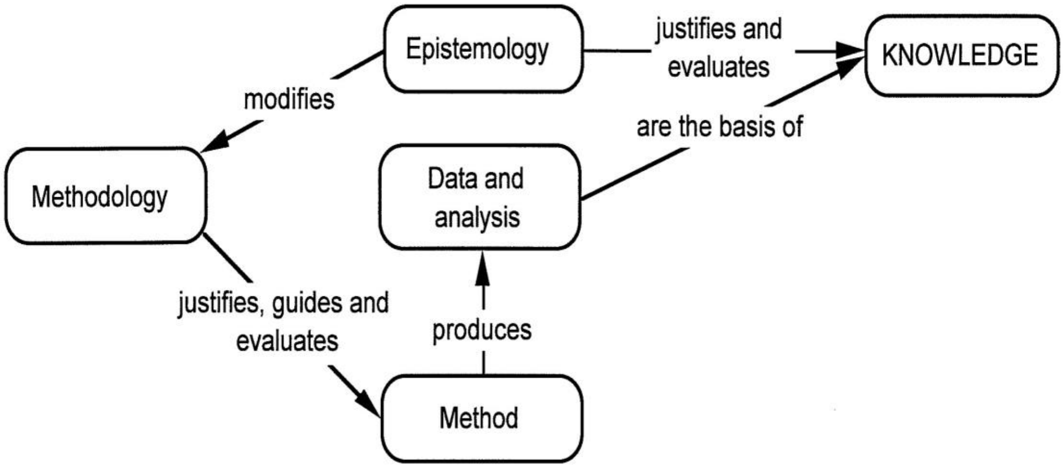
(Giddings and Grant, 2007, p.56). They define research methodology as a 'thinking tool'; namely, the worldview or paradigm that influences the way an individual researcher presents a research question and decides on specific methods and strategies for data analysis. Methodology therefore refers to 'the theoretical assumptions and values that underpin a particular research approach' (Giddings and Grant, 2007, p.56). In contrast, research methods 'are much more concrete and practical, they are the doing tools for collecting and analysing data' (Giddings and Grant, 2007, p.56). As Carter and Little (2007) state:

> In the literature, the term methodology is used loosely. Various authors, for example, refer to formal theories, schools of thought or movements such as symbolic interactionism or feminism, whole disciplines such as anthropology, or methods such as focus groups or observation as 'methodologies' (Carter and Little, 2007, p.1318).

In contrast, writers such as Kaplan (1964) define methodology as 'the study – the description, the explanation and the justification – of methods, and not the methods themselves' (Kaplan, 1964, p.18). Kaplan further states that the aim of methodology is 'to describe and analyse… methods, throwing light on their limitations and resources, clarifying their presuppositions and consequences… to help us to understand, in the broadest possible terms, not the products of scientific enquiry but the process itself' (Kaplan, 1964, p.23). Koch (1996) suggests that methodology describes 'the process by which insights about the world and the human condition are generated, interpreted and communicated. In terms of research practice, it means recording the way in which a study is accomplished'. This description is important, and helps demonstrate 'congruence with regard to philosophical approach and the establishment of rigour' (Koch, 1996, p.174). Evident is that methodological question(s) cannot be reduced to a question of methods alone; methods must be fitted to a predetermined methodology (Miles and Huberman, 1994).

Over the last six decades, there has been a growing articulation of distinct strategies for approaching qualitative research; in effect, a set of reconstructed logics which authors describe as methodologies (Schwandt, 2001; Ritchie et al., 2014). Such methodologies then justify the specific methods used in qualitative research. Fig 5 below illustrates the relationship between epistemology, methodology and method, highlighting the interaction of each within the research process.

Fig 5: The Relationship between Epistemology, Methodology and Method



Source: Carter and Little (2007, p.1317).

Carter and Little (2007, p.1319) describe how qualitative research reporting is 'frequently insufficient' within the areas of epistemology, methodology and research methods, and suggest several methodological problems are frequently observed. The first is methodological fundamentalism; insistence that a particular methodology is the 'one true' approach to qualitative research and therefore should never be changed or combined with elements of other methodologies. The second is the use of methodological labelling to describe study designs which actively conflict with accepted interpretations of that methodological tradition. Thirdly, particularly in the context of health research, they suggest there is a sense that research guided by a specific methodology is viewed as more 'esoteric', less 'practical' and therefore less fundable.

2.9 Research Methods employed

As stated above, in contrast to research methodologies, research methods 'are much more concrete and practical, they are the doing tools for collecting and analysing data' (Giddings and Grant, 2007, p.56). Methods could also be described as the ‘engine room’ of any project, as they facilitate data collection upon which the project’s findings are dependent.

The research methods employed for data collection in this study included:

- A review of relevant literature from 1998-2021.
- An exploratory study involving face to face semi-structured interviews with a range of community-based practitioners from different EOL contexts. This included community nurses from Kent community Health Foundation Trust (NHS) and Pilgrims Hospices, Kent), so that perceptions and experiences of caring for EOL community-based patients could be compared.
- Interviews were digitally audio recorded, transcribed and then subject to thematic analysis. Interviewing attempted to ascertain practitioner definitions of spirituality, spiritual care, spiritual needs and spiritual distress and whether/how spiritual distress in EOL patients was identified, assessed and managed.

2.10 Ontological perspectives

Hennink et al. (2011) suggest that some ontological perspectives are more relevant for qualitative research, particularly where ‘reality is assumed to consist of meanings, perceptions, beliefs and underlying motivations’ (Hennink et al., 2011, p.11). For example, the interpretative paradigm is an approach to research that seeks to understand the lived experience of individuals from the ‘emic’ or inside perspective. This school of thought ‘stresses the importance of interpretation as well as observation in understanding the social world’ (Ritchie et al., 2014, p.13). It also claims that the methods of natural science are inappropriate for social investigation because the social world is not governed by regularities which display law-like properties. Social researchers must therefore explore and seek to understand the social world through the study participants and their own unique perspectives. This summarises my own view and underpins my desire to allow participant voices to be heard within this study. Interpretivism also appears congruent with both critical realism and post-positivism.

The recent emphasis upon evidence-based health care increasingly expects health care professionals to utilise clinical expertise to actively integrate research evidence alongside the clinical state and circumstances of the client, their values and preferences (Hoare et al., 2013, p.723). Certainly, this appears relevant for EOL care. Charmaz (2014) also suggests that researchers should attempt to utilise methods to allow the world to be seen 'from the inside', so accessing the specific situations of the participants. As Charmaz states:

> Methods extend and magnify our view of studied life and, thus, broaden and deepen what we learn of it and know about it. Through our methods, we first aim to see this world as our research participants do – from the inside. Although we cannot claim to replicate their views or reproduce their experiences in our own lives, we can try to enter their settings and situations to the extent possible (Charmaz, 2014, p.24).

For the inexperienced or novice researcher,

> the numerous approaches or isms, with their specific set of philosophical beliefs and associated methodological preferences, can be overwhelming. So too can the multiple terms used to describe these approaches; 'schools', 'traditions', 'interpretative frameworks', 'theoretical positions', 'paradigms', to name but a few (Ritchie et al., 2014, p.11).

Certainly, this has been my experience. Trying to understand current qualitative approaches has often felt like progressing down a complicated mind map, where at each new term the map then repeatedly subdivides. It has been confusing and at times, frustrating. As Patton (2002) states: 'qualitative inquiry is rife with ambiguity' (Patton, 2002, p. 242), reflecting the existence of both multiple methodologies and data analysis methods more accurately understood as methodologies. For example, Interpretative Phenomenological Analysis, Discourse analysis and Grounded theory all constitute much more than methods for data analysis. Instead, they represent complete theoretical frameworks for conducting an individual study. Although qualitative methodologies are unique, many also share similar features, akin to siblings in a family. Like siblings, some methodologies are more similar than others, and share similar core assumptions. In effect, some methodologies get on far better with others (Braun and Clarke, 2013, p.32).

A further danger is 'epistemological determinism': in effect, choosing either to ignore specific traditions or instead, becoming fiercely vocal proponents of a particular tradition. For example, Silverman (2011) views polarisation between different traditions as dangerous and cautions researchers against impulsive alignment with any one tradition, stating: 'At best, they are pedagogic devices for students to obtain a first grip on a difficult field – they help us learn the jargon. At worst, they are excuses for not thinking, which assemble groups of sociologists into armed camps, unwilling to learn from one another (Silverman, 2001, pp.24-25). Clearly, this view is contested, but resonates powerfully with my own experience as a novice researcher.

2.11 Axiology

Axiology is the study of values (or of one's values as an individual researcher). Our values influence why and how we carry out research and what we value in the results of our research. Epistemic tensions in qualitative research also illustrate that epistemology is axiological:

> Axiology relates to epistemology in two ways: It is in epistemology itself, and it is in the cultural context that informs epistemology…. Epistemology contains values, in that epistemology is normative. It is the basis for explaining the rightness or wrongness, the admissibility or inadmissibility, of types of knowledge and sources of justification of that knowledge…… Epistemology is also surrounded by axiology, in that the knowledge that is generated by a project will be discussed, evaluated and justified in relation to broader cultural values (Carter and Little, 2007, p.1322-3).

New knowledge is therefore likely to be discussed, evaluated and justified in relation to the broader values of the surrounding culture, both scientific and wider. In this sense, epistemology is profoundly value laden, regardless of the individual position of the researcher or the research methods employed. Such entrenchment can also underestimate the influence of philosophic assumptions upon research methods. As Maxwell (2010) states: 'Ontological, epistemological and axiological assumptions are real properties of researchers and evaluators…. These assumptions inevitably influence researchers' purposes and actions to some degree and are often implicit and not easily abandoned or changed' (Maxwell, 2012, p.147). It seems unrealistic to simply urge researchers to set aside such assumptions. Similarly, this study is underpinned by Axiological assumptions. These include:

- The assumption that practitioners should attempt to deliver holistic, palliative care of the highest quality to those approaching the end of their lives, particularly within community contexts.
- Integral to my Christian faith is a responsible, motivated search for truth and meaning**,** which seeks to benefit others. I therefore aim for my research to be as inclusive as possible and accessible to all.
- As a Christian, I value the inherent worth and dignity of all people, recognising that we are made in the image of God and privileged to individually reflect the 'Imago Dei'. As far as possible, I aim to appreciate and value the perspectives of others, including those with differing views to my own.
- I believe much published nursing and related literature possesses an inherent value and objectivity which allows researchers to access its key meaning(s) and applicability to specific aspects of research. The literature review in Chapter 3 is founded upon this assumption.
- The perceptions of study participants regarding spiritual distress constitutes knowledge, which is valuable, distinct, and at least partially accessible using semi-structured interviewing. This accessibility is sufficient for the research questions integral to this study to be addressed.
- Interviews are likely to have been influenced, at least in part, by my own nursing experience, my naivety as an interviewer, the degree of rapport established between myself and individual participants and the context(s) within which interviews were conducted.

2.12 Qualitative Research: Criticisms

It is evident that qualitative research provides a focus of criticism from researchers, particularly those who situate themselves within the positivist research paradigm (Bryman, 2012). Central to this criticism is that qualitative approaches lack the degree of objectivity assumed to be present within quantitative research methods. For example, Bryman (2012) describes four key critiques of qualitative research, principally originating from the quantitative/positivist research paradigm. These are:

- Qualitative research is too subjective.
- Qualitative research is difficult to replicate.
- Qualitative research poses problems relating to generalisation.
- Qualitative research lacks transparency.

Despite such criticisms, qualitative research is valued for its complex and detailed subjective understanding of the social world, while respecting the unique contributions of each participant. Additionally, a reflective approach on the part of the researcher is integral to the research process, bringing their unique ability to analyse, interpret and make sense of complex concepts and situations, often as an attempt to solve real world issues. Within the healthcare setting, there is also a growing commitment to understand the individual experiences of patients, so that patient care and the provision of patient services can be improved. This commitment has resulted in a greater emphasis upon qualitative methods and their use (Streubert & Carpenter, 2011).

Writers such as Williams (2000) argue that, in many cases, qualitative researchers produce 'moderatum generalisations', where aspects of the research focus (e.g. a particular group of participants) 'can be seen to be instances of a broader set of recognisable features' (Williams, 2000, p.215). Moderatum generalisations will always be limited and more tentative than the statistical generalisations normally associated with probability sampling. However, they do allow limited (modicum) generalisation and help counter the view that generalisation beyond the immediate evidence/case is impossible in qualitative research (Williams, 2000, p.215).

2.13 Analytical framework: Thematic analysis

I chose thematic analysis as a framework for data analysis, as described in sections 4.12-4.22. Thematic analysis is the most widely used method for analysing textual data in contemporary qualitative research (Wiltshire and Ronkainen, 2021). Thematic analysis offers independence from other approaches whilst constituting a unique stand-alone framework which is both comprehensible and accessible (Braun and Clarke, 2006). This accessibility provides an approach to data analysis which is useful for inexperienced researchers. This framework also appears congruent with my own values and assumptions, recognising both the efficacy of semi-structured interviewing as a data collection tool and the uniqueness and value of the perceptions/insights obtained from participants using this method. It was important to me that participant voices were 'heard', and I believe thematic analysis offered an approach for data analysis which both valued participant insights and which sought to accurately identify and represent those insights using specific codes which were accessible and believable to those reading the study.

Thematic analysis can also be utilised within both realist and constructionist frameworks. As stated earlier, epistemology guides what an individual researcher can say about their data and informs how meaning is theorised. With an essentialist/realist approach, it is possible to 'theorise motivations and meanings in a straightforward way, because a simple, largely unidirectional relationship is assumed between meaning and experience and language (language reflects and enables us to articulate meaning and experience)' (Braun and Clarke, 2006, p.44). This summarises my own position. In contrast, from a constructionist perspective, meaning and experience are socially produced and reproduced, rather than residing within individuals (Ryan, 2017). Therefore, 'thematic analysis conducted within a constructionist framework cannot and does not seek to focus on motivation or individual psychologies, but instead seeks to theorise the sociocultural contexts and structural conditions that enable the individual accounts that are provided' (Braun and Clarke, 2006, p. 44).

Thematic analysis therefore constitutes a valuable, accessible and comprehensible analytical framework for coding interview data, allowing key themes to be identified and utilised.

2.14 Critical realism and data analysis

A series of assumptions based upon my own critical realist positioning also influenced the analysis of participant interview data. These are described in more detail in 6.2.

2.15 Summary

This study utilised semi-structured interviews conducted at participant workplaces as the primary method of data collection. The research design is underpinned by a critical realist ontology and post-positivist epistemology, as described above. Textual data from interviews was then analysed using thematic analysis, as described in 4.12.

3 Chapter 3: Literature review

3.1 Introduction

This literature review attempts first to situate spiritual distress within a wider context of spirituality, spiritual needs and spiritual care, which collectively provide an important backdrop to the identification, assessment and alleviation of such distress.

The review then examines suffering and distress at the EOL, before exploring definitions of spiritual distress, its identification, and assessment. This area of the review is important for research questions 2 and 3, which specifically relate to ascertaining participant perceptions regarding spiritual distress, and how such distress is identified and assessed within the participant's own contexts. In addition, I offer my own definition of spiritual distress.

The review also highlights ambiguity in terminology associated with spiritual distress, identifies key variables that may influence the experience of spiritual distress in EOL patients, examines relevant literature regarding spiritual history taking as part of initial nursing assessment protocols, and seeks to identify key challenges related to the use of assessment tools with patients who may be close to death.

The review then concludes with a brief consideration of conceptual meaning making for practitioners. How specific meanings are developed by practitioners is important, and relates both to spiritual distress and the use of specific interventions which attempt to alleviate such distress (e.g. palliative sedation administered using a syringe driver). Meaning making is a highly theoretical concept and there would appear to be no literature which specifically attempts to apply meaning making to practitioners working within community-based EOL contexts.

3.2 Inclusion and exclusion criteria

Inclusion and exclusion criteria are shown below.

3.2.1 Inclusion criteria

- Literature examining definitions of spirituality, spiritual needs and spiritual care.
- Literature examining definitions of spiritual distress.
- Literature relating to spiritual distress in a community setting.

- Literature describing the use of specific tools in clinical settings to assess spiritual distress.
- Published literature only.
- English language only.
- Literature from the years 1998-2021.
- Peer reviewed studies only.

3.2.2 Exclusion criteria

- Not English language.
- Unpublished literature.
- Pre-1998.
- Not peer reviewed.

3.2.3 Data Bases used

- CINAHL.
- Medline.
- PsycInfo.
- Pubmed.
- BNI.
- CancerLit.
- RCNi.
- Google Scholar.

These data bases were chosen as they provide access to a wide spectrum of relevant nursing literature, including European, American, and literature from other contexts. They also include both specific palliative care studies and more generalised nursing and medical sources.

3.3 Spirituality

Within nursing, a desire to embrace holism has led to increasing emphasis upon the integration of spirituality within nursing practice, with nursing models including spiritual dimensions of care either implicitly (e.g. Roy, 2008) or explicitly (Neuman, 1995; Roper et al., 2000).

Authors from a range of health care professions (Culliford, 2002; Henery, 2003; McSherry and Cash, 2004; Puchalski et al., 2006; Clark, 2013) have attempted to explore the concept of spirituality. Spirituality is described as 'essential to healthcare and seeking to address meaning and purpose in life' (Puchalski et al., 2006, p.398). Spirituality has also been described as 'a critical dimension of comprehensive palliative care' (Ferrell and Munevar, 2012, p.66) and is viewed as a universal human characteristic (Woll et al., 2008). Spirituality 'embraces the arts and humanism, as well as cultural beliefs and practices' and can be understood as 'the inner life of a person' (Puchalski, 2012, p.iii49). In addition, spirituality has become an increasingly common theme within nursing literature, as reflected in the growing number of published concept analyses (Taylor, 2008; Pesut et al., 2009). The term is progressively used within nursing practice and literature, yet its exact definition and conceptualisation remains difficult (Harrad et al., 2019; O'Brien et al., 2019). Clarke (2013) suggests that for over three decades the nursing press have written about spirituality and nursing as though they fit 'hand in glove', despite ongoing conceptual confusion regarding specific meaning(s). Further, definitions often reflect individual interpretation and understanding alone and therefore lack objectivity (McSherry and Cash, 2004). Spiritual care (see 3.9) is also integral to nurse training curricula and systematic approaches to care (McSherry, 2006). Yet, successive surveys suggest that nurses do not understand the concept of spiritual care, nor its implementation, and lack confidence in its delivery (Clarke, 2013, p.1; Abell et al., 2018). This has been my observation. Over recent years spirituality has also received increasing attention within medical oncology (Kruizinga et al., 2018). Vachon et al. (2009, p.53) highlight that this lack of understanding is also evident within palliative care contexts, stating: 'Despite the considerable body of literature that has recently emerged on the concept of spirituality in palliative care, the definition of spirituality remains the subject of endless debate'.

Doctoral studies within a nursing context frequently begin with an attempt to define spirituality: this is problematic, as literature is clearly replete with definitions, many of which differ. Often, spirituality definitions are based on a search for ultimate meaning, purpose and connectedness to self, others and the significant or sacred (Puchalski et al., 2009) or highlight relationship to the transcendent and how this may be expressed in the life of the individual

(Markowitz and McPhee, 2006). Evident is that 'spirituality is expressed through beliefs, values, traditions and practices' (Puchalski et al., 2019, p.2).

Authors such as Cobb (2002) question whether any form of definition is either possible or necessary, stating:

> Spirituality represents something of a conundrum. It is a term both ancient and modern, an anachronism and a contemporary issue. It occupies an increasingly popular space in western culture and yet is shrouded in mystery and ambiguity. Spirituality is to be found at the very foundation of the modern hospice movement, and it receives copious mention in palliative care, but it has no standard definition, practice or policy (Cobb, 2002, p.11).

Several authors also suggest that current explanations of spirituality within nursing display insufficient critique (Swinton, 2006; Pesut, 2008a; 2008b; Paley, 2008a, 2008b). Analysis of definitions in nursing research also reveals inconsistencies and confusion regarding associated mental health concepts (Reinert and Koenig, 2013). Pesut (2008a p.98) proposed that 'definitions of spirituality are undergoing transition in the nursing literature'. Having effectively lost its religious roots, 'spirituality is increasingly being defined by a universal search for meaning, connectedness, energy, and transcendence'. For palliative patients, such 'generic' approaches may 'obscure and relativise the important values and beliefs that inform the critical questions many patients grapple with at the end of life'. Effective EOL care therefore requires a 'more nuanced understanding of spirituality than currently offered by such one-size-fits-all approaches' (Pesut, 2008a, p.98). Writing from a sociological perspective, Walter (2002, p.6) states that debates about the nature of spirituality are political, describing spirituality as 'a discourse used at the present time in the English-speaking world by those who wish to move beyond or distance themselves from institutional religion'. From the perspective of Psychology, Pargament (2001) defines spirituality as 'the search for the sacred'.

This lack of conceptual clarity reflects both the wider context of a pluralistic, post-modern society (Paley, 2008b; Pesut et al., 2008) and the absence of an agreed 'gold standard' for the definition of spirituality (Reinert and Koenig, 2013). It is also evident that conceptualisations of spirituality may be significantly affected by cultural, philosophical, religious or secular influences (Swinton, 2006; Lundberg and Kerdonfag, 2010; Mok et al., 2010; Pike, 2011). Pattison (2001) describes how the impetus to both identify and seriously attend to the spiritual dimension of individual patients or users within modern health care practice received a significant boost with the adoption of the patient's charter (Department of Health, 1991). The charter stated that service users were entitled to have their spiritual needs met within health services in the United Kingdom. However, the charter made no attempt to define the term 'spiritual needs', initiating a quest for discovery and definition that has continued to the present day. As Pattison (2001) stated:

> notions of 'spirituality' that are presently in play are diffuse, vague and contradictory. 'Spirituality' seems to function like intellectual Polyfilla, changing shape and content conveniently to fill the space its users devise for it. Having mostly departed from the theories and practices of religion, theorists and practitioners of spirituality are muddled about what actually constitutes their subject matter (Pattison, 2001, p.37).

This sense of 'muddle' is evident in much contemporary literature concerning spirituality, and within nursing itself, where the term is utilised to describe a wide range of seemingly unrelated aspects of care. For example, Steinhauser et al. (2017) describe how within palliative care literature, spirituality is often 'operationalised' as a single descriptive term containing a wide range of different 'dimensions' or components. These include 'diverse spiritual or religious beliefs, rituals and practices, coping, distress, relationship with the transcendent and sense of meaning or life purpose' (Steinhauser et al., 2017, p.429). Nearly twenty years ago, Carr (2001, p.27) suggested that 'Spirituality today is becoming a vogue theme, both within and outside the churches. There seems to be a discernible longing to recognise a spiritual dimension to existence while at the same time not turning to established religion for its articulation'. Subsequently, the term spirituality would appear to describe an ever-expanding assortment of components, many of which display contextual ambiguity. As Greenstreet (2006, p.7) states: 'It [spirituality] is particularly intangible and eludes true definition, needing to be grounded in a specific context if any attempt to describe it is to be helpful'. She also suggests that for professional practitioners, spirituality 'constitutes a perspective of care', with the potential to influence how care is both focused and administered.

For this reason, an understanding of what is meant by spirituality within a nursing context is important. If practitioners struggle to understand the term, or its utility, its influence upon patient care is likely to remain minimal. This reflects my own experience within community nursing. Also evident in recent decades are attempts within nursing to produce definitions which are 'inclusive of others who do not subscribe to a religious worldview but rather see spirituality as more related to a relationship with themselves, others or the environment' (Reinert and Koenig, 2013, p.4) (see also Reed, 1992; Narayanasamy, 1999; O'Hara, 2002).

Robinson et al. (2003, p.23) suggest that spirituality is about 'the practice and outworking of the spirit and the ways in which it is developed, with its different aspects and relationships connected, sustained and understood'. This 'outworking' may involve solely the spirituality of the individual or be developed through the disciplines and practices of a specific group, for example, a church community, gardening or rambling group. As the authors state, 'spirituality is relation and action centred, and about making connections with different aspects of life. It is also holistic and embodied, involving more than simply intellectual understanding and awareness' (Robinson et al., 2003, p.23). In their view, spirituality is therefore tri-partite, involving three principal areas of self-awareness/development. These are:

- Developing an awareness and appreciation of the other (including the self, the other person, the group, the environment and, where applicable, deity).
- Developing the capacity to respond to the other. This involves putting spirituality into practice, so embodying spirituality and facilitating continued relationship with the other.
- Developing an ultimate life meaning based upon all aspects of awareness and appreciation of and response to the other.

This tri-partite understanding emphasises connection, both to the other, but also to the self and to ontological security; effectively energising the individual. Awareness and appreciation of the 'other' refers to the other beyond the self, either a person, group, environment or the divine; each may be seen to provide ultimate value. Similarly, Bellmay (1998, p. 185) suggests the term ‘spiritual’ concerns three principle aspects of human experience:

- Values: that which is valued and the way in which it is valued.
- Meaning: the quest for life-enhancing meaning which does not preclude mystery, but which does not necessitate looking for a supernatural factor.
- Relatedness: the human need to find self-worth and identity, to love and be loved, to be accepted or forgiven. This relatedness may involve the self, other people, the environment or the transcendent.

3.4 Spirituality and palliative care

The context of palliative care is also problematic regarding spirituality. For example, Steinhauser et al. (2017) highlight that reviews within current literature have identified a lack of consistency in operational definitions, identification of dimensions that collectively constitute the ‘construct’ of spirituality and specific description of the relationship(s) between these dimensions and actual observed outcomes. The authors also suggest that within palliative care literature, the term spirituality frequently serves as a repository for a multitude of diverse ‘dimensions’, including spiritual or religious beliefs, rituals, practices, coping mechanisms, distress, relationship with the transcendent and sense of meaning or life purpose. In contrast, the authors suggest that the absence of definition directly influences any research process, stating: ‘The lack of definition and taxonomy inhibits clear study design, increases potential for confounding constructs, and impedes independent investigations from systematically informing on another’. In this sense, significant theoretical problems exist alongside very real problems of utility (Steinhauser et al., p.429).

3.5 Spirituality: assessment is problematic

Nurses often care for people when they are at their most vulnerable. Questions regarding mortality, suffering and the inevitability of death are fundamental to human experience and touch upon spiritual understandings of human existence. Evident is that many nurses have difficulty addressing spirituality with their patients or clients (Molzahn and Shields, 2008; Ellis and Narayanasamy, 2009). In an American study of 921 adults, McCord et al. (2004) found that

83% of participants wanted physicians to ask them about their spiritual beliefs under certain circumstances. These were when faced either with life-threatening illnesses (77%), serious medical conditions (74%) or when dealing with the loss of loved ones (70%). Further, individuals who are coping with serious illness or loss report that spiritual and/or religious support is important to them (Brady et al., 1999). Best et al. (2015), in a systematic literature review (n=54) comprising over twelve thousand patients found that most wanted to be asked about religion/spirituality by their doctor. However, it was unclear how to identify those patients who desired to discuss religious or spiritual issues and patients and medical staff did not always agree on what such discussion should entail. There was therefore a mismatch in perception between patients and doctors regarding these discussions and whether they had taken place. The authors suggest that medical staff should endeavour to identify which patients would welcome such conversations but provide no guidelines as to how this identification could be affected. Further, the term spirituality may be foreign to patients and therefore listening to the individual vocabulary of patients is crucial (Best et al., 2020).

Several nursing models also address spirituality as an integral component within the nursing theories upon which the models are based. For example, Neuman (1995) expanded the traditional biopsychosocial model to include spirituality, and over the last two decades there has been growing interest in holistic approaches which seek to care for the whole person (Harrad et al., 2019). It is also evident that many nurses consider spirituality to be an important aspect of their practice and research, as seen in the growing interest in parish nursing which focuses upon the spiritual needs of community members (Van Dover and Pfeiffer, 2007).

In addition, there is considerable evidence linking spirituality to health and well-being. For example, Brady et al. (1999) found that in people living with cancer, spirituality and physical well-being were associated with quality of life to the same degree. However, ‘despite evidence of the positive effects of spirituality on well-being, nursing curricula provide few opportunities for discussions of spirituality, and nurse educators and nursing students repeatedly report that spirituality is not discussed’ (Molzahn and Shields, 2008, p.26). Other authors have similarly identified deficiencies in addressing spirituality within nurse education (McSherry et al., 2004; McSherry, 2006; Noble and Jones, 2010; Attard et al., 2014).

3.6 Spirituality: A thematic approach

I believe a more helpful approach is to look for key themes within spirituality which connect with personal experience, as described by Sessanna et al. (2007, p.254) who adopted this approach in a comprehensive thematic analysis of nursing and health related sources (n=73). Their analysis identified four key themes within spirituality, namely:

- Spirituality as religious systems of beliefs and values (spirituality=religion).
- Spirituality as life meaning, purpose and connection with others.
- Spirituality as non-religious systems of beliefs and values.
- Spirituality as a metaphysical or transcendent phenomena.

Definitions of spirituality frequently cannot be neatly categorised in this way, arising both from single themes as well as a combination, underlining the difficulty in attempting to define spirituality within nursing. For example, several authors maintain that a person can be ‘spiritual’ without having explicit religious beliefs and practices (Bickerstaff et al., 2003; McSherry, 2006; Clarke, 2013) and authors such as Nolan and Mock (2004, p.354-5), Reed (1992, p.351-2) and White (2006, p.91) all suggest that spirituality contains a central theme of transcending or rising above the everyday. Sessanna et al. (2007) also suggest that these four identified themes can be situated within two principal domains: intrinsic (innate, intrapersonal) and extrinsic (tangible, interpersonal) attributes/properties.

Over thirty years ago Murray and Zentner (1989, p.259) defined spirituality as:

> A quality that goes beyond religious affiliation, that strives for inspirations, reverence, awe, meaning and purpose, even in those who do not believe in any good. The spiritual dimension tries to be in harmony with the universe, and strives for answers about the infinite, and comes into focus when the person faces emotional stress, physical illness or death.

Reflecting on this definition, McSherry (2006, p.48) suggests four dominant themes can be identified, specifically:

- Spirituality is a universal concept relevant to all individuals.
- The uniqueness of the individual is paramount.
- Formal religious affiliation is not a prerequisite of spirituality.
- An individual may become more spiritually aware during a time of need.

This definition also highlights the holistic impact of spirituality, alongside the presence of both mystery and a desire for transcendence; all appear interrelated and interconnected. Best et al. (2020, p.2) also suggest that spirituality is multi-dimensional, consisting of:

- Existential challenges (e.g. questions concerning identity, meaning, forgiveness, hope and despair).
- Value based considerations/attitudes (e.g. what is most important for each person, such as relationships to family, friends, work and nature).
- Religious considerations and foundations (e.g. faith, beliefs and practices, relationship with God or the ultimate).

The authors also state that it is critical patients be asked what form their own spirituality takes. This reflects my own view. Also evident is the recurring theme of connection, which I regard as the most prominent and important theme within spirituality. What important connections (e.g. to God, self, others, creation or creativity) are unique to this person, and provide a source of perspective, energy and motivation which enhances their resilience and enables them to cope with their illness? In my experience, this simple question would appear to be frequently omitted from nursing assessments, leaving an important aspect of holistic care effectively ignored. Within palliative care contexts, this is particularly concerning.

3.7 Spirituality: Cultural/faith differences at the EOL

Multiple factors influence access to EOL care, and experiences of such care by culturally and spiritually-diverse groups shows wide variability. Accessing EOL care (e.g. health and social support at home or in hospices) is also more difficult for ethnic minorities compared to white European groups (Lan Fang et al., 2016). How ethnicity, age, and spirituality affect decisions when death is imminent are also important considerations within EOL care.

Culture itself is a 'complex and multifaceted construct, shaped by the interaction between numerous socio-demographic factors and continuously redefined by historical experiences and social realities' (Bullock, 2010, p. 84). Culture incorporates a range of concepts, including race (ethnicity), religion, language, national origin, and other factors. Understanding those factors that influence attitudes, beliefs and behaviours towards EOL and palliative care can therefore assist practitioners to achieve cultural competence in the delivery of such care (Ibid). The cultural variants of a particular group of people significantly determine how they make sense of life and death (Manzenec and Tyler, 2003; Parry & Ryan, 2000), and approach EOL decision making (Bullock et al., 2005; Ludke & Smucker, 2007; Smith et al., 2009; Lopez-Sierra and Rodrıguez-Sanchez, 2015).

As populations become more racially, ethnically, and culturally diverse, so this diversity will also be reflected in patient populations, therefore increasing the likelihood that patient values may differ to those of traditional Western-based medicine. In addition, both family structures and functioning may also no longer fit conventional paradigms for providing care.

In a further American literature review (n=26), Lopez-Sierra and Rodriguez-Sanchez (2015, p. 88) concluded that:

- Different cultures can provide the necessary social networks and cultural practices that can assist patients receiving EOL care.
- Healthcare providers can tap into the patient's social care networks and cultural practices to enhance their care.
- Religion and spirituality generally exert a positive influence on EOL care.
- Religion and spirituality provide patients receiving EOL care with inner strength(s) and facilitate transcendence.

Paiva et al. (2013), in a study of Brazilian breast cancer patients during chemotherapy, similarly highlight that religious practices are significantly associated with QOL within palliative contexts. Pederson et al. (2013), in a study of Danish and American women treated for breast cancer in a secular society, found that patients who had religious faith expressed a significantly higher degree of certainty, compared to women reporting ambiguous faith. Shores (2014), in a study of spiritual interventions and the impact of a faith community nursing programme in an African-American community, found the programme was a key connection between spiritual and physical health, positively influencing individual spirituality.

Importantly, Balboni et al. (2013) found that terminally ill patients who were well supported by religious communities access both hospice care and aggressive medical interventions less frequently near to death. The provision of effective spiritual care and EOL discussions between patients and members of the MDT also reduced the frequency of aggressive treatments, again highlighting the importance of spiritual care.

Within a Chinese cultural context, Hau Yan Ho et al. (2013) argue that living and dying with dignity manifested differently than in other cultures, highlighting values of legacy, resilience/fighting spirit, enduring pain, moral transcendence, spiritual surrender and transgenerational unity.

Manzanec and Tyler (2003) further argue that ethnicity, age, and religious and spiritual beliefs can affect EOL care (other important components include race, gender, sexual orientation, physical and mental abilities, and socioeconomic factors). For example, diversity in practices adopted at death by African-American, Chinese American, Filipino-American and Hispanic/Latino cultures focused upon the role of the family, the immediate environment, and preparation of the body of the deceased. The authors also identify barriers to 'cultural competence', which they classify as relating to both 'providers', and 'systems'. For example, individual practitioners (providers) may lack knowledge of their patients' cultural practices and beliefs, or the individual beliefs of practitioners may significantly differ from those of their patients, creating potential difficulties when patient responses may be deemed inappropriate. Systems related barriers exist where palliative care contexts fail to reflect cultural diversity, instead 'mirroring' the culture in which they are situated regarding belief and practice. For example, in hospital based units, it may not be possible to facilitate the belief that a window should be left open whilst a loved one is dying, to allow the soul to leave. Nor may other specific cultural practices be possible after death, if there are time constraints caused by other patients waiting for a bed to become available.

Bullock (2011) highlights that practitioners need to understand the need of many patients, irrespective of cultural background, to involve their family/loved ones when receiving palliative and EOL care (Kehl et al., 2009; Hudson et al., 2010; Townsend et al., 2010). For ethnic minority patients, who tend to rely more on informal than formal support structures, family/loved ones frequently represent a significant aspect of the patients' care plan. For practitioners who operate on a Western-based medical model of care, this involvement may provide a source of contention, particularly if the goal of care would appear to be directed less at the patient than at the family. When conflicts between the value systems of health care provider and the patient arise (Lo, 2010), failure to deal with them appropriately may result either in inadequate care or lack of care (Fins, 2006).

In a further scoping review, Lan Fang et al. (2016) identify that multiple factors influence the experience of EOL care by culturally and spiritually diverse groups, and argue that access to EOL services (e.g. health and social support at home or in hospices) is difficult for ethnic minorities compared to white European groups. The authors identified barriers and enablers at the systems, community and personal/family levels. Primary barriers include cultural differences between healthcare providers; persons approaching EOL and family members; under-utilization of culturally-sensitive models designed to improve EOL care; language barriers; lack of awareness of cultural and religious diversity issues; exclusion of families in the decision-making process; personal racial and religious discrimination; and lack of culturally-tailored EOL information to facilitate decision-making.

In summary, knowledge and awareness of patient spirituality, cultural values, attitudes, and behaviours can assist practitioners in avoiding stereotypes and biases, create positive interactions with patients, improve the quality of EOL care and lead to better patient outcomes.

3.8 Spirituality: summary

As described earlier, spirituality may be expressed in terms of values, an experience of the transcendent, a desire for personal growth and in the activity of prayer, to name just four potential expressions. The task of the nurse seeking to engage with a person's spirituality is to do so without presuppositions about what their spirituality may be or what spirituality means to them. In this way, practitioners can respect the religious, spiritual and cultural needs of the individual, as outlined in the NMC code of conduct (NMC, 2018). Although spiritual, emotional or psychological struggles may become intertwined, emotional or psychological support alone may not address the root of the problem, particularly if the need is spiritual. The ongoing challenge to define spirituality within health care has led to a wide range of definitions within nursing contexts. This range of definitions has effectively led to the incorporation of any non-physical aspect of the individual into the 'spiritual', making it difficult for nurses to differentiate spiritual care effectively from psychosocial care. This accumulation 'leads to nurses naturally believing that because they are attempting to address the former, they are also addressing the latter, a much easier option than attempting to discern spiritual needs' (Clarke, 2009, p.1670). Though viewed as 'universal', the accessibility of spirituality to practitioners remains limited, resulting in uncertainty as to the role and meaning of spirituality within daily nursing practice. Further, it is profoundly difficult to answer questions regarding the nature of spirituality in nursing if there remains no clear sense of what spirituality is. This is unfortunate and effectively disenfranchises practitioners from an important aspect of patient care.

Within secular societies, the connection between healthcare and spirituality is also frequently unclear (Cobb et al., 2012). This lack of connection is further reflected in the increasing number of patient assessments and care plans that include minimal or no reference to either spirituality or spiritual needs (NHS England, 2015).

Having highlighted the value of a thematic approach to defining the nature of spirituality, I would now like to consider spiritual care, which forms a further important aspect of holistic nursing practice, particularly within palliative contexts.

3.9 Spiritual care

Nightingale (1860) stated that the aim of nursing was to create conditions so that 'nature can act, and self-healing occur' (Nightingale, 1992). Subsequently, the development of nursing theory has led to the emergence of 'holistic care' as a hallmark of contemporary nursing. The term is generally understood as nursing care which seeks to integrate the biological, psycho-social and spiritual aspects of health, viewing these components either separately or synergistically (Cavendish et al., 2004). However, during the last century, nursing has progressively mirrored an increasing societal emphasis upon empiricism and the separation of the spiritual from the physical (Cavendish et al., 2004; Gilbert, 2010). This loss of the spiritual from health care has also been exacerbated by economic models that appear to value finance above quality of patient care (Gilbert, 2010).

The spiritual domain also continues to be the least understood and incorporated into nursing practice (Chan, 2010) and there is little consensus regarding an agreed definition for spiritual care (Narayanasamy and Owens, 2001; Daaleman et al., 2008; Gijsberts et al., 2011), particularly within palliative contexts. For example, Taylor (2002) describes spiritual care as specific actions seeking to integrate spirituality into life. This is ambiguous, and therefore difficult for practitioners to utilise in practice. Spiritual care has also been described as essential to effective palliative care, as the ability to integrate meaning and purpose in life is frequently compromised in patients facing either a life-threatening illness or those deemed to be EOL (Taylor, 2002; McSherry, 2006; Puchalski et al., 2006; Ferrell and Munevar, 2012). The provision of spiritual care exemplifies compassionate and altruistic caregiving and forms an important element of professionalism amongst healthcare professionals. Spiritual care includes spiritual history taking, the assessment of spiritual issues/resources of strength and the incorporation of patients' spiritual beliefs/practices into care planning. The provision of spiritual care is also the responsibility of every member of the interdisciplinary team (Puchalski et al., 2006, p.398).

Many studies examining spiritual care within palliative care contexts originate from the USA, leaving other contexts relatively unexplored. A review of spiritual care research within a European context (n=53) is provided by Gijsberts et al. (2019). In this study, 'spiritual care involved attention for spirituality, practitioner presence, patient empowerment and bringing peace'. Requirements for implementing spiritual care ('spiritual competency') in palliative contexts included practitioner self-reflection and ensuring the visibility of spirituality and spiritual care across existing organisational structures (Gijsberts et al., 2019, p.1).

Across Europe, the level of unmet need in spiritual care appears unclear and variable levels of support are evident (van de Geer et al., 2017; Selman et al., 2018). Also, evidence for spiritual care interventions would appear to be low (Gijsberts et al., 2019, p.15). Spirituality and spiritual care also frequently display significant ambiguity in relevant literature, particularly as nurses and patients may perceive spirituality very differently. However, nurse-patient relationships allow spiritual care to be given ‘through actions of care and transpersonal moments’ (Stern and James, 2006); this is important, given the lack of common language and present efforts to establish spirituality as a unique concept within nursing (Pike, 2011, p.747). Outside of formal education settings, few researchers appear to have considered the process whereby practitioners acquire knowledge regarding spiritual care (Hood et al., 2007), nor how this knowledge is then utilised within practice settings. If nursing claims to provide holistic care, then spiritual care is clearly integral to this process, and cannot be separated from other aspects of care. Evident is that nurses consider it authentic to provide spiritual care (Pike, 2011). However, although able to identify spiritual needs, practitioners appear less able to respond to them (Ross, 2006), a lack of response described by Middleton-Green (2008) as ‘commonplace’.

Globalisation also presents a growing challenge to spiritual care, particularly where patient values and beliefs may differ from those of practitioners (Ruard Ganzevoort et al., 2014). Effective spiritual care requires understanding and acceptance of such diversity (Balducci and Innocenti, 2017). An associated lack of critique has also produced a bias within nursing literature towards ‘broad, generic, existential definitions which, together with an intentional divorce from religion and theology, have led to definitions of spiritual care indistinguishable from psychosocial care, hard to explain to patients and difficult to put into practice’ (Clarke, 2009, p.1666).

The importance of spiritual care is also identified within several oncology guidelines e.g. WHO (2015) and associated with better overall QOL and enhanced psychosocial and spiritual well-being (Balboni et al., 2010; Kruizinga et al., 2016). In an American study of 75 patients and 339 cancer physicians and nurses, 78% of patients, 71% of physicians and 85% of nurses believed that routine spiritual care would have a positive influence upon patients (Phelps et al., 2012). Spiritual wellbeing is also associated with multiple health related benefits for patients, including greater tolerance of the emotional and physical demands of illness (Balducci, 2019), decreases in pain, stress and negative emotions, such as despair (Blaber et al., 2015) and lower risk of suicide (Balducci, 2019).

A recognition of individual spirituality has also been demonstrated to impact health outcomes of patients with cancer ‘across the trajectory of the disease’, as well as in more specific settings (Puchalski, 2012). These include:

- Advanced stage cancer.
- Early stage cancer.
- Patients receiving active treatment.
- Palliative care.
- Specified types of cancer (e.g. breast, prostate, colorectal, lung, brain).

However, ‘While increased attention in oncology has been given to psychological and social aspects of care, spiritual care is often neglected’ (Puchalski et al., 2019, p.1). Adequate spiritual care also correlates with higher satisfaction of hospital care and treatment (Yardley et al., 2009; Williams et al., 2011) and there is growing evidence that spiritual care at the EOL is important to patients and their families (Maclean et al., 2003; Best et al., 2015). Also evident is that lack of spiritual care and support is associated with poor QOL, dissatisfaction with care, less hospice utilisation, more aggressive treatment and increased costs, particularly among ethnic minorities and patients with high levels of religious coping (Balboni et al., 2007, 2010, 2011).

However, health care professionals consistently struggle to define what constitutes spiritual care (Govier, 2000; McSherry et al., 2002; Strang et al., 2002; Barnett, 2013; Rushton, 2014). Also, patients consistently fail to receive spiritual care from their oncology nurses or physicians (87% and 97% respectively); the strongest predictor of spiritual care provision by nurses was the provision of spiritual care training (Balboni et al., 2013). Assessment of need on admission to either a health or social care context may identify practical aspects of spiritual care required by an individual patient or client, resulting in activity which constitutes ‘doing’ in relation to spiritual care. As Greenstreet (2006) identifies, much of spiritual care relies on the nature of the ‘therapeutic’ relationship between health care professional and patient/client as well as the nature of the carer's ability to 'be with' that individual in what may be very difficult circumstances, such as impending death. Within palliative contexts, spiritual care is focused upon 'healing' rather than cure and wholeness rather than 'recovery' (Greenstreet, 2006c, p.50.).

Definitions of spiritual care vary. For example, 'Spiritual care aims to support patients to maintain meaning in their lives, particularly during times of injury or illness' (Caldeira and Timmins, 2017, p.54). Kelly (2012, p.19) states that spiritual care 'is person-centred care which seeks to help people (re)discover hope, resilience and inner strength in times of illness, transition and loss'. NHS Scotland similarly describe spiritual care as:

> that care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship and moves in whatever direction need requires (NHS Education for Scotland, 2009, p.446).

The Royal College of Nursing have also adopted this same definition (RCN, 2011, p.3).

Essential components of spiritual care include:

- Recognising, respecting, and meeting patients' spiritual needs.
- Facilitating participation in religious rituals.
- Communicating through listening and talking with patients.
- Being with the patient by caring, supporting, and showing empathy.
- Promoting a sense of well-being by helping patients find meaning and purpose in their illness and overall life.
- Referral to other professionals, including the chaplain/pastor.

(Baldacchino, 2015, p.594).

Spiritual care therefore attempts to assist the individual to connect (or re-connect) with that which infuses his or her life with meaning, and which brings energy and hope. This could be relationship(s) with God, others, with the created order or with self, where either have been undermined or indeed lost by the stress and fear frequently associated with disease or the unknown. Caldeira and Timmins (2017, p.54) utilise the acronym ABCDE for the essential components of spiritual care, representing:

- **A**ssessment
- **B**eing
- **C**ollaboration
- **D**iagnosis
- **E**thics

Drawing on earlier work by O'Connor (1988), Puchalski et al. (2009, p.890) link spiritual care to the theme of connection, stating:

> Spiritual care models offer a framework for health care professionals (or encourages practitioners) to connect with their patients; listen to their fears, dreams, and pain; collaborate with their patients as partners in their care; and provide, through the therapeutic relationship, an opportunity for healing. Healing is distinguished from cure in this context. It refers to the ability of a person to find solace, comfort, connection, meaning, and purpose in the midst of suffering, disarray, and pain. The care is rooted in spirituality using compassion, hopefulness, and the recognition that, although a person's life may be limited or no longer socially productive, it remains full of possibility.

This definition assumes conceptual clarity regarding spirituality on the part of practitioners: this may be optimistic. Spiritual care may also involve other members of the multidisciplinary team such as the chaplaincy service, as well as the patient's family (Mcsherry and Jamieson, 2011; Baldacchino, 2015). In addition, spiritual care is legally expected of nurses, and nursing staff are expected to be competent in its delivery at the point of registration (NMC, 2010). However, competency in spiritual care is clearly dependent upon multiple factors, including knowledge, skills, attitudes, experience and cultural background. All are likely to influence how the nursing practitioner approaches the individual patient. Whilst spiritual care competency frameworks exist for palliative care (Marie Curie Cancer Care, 2003) and chaplaincy (NHS Education for Scotland, 2008), work has only recently begun on developing frameworks for nursing, as highlighted by Attard et al. (2014, p.1460) and Van Leeuwen et al. (2009, p.446). Whilst the expectation is that nurses will be competent in spiritual care at the point of registration, little is known about the factors that contribute to the acquisition of spiritual caring skills and spiritual care competency by student nurses/midwives (Timmins and Neill, 2013; Attard et al., 2014; Ross et al., 2016).

Spiritual care within health settings has tended to focus either upon palliative care or the support of staff, two key areas of focus of modern-day health care chaplaincy. Notably absent from contemporary literature are studies which focus upon the spiritual care of patients within community settings, including that of the home. However, authors such as Neuberger (1998) suggest that spiritual care has a much wider remit than chaplaincy alone and is an aspect of care which may not be primarily mediated or delivered by chaplains at all. Instead, Neuberger believes that spiritual care falls within the remit of every member of the multidisciplinary healthcare team, assuming those team members possess the insight, sensitivity, skills and ability to deliver such care. Of interest is that Neuberger focuses particularly on the role of the cleaning and portering staff within a typical acute hospital, 'who often, by their very common sense and willingness to talk where health care staff fear to tread, provide some of the best spiritual care in our health care settings' (Neuberger, 1998, p.7). This illustrates how spiritual care may be 'delivered', often under the radar of 'social structure'. It also highlights the importance of the MDT. Neuberger also suggests that in essence, spiritual care is primarily relational; it centres upon listening to the individual, developing relationship with them (relationships which are 'therapeutic' in focus), getting to know them and being there for them, all of which are undermined by the pressure and task orientation of much of modern day healthcare (Neuberger, 1998, p.9). As identified above; 'The cleaning staff play a major role in providing spiritual care, and they are not recognised for doing it. One of the reasons it happens that way is that they are there, around the beds and the wards, with their mops, and familiar to patients, unthreatening, in a way that the chaplaincy team cannot be' (Neuberger, 1998, p.19). It is difficult for chaplains to be around for enough time for so called 'ordinary conversations' to then lead on to the more 'important ones', which may facilitate the sharing of those issues which are of primary importance to the individual patient.

Given the increasing impetus internationally towards nurses providing spiritual care, and the growing cultural and religious diversity of client groups, it is essential that nurses can understand and conceptualise what is meant by spirituality and spiritual care, to adequately support patients. It is also apparent that nurses view such care as essential and integral components of their duty of care. Furthermore, many nurses believe that attending to the spiritual needs of patients enhances the overall quality of their nursing care (McSherry and Jamieson, 2011). Evident is that papers promoting the delivery of spiritual care do not always critically examine the rationale for such delivery, assuming instead that meeting spiritual needs is a nursing responsibility (Pike, 2011). Prior to 2006, multiple studies also highlighted an overwhelming need for education in spiritual care (Ross, 2006). Buswell et al. (2006) rightly ask should there be boundaries between nurse and patient regarding spiritual care? This is important, as some patients may not wish to receive spiritual care. As Pike (2011) highlights, most research over the past two decades has explored nurses' perceptions of spiritual need rather than that of patients. There is a paucity of research to suggest that UK patients wish to receive spiritual care from nurses where patients have identified spiritual needs and an associated dearth of research into spirituality from the perspective of the patient (Pike, 2011). For practitioners, the delivery of spiritual care may also involve coping with loss and grief. In grief, nurses may experience significant role conflict, having to combine acting as a source of support for relatives whilst often being profoundly affected by the loss of someone in whose care they have been intimately involved for a significant time. A recognition that nurses need opportunity to grieve and achieve a healthy resolution regarding the death of individual patients is foundational to the maintenance of physical, mental and spiritual health. In contrast, 'maladaptive grieving can lead to emotional distancing and depression, non-caring, anger, and burnout' (Brunelli, 2005, p.128).

Maladaptive grieving may also result in attrition amongst nurses or the delivery of ineffective nursing care (Brosche, 2003). Gerow et al. (2010, p.122) describe how nurses dealing with patient death(s) can create a 'curtain of protection' to lessen the grieving process and enable them to provide supportive nursing care to others. The curtain 'envelops the patient and nurse together, allowing vulnerability to be expressed as well as constrained' (p.124). Such relationships went beyond modern cultural assumptions regarding professionalism, which is often 'a one-way experience void of deep caring' whereby the professional provides previously agreed services to the client. Instead, the relationship was a reciprocal experience whereby the nurse also obtained something of value (but intangible) from the patient or the patient's family, such as 'emotional support or the recognition of the nurse's contribution to the quality of care received' (Gerow et al., 2010, p.125).

Themes integral to this 'curtain' include:

- Such reciprocal relationships transcend the professional relationship.
- Nurses' coping responses frequently incorporate spiritual worldviews and caring rituals.
- Remaining 'professional' requires the 'compartmentalising' of experience.

Barriers to spiritual care include lack of time, personal, cultural or institutional factors, and professional educational needs. In contrast, spiritual care is enhanced by 'the way physical care was given, by focusing on presence, journeying together, listening, connecting, creating openings, and engaging in reciprocal sharing' (Edwards et al., 2010, p.753). Other recognised barriers to the delivery of spiritual care include lack of knowledge and skills, fear of making mistakes, fear of not knowing what to say and viewing spirituality solely as the responsibility of the pastoral care team (Magnussen, 2017).

In summary, spiritual care appears to constitute a further area of nursing practice characterised by conceptual confusion amongst practitioners, therefore influencing its delivery and impact upon patient care.

3.10 Spiritual needs

Nurses are increasingly required to nurse holistically, integral to which is caring for spiritual needs. However, the way in which nurses learn about spiritual aspects of care remains unclear (Hood et al., 2007). As living creatures, we all have basic needs deemed essential for ongoing survival and wholeness. These situate within the physiological, social and psychological, such as the need for food, water, relationship and meaning. Deprived of such needs for any prolonged period, health rapidly deteriorates. Authors such as Harrison (1993, p.23) suggest that a further requirement is that of spiritual needs; the 'deepest requirement of the self which, if met, make it possible for the person to function with a meaningful identity and purpose, so that in all stages of life that person may relate to reality with hope'. The fulfilment of such needs allows the individual to find meaning, purpose and hope, even when they may be facing significant threat or death. Spiritual needs may also vary in different situations or stages of life, for example in children, families, in acute or chronic illness, at key life transitions, at the EOL, in death or after bereavement (O'Brien, 2018). There is also evidence to suggest that attending to the spiritual needs of patients can improve their health outcomes (Koenig, 2013; 2015).

In contrast, unmet spiritual needs appear to significantly impact patient wellbeing and correlate with reduced QOL, increased risk of depression and reductions in perceptions of spiritual peace (Pearce et al., 2012; Selman et al., 2018). Internationally, an increasing emphasis upon the importance of spiritual needs is also evident (Paal et al., 2015). However, several authors highlight a tendency of medical staff to undervalue or ignore spiritual needs within 'biopsychosocial paradigms' and to devalue non-medical input within multidisciplinary team discussions (Payne and Haines, 2002; Best et al., 2015). Patients also indicate that their spiritual needs frequently remain unmet within 'standard clinical environments' (Balboni et al., 2007; Delgado-Guay et al., 2011). Some authors also appear to use the terms existential and spiritual needs simultaneously (Moadel et al., 1999).

Kellehear (2000) developed a model of spiritual needs situated within palliative contexts. He describes spiritual need as the activity of seeking and finding meaning such that hardship and suffering can be transcended and provides a multidimensional framework incorporating three dimensions of spiritual need; religious, sacred and secular. This is shown below.

Dimensions of spiritual need (adapted from Kellehear, 2000, pp.151-153)

Situational (derived from the individual's need to question and reflect about suffering and life changes)

- Purpose.
- Hope.
- Meaning and affirmation.
- Mutuality.
- Connectedness.
- Social presence.

Moral and biographical (needs which arise from the direct situation of the individual)

- Peace and reconciliation.
- Reunion with others.
- Prayer.
- Moral and social analysis.
- Forgiveness.
- Closure.

Religious (which may emerge from moral and/or biographical reflections)

- Religious reconciliation.
- Divine forgiveness and support.
- Religious rites/sacraments.
- Visits by clergy.
- Religious literature.
- Discussions about God, eschatology, or eternal life and hope.

Several authors, including Highfield and Carson (1983), Narayanasamy (1991, 2001) and Taylor (2002) have also identified specific needs which they identify as spiritual in nature, though none of these situate their research within a community nursing context. Drawing upon the work of these authors, McSherry (2006) provides a useful summary of spiritual needs, as shown below:

A summary of spiritual needs: (adapted from McSherry, 2006, pp.56-7)

Meaning and Purpose

All of us have a need to identify meaning in life, which is responsible for providing motivation, purpose and fulfilment. This search is lifelong and continues in both health and times of illness.

Love and harmonious relationships

Without the intimacy and comfort gained by sharing life with others (e.g. spouse, partner, family members or close friends) it is easy to experience isolation, loneliness, insecurity alongside a feeling of being unloved or unwanted. All these needs are derived from our personal interaction with others.

A Need for forgiveness

Conflict in life is commonplace, and there are many effective strategies to help alleviate or resolve this. However, unresolved anger, guilt or unforgiveness can all be significantly detrimental to health and wellbeing.

A Need for a source of hope and strength

Spirituality is often described as a source of inner strength and hope (Clayton et al., 2008), though the nature of individual spirituality may differ significantly. Personal beliefs, values and attitudes can all provide a source of hope to individuals, enabling strength to be drawn from those convictions and commitments.

Creativity

This is a key aspect of spirituality, referring to the ability to find meaning, expression and value in a wide range of activities, such as literature, art, music and science. All have their origin in the creative nature of the human individual, and each provides expression and meaning as well as a means of communication, often at a level beyond words. Each may also allow the individual to transcend their immediate surroundings or circumstances. Creativity can clearly be a source of inspiration as well as creation.

Trust

The absence of trust can quickly lead to isolation and neglect. Trust is a prerequisite for any meaningful relationship, be this the establishment of friendships to the establishment of a therapeutic relationship between nurse and patient. Trust is therefore fundamental to human existence and communication, leading to a sense of value, self-worth and acceptance by the self and others.

Ability to express one's own personal beliefs and values.

Throughout life, all of us have need to express our own beliefs and values, both verbally but also in the way that we choose to live out these beliefs and values in the everyday. The inability to do this can lead to dissonance, frustration and eventually hostility or despair.

Maintaining spiritual practices

Throughout life, certain spiritual practices may become established and then subsequently developed. Such practices may be religious in nature, such as the need for attendance at church services, synagogue, mosque or temple. However, an individual may also derive spiritual nourishment through walking, gardening or by partaking in some form of sport. During illness or hospitalisation, there is a need, wherever possible, for such practices to be incorporated in the spiritual care of that individual.

Expressing one's own belief in God or deity

An important dimension of spirituality for many individuals is a belief in God, or supreme power. The word 'belief' is potentially problematic in this context, as it can imply intellectual assent alone. This may be belief in God both as creator of the world, and yet who can be known intimately, in relationship (Judeo-Christian tradition). However, for other individuals, God or deity may be self-defined. It is important that such belief can find expression, both in health and at times of illness.

As highlighted above, the growth of holism within key areas of health care effectively underpins much contemporary discussion concerning spiritual needs. This development has promoted a dramatic shift in perspective which now includes spiritual aspects of health, alongside the biological, psychological and social. As Cobb states: 'the implication is that being human involves a spiritual dimension that is integral to health and significant to illness' (Cobb, 1998, p.106). Of concern is the current Nursing and Midwifery (NMC) code of conduct. The code ‘sets out common standards of conduct and behaviour’ for those on the current register and ‘provides a clear, consistent and positive message to patients, service users and colleagues about what they can expect of those who provide nursing or midwifery care’ (NMC, 2018). Section 3 of the code states: ‘Make sure that people’s physical, social and psychological needs are assessed and responded to’. Evident is no mention of spiritual needs, nor of spirituality; a significant oversight for an organisation that consistently advocates holistic approaches to nursing, and which further highlights the current ambiguity concerning spiritual needs within nursing.

Assessment of Spiritual needs

The assessment of spiritual needs presents numerous challenges, as outlined by McSherry (2006). For example, nurses may be uncertain as to how to communicate with patients regarding spirituality or religious belief and may be wary of using inappropriate language or fearful of causing offence. As a result, sections within nursing assessments dealing with ‘spiritual needs’ are frequently left blank. McSherry (2006, p. 106) suggests there are several reasons for spiritual needs being effectively ignored in nursing assessment documentation. These include:

- The subject of spiritual needs is too intrusive and personal to address on admission.
- The admitting health care professional did not feel comfortable in addressing questions relating to spiritual needs.
- The patient did not want to answer the question or did not identify any spiritual needs at the time of admission.
- The patient and/or admitting nurse did not understand the term ‘spiritual needs’.
- The patient identified spiritual needs considered too private or sensitive to disclose in his or her care plan.

Because of the sensitive nature of spirituality, an individual may not choose to reveal such information during an initial assessment, particularly before the nurse-patient relationship could be deemed to be ‘therapeutic’. Such relationships also require considerable knowledge of the patient, which may itself be lacking. Patients may also be reluctant to share their own attitudes towards death and dying, spiritual needs or sexuality, or indeed, be unsure as to the meaning of the term spiritual needs, making assessment problematic.

Forty years ago, authors such as Burnard (1988) recognised there are aspects of health care that were considered taboo, such as sexuality, death, dying and spirituality. It is also an untested assumption that patients wish to face the degree of intrusion required to facilitate such assessment(s) (Randall and Downie, 2006). NICE also suggest that a person's religious or spiritual needs should be assessed at key points during their illness (e.g. at the time of diagnosis, treatment episodes or as death approaches) but provide no guidance on how such assessments should be made or particular assessment tools deemed appropriate for the task (NICE, 2016).

There is also a current lack of agreement amongst nurses regarding the necessity of spiritual assessment being integral to holistic care. For example, in a study of 71 British hospital nurses, nearly half chose not to document patient spirituality at all. These nurses reported they were uncompliant either because they did not think spiritual assessment was necessary or they thought that assessment questions were intrusive (Swift et al., 2007, p. 1281). Only 23% of the 30 uncompliant nurses identified lack of time as an obstacle, which suggests a reluctance to engage in spiritual assessment. This study is again set within a hospital rather than a community context. The study also found that three-quarters of the nurses agreed that knowing what the spiritual assessment data would be used for and receiving more education about how to assess and care for spiritual distress would improve their performance (Swift et al., 2007, p.1281).

The assessment of spiritual needs therefore remains problematic, due to ambiguity, an apparent lack of confidence amongst practitioners and a lack of effective assessment tools. Also evident is a paucity of material relating to the assessment of spiritual needs within community contexts. This is concerning and suggests an important aspect of holistic care is effectively being omitted within palliative and community settings.

3.11 Suffering and distress at the EOL

Suffering and distress are commonly experienced by patients receiving palliative care (Abraham et al., 2006; Delgado-Guay et al., 2009) and although the terms are frequently used interchangeably, they refer to different experiences. In a comprehensive literature review of suffering and distress in EOL patients, Krikorian et al. (2012) highlight the integrative nature of such suffering, which frequently involves physical, psychological, social and spiritual dimensions, and is unique to the individual. Suffering has been defined as 'a complex negative affective and cognitive state, characterised by a perceived or actual threat to the integrity of the self': perceived helplessness and exhaustion of psychosocial and personal coping resources frequently accompany such threats (Chapman, 1993). Similarly highlighting the importance of personal identity, Cassell conceives suffering as 'a specific state of severe distress related to the imminent, perceived or actual threat to the integrity or existential continuity of the person' (Cassell, 1982). Suffering constitutes 'a unique, comprehensive and holistic experience, which includes physical, psychological, social and spiritual phenomena' (Krikorian et al., 2012). The experience of suffering is also influenced by the individual's personality and the meaning(s) assigned to aspects of their personhood such as their body, identity, life experiences, activities and relationships with others (Ibid). Due to its subjective nature, suffering also is challenging to assess and measure.

As the EOL approaches, patients commonly experience a range of symptoms, emotions, spiritual issues and social circumstances concurrently; collectively, these may be profoundly challenging for the individual (Wilson et al., 2007). Within this context, Saunders (1972) first described the experience of 'total pain', referring to the cumulative relationship/interaction between such factors and the profound holistic impact this may have on the individual.

Distress is a key component of suffering and encompasses a 'unique discomforting emotional response experienced by an individual in response to a specific stressor or demand' which is psychological, social or spiritual in nature (Krikorian et al, 2012; Kelly et al., 2006; NCCN, 2018; Rhodes and Watson, 1987). The NCCN (2018) elaborate further on this definition, defining distress in patients with cancer as:

> a multifactorial experience of a psychological (i.e. cognitive, behavioural, emotional), social, spiritual and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common, normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.

3.12 Non-spiritual distress

Not all distress experienced by patients at the EOL may be spiritual in nature. Distress can manifest in numerous ways but is often expressed as either agitation or emotional lability (NHS Scotland, 2020). This may be due to physical, psychological, social, or spiritual causes, or a combination of such factors. For example, a patient experiencing protracted cancer related pain that is poorly controlled (a psychological and physical experience) is likely to experience distress. In this case distress may directly influence their mood and ability to cope with their illness but may not arise from a spiritual aetiology. In contrast, the term spiritual distress is generally associated with areas of challenge which could be described as existential or spiritual in nature, (e.g. impending death, loss of connection and/or significant relationships, grief, and fear of the unknown) and which are commonly linked to personal suffering and/or adversity (see 3.15).

3.13 Pain and Suffering

Other authors further distinguish between pain and suffering, describing pain as ‘a physical sensation or signal indicating an event within the body’ (Siler et al., 2020). This could refer to both physical (e.g. injury) and non-physical causes (e.g. loss and grief). In contrast, suffering is viewed as ‘the interpretation of that event and involves thoughts, beliefs, or judgments, and reflects the human experience of pain’ (Siler et al., 2020; Chapman and Gavrin, 1993; 1999). Cassell (1982) further defined suffering as ‘a specific state of severe distress related to the imminent, perceived or actual threat to the integrity or existential continuity of the person’. For patients who are approaching EOL, such threats may be multiple, and co-existent. Suffering is also frequently comprehensive and integrated in nature, as multiple factors may interact and influence each other. This interaction is the reason suffering may be so debilitating for the individual. Cassell (1991) further identifies that while the nature of the pain experience may vary, suffering arises directly from the meaning an individual ascribes to the experience of such pain and/or the apparent meaninglessness of a situation.

3.14 Dimensions of suffering

Suffering is also frequently classified using taxonomies. For example, Krikorian et al. (2011) describe four 'dimensions' of suffering, all of which are relevant to patients with terminal illness.

The Physical dimension

Terminal illness is commonly associated with significant symptomology, such as pain, fatigue, dyspnoea, nausea, loss of appetite, depression, and insomnia. Generally, such symptoms occur concurrently.

The Psychological dimension

EOL patients commonly face multiple challenges that may profoundly test their resilience and lead to significant distress. Psychological suffering may relate to enforced life changes, job losses, loss of hope, sadness, guilt, changes in appearance, dependence, powerlessness and limitation on activity (Wilson et al., 2007; Abraham et al., 2006). Over half of patients with advanced cancer display evidence of anxiety or depressive illness and mental disorders of this type are associated with increased severity of physical symptoms and suffering (Wilson et al., 2007).

The Spiritual/existential dimension

Accessible definitions of spirituality commonly focus on the theme of connection (e.g. to the moment, to others, to self, to nature, and to the sacred), and the expression of meaning and purpose. Spiritual pain has commonly been used synonymously with suffering and describes an experience which typically encompasses loss of autonomy, low self-esteem, loss of connection and hopelessness. Such pain may be expressed emotionally or behaviourally (e.g. in treatment decisions) (Chochinov, 2006). In EOL patients, spiritual distress is an example of this form of suffering.

The Social and Cultural dimension

Suffering is also influenced by a range of social and cultural variables. For example, gender would appear to influence coping strategies utilised in pain (Kirkova et al., 2010; Rao, 2009). Age would also appear to influence the experience of suffering, with younger patients manifesting enhanced levels of suffering and emotional distress and lower levels of well-being, particularly as the severity of their illness increases (Kirkova et al., 2010). Social isolation, poor levels of support and a familial history of suicide as also risk factors for suicide in terminal illness (Breitbart, 1987; Robertson, 2008; Zaorsky et al., 2019). Culturally influenced factors such as the meaning ascribed to an illness, communication of disease-related issues, such as prognosis, family dynamics and the role of caregiver may also influence the experience of suffering (Krikorian et al., 2011).

Quinn et al. (2015, p.61) advocate for a whole-person approach to pain at the EOL, suggesting that pain 'is understood in and through a person's key relationships with others, themselves, their body, the world, and their beliefs and values'. From this perspective, different dimensions of pain arise from disruption to one of more of these key relationships. Specific dimensions include:

- Physical pain: arising from disturbance or disruption in the relationship between the person and their body.
- Social pain: arising from disturbance or disruption in the relationship between the person and their world, including work and society.
- Emotional pain: arising from disturbance or disruption in the relationship between the person and how they view themselves (i.e. self-image).
- Spiritual pain: arising from disturbance or disruption in the relationship between the person and their beliefs and values.

Due to the individuality of the suffering experience and the frequently holistic nature of suffering, the use of taxonomies which propose clear distinctions between proposed dimensions of suffering may be unrealistic (Cassell and Rich, 2010; Rousseau, 2001). However, spiritual pain/distress constitutes a significant form of suffering for many EOL patients and is frequently multidimensional in nature. Spiritual distress is also frequently overlooked in healthcare settings that focus on physical manifestations of pain alone (Johns, 2004; Magnussen, 2017).

3.15 Spiritual Distress

This study centres upon the phenomenon of spiritual distress. Unfortunately, such distress currently lacks an internationally agreed definition as well as agreement as to its defining characteristics, antecedents and effects upon patients. Evident is that the nature of the cancer experience commonly includes suffering and/or distress which is psychosocial and spiritual in nature, rather than purely physical (Puchalski et al., 2019). Spiritual distress may also be associated with other terminal conditions such as end-stage organ failure, motor neurone disease or frailty associated with ageing (Casey and Hodson, 2003; Whitehead et al., 2012). Such suffering is personal in nature, rather than purely physical, presenting unique challenges that 'threaten the intactness of the person' (Cassell, 2004). Forty years ago, Burnard (1987, p.377) stated that 'Spiritual distress is the result of a total inability to invest life with meaning. It can be demotivating, painful and can cause anguish to the sufferer'. Terms such as 'total inability', 'meaning' and 'anguish' clearly require explanation, but use of the term spiritual distress can be seen to apply principally to the spiritual and psychological, rather than the physical. It is also evident that both spiritual distress and spiritual well-being can significantly impact key health measures (Park et al., 2016). For example, among patients with terminal illness, spiritual well-being reduces despair, depression, the desire to die and improves QOL (Brady et al., 1999; Nelson et al., 2002; McClain et al., 2003; Rabow and Knish, 2015). Problematic is ascertaining the exact prevalence of spiritual distress amongst patient populations, which would appear to vary significantly. For example, in a US based study (n=57) Mako et al. (2006) report that 96% of patients with advanced stage cancer experienced spiritual pain/distress. In contrast, an Indian study by Gielen et al. (2017) (n=300) found the incidence of spiritual distress amongst cancer patients to be 17.4%. An Israeli study by Blinderman and Cherry (2005) (n=40) found that existential distress was present only in 10% of patients with advanced cancer. In contrast, amongst cancer patients within a European context, Caldeira et al. (2017) (n=170) found incidences of spiritual suffering/distress of 40.8%.

An earlier cross sectional study (n=35) suggested the incidence of spiritual suffering across a range of contexts was 60% (Caldeira et al., 2013). Chaves et al. (2011), in a Brazilian study of patients with Chronic Renal Insufficiency (n=120) identified spiritual distress in 25.8 - 35.8% of patients. In a further recent systematic review (USA), the prevalence of spiritual distress within in-patient settings varied from 16% - 63%; 96% of patients had also experienced pain which was ‘spiritual’ in nature (i.e. pain ‘deep in the being that is not physical’).

In other studies, spiritual distress has also been associated with enhanced levels of physical, social and emotional distress (Seyedrasooly et al., 2014; Jim et al., 2015). Important ‘gaps’ in current literature include ‘a narrow spectrum of populations, limited consideration of family caregivers, and inconsistent terminology’ (Roze des Ordons et al., 2018).

It would appear that prevalence may also be influenced by key definitions/assumptions, assessment tools, the specific context, the individual researcher(s), the patient, and cultural factors. My own experience, though anecdotal, highlighted that spiritual distress was a significant phenomenon, affecting approximately 20% of community-based EOL patients in whose care I was personally involved.

3.16 Defining characteristics

Caldeira et al. (2013) identify 35 defining characteristics of spiritual distress taken from 37 separate sources. Problematic is the lack of definition as to what constitutes spiritual distress as a human response. The authors suggest that spiritual distress be defined as ‘a state of suffering relating to the impaired ability to experience meaning in life through connectedness with self, others, the world or a Superior being’ (Caldeira et al., 2013, p.82). This is very similar to the NANDA 1 definition contained in the NANDA 2017 list of nursing diagnoses (Herdman and Kamitsuru, 2014, pp.372-3) and also relates to a central theme of much spirituality writing; the theme of connection. The authors suggest this definition contains the four essential attributes of spiritual distress; suffering, impaired spirituality, a form of distress contrary to spiritual well-being and related to meaning in life. Schultz et al. (2017) suggest that this definition corresponds well with consensus definitions of spirituality, which emphasise each of these aspects of humanity. In contrast, Chaves et al. (2010) have suggested the diagnostic label spiritual distress be changed to ‘impaired spirituality’ and more attributes of the concept added. The term ‘spiritual distress’ also appears to be used interchangeably with ‘spiritual suffering’ and ‘spiritual pain’ in some studies, along with a wide range of other synonyms, including:

- Suffering.
- Existential distress.
- Existential suffering.
- Existential pain.
- Spiritual distress.
- Spiritual suffering.
- Spiritual pain.
- Psychospiritual distress.
- Psychoexistential suffering.
- Total pain.
- Demoralisation.

(Best et al., 2015, p.1336)

In a further recent systematic literature review ‘spiritual suffering’ is defined as:

> An all-encompassing, dynamic, individual phenomenon characterised by the experience of alienation, helplessness, hopelessness and meaninglessness in the sufferer that is difficult for them to articulate. It is multidimensional and usually incorporates an undesirable, negative quality (Best et al., 2014, p.6).

The impact of spiritual distress is seen not only in the death experience of the individual patient, but upon family members and their later grief experience. It is also challenging to measure a concept which is both individualised, experiential, relational, inherently complex and existential in nature. In contrast, spiritual well-being is not formally defined. A strong inverse-correlation has similarly been demonstrated between spiritual distress and varying measures of spiritual well-being. Spiritual distress has also been shown to augment physical and emotional suffering (Benito et al., 2014). As such, effective spiritual care is integral to holistic EOL care. However, because 'lack of spiritual well-being' does not constitute a formal diagnosis it cannot be assumed that spiritual distress is a precise inverse of spiritual well-being (Schultz et al., 2017, p.67). Suffering in EOL contexts may also remain unrecognised by care givers (Kahn and Steeves, 1995; Arman et al., 2004). Also, until the spiritual dimension of pain is addressed, it is not possible to either achieve or maintain optimal pain management (Kearney, 2000; Quinn, 2018).

McSherry (2006, p.59) suggests that if spirituality and spiritual needs are integral to our make up as human beings, then it logically follows that when a crisis or sudden event occurs in life we may experience not only physical, psychological and social distress but also spiritual distress. Burnard (1987), writing over three decades ago, stated that 'spiritual distress is the result of the total inability to invest life with meaning. It can be demotivating, painful and can cause anguish to the sufferer' (Burnard, 1987, p.377). This definition implies that integral to this form of distress is loss of function, dispiritedness, and a recognition of behaviour or feelings that convey an altered spiritual integrity (McSherry, 2006). Spiritual distress 'becomes acute when the meaning, value and relationships that secure authentic humanity are seriously threatened. Spiritual distress may coincide with physical or emotional distress, but manifests a deeper kind of pain, reflecting a different and profoundly disturbing human dis-ease' (Whipp, 1998, p.140). The author further suggests that health care professionals need a greater appreciation of those situations likely to provoke spiritual distress, such as social, economic, ethical and existential threats to the individual (Whipp, 1998, p.142). More recently, spiritual pain (distress) has been described as pain 'arising when there is a disturbance or disruption in the relationship between the person and their beliefs and values' (Quinn, 2020, p.61). The American National Comprehensive Cancer Network (NCCN) identifies key components of spiritual distress ranging from feelings of vulnerability, sadness and fear to more disabling problems such as 'depression, anxiety, despair and existential spiritual crisis' (NCCN, 2003).

Labun (1988), writing over three decades ago, identified seven facets of human spiritual experience which could be regarded as potential constituents of spiritual distress, though not all seven may necessarily be present at any one time in a single individual. Labun (1988) suggested these seven experiences all demonstrate alteration in the spiritual integrity/wellbeing of the individual, leading to spiritual distress. These are: spiritual pain, alienation, anxiety, guilt, anger, loss and despair (Labun, 1988, p.317). Table 1 below illustrates these seven facets of spiritual distress, along with their possible behavioural manifestations.

Table 1: Examples of altered spiritual integrity (spiritual distress) and their associated behaviours (Labun, 1988, p.317)

Experiences of altered spiritual integrity (component of spiritual distress)	Behaviours or expressions of altered spiritual integrity
Spiritual pain *Experiences of discomfort related to one's human and/or transcendent relationships as well as one's transcendent beliefs and values*	• *Behaviours conveying discomfort or suffering relative to one's relationship with God, fellow human beings and/or transcendent values and beliefs.* • *Expression of feelings related to lacking spiritual fulfilment or of feeling empty in relation to fulfilment and meaning.* • *Inability to come to terms with one's reason for being or one's relationship with the source of creation.*
Spiritual alienation *Experiences of loneliness not filled by other human relationships*	• *Feelings of estrangement and remoteness between the events in a person's life and personal meaning and purpose for being.* • *Feelings that no one can come to 'the core of one's being' and understand the person; that there is no 'connectedness' between oneself and other beings.* • *A negative attitude towards receiving help or comfort from another spiritual being.*
Spiritual anxiety *Fear of the unknown and/or of impending doom for oneself or one's loved ones. This*	• *Worry about, or fear of, a God that is displeased, full of anger, or threatening punishment to oneself.*

may be based on specific events, on the unknown, or on possible events.	• *Worry that those sources of ultimate strength or stability such as God, or the order of the Universe might not take care of one, either immediately or in the future.* • *General fear of the future or of annihilation without a purpose or meaning.*
Spiritual guilt *Concern about one's lifestyle and the values and beliefs which it has expressed*	• *Doubt or remorse about the life one has lived.* • *Expressions suggesting that one has failed to live up to an idealized value or norm.* • *Expression of regret about the 'kind' of life one has lived.*
Spiritual anger *Feeling about the injustice of a situation, blaming an undefinable transcendent source, God, or experiencing diffuse anger.*	• *Expressions of outrage or feelings of powerlessness towards transcendent powers such as God or other undefinable sources for having allowed illness or other trials.* • *Negative criticism or blaming of institutionalized religion and those who represent it.*
Spiritual loss *Feeling of having lost hold of those aspects of life which give ultimate and transcendent meaning and purpose.*	• *Feelings of having lost or terminated the love of God or other deeply meaningful transcendent relationships.* • *Expressions of fear that one has lost contact with God or that one's faith in a spiritual belief has been misplaced.* • *Verbalization of hollowness or flatness regarding previously meaningful ultimate or transcendent beliefs.* • *Listlessness or 'drifting' regarding things of ultimate or transcendent*

	meaning which were meaningful in the past.
Spiritual despair *Feeling that the person's hope in ultimate values, beliefs and transcendent experiences which were previously meaningful are no longer possible or that they will never be possible.* *A feeling that life makes no sense and that it is not possible to make sense of it.*	• *Feelings that God no longer can or does care for one. No hope of ever experiencing fulfilment in a relationship with God or through transcendent experiences.* • *No hope in past beliefs, or values, with a total feeling that life has become meaningless and purposeless.* • *No hope of finding a philosophical explanation for life or of finding meaning or purpose.*

All components suggest the individual may become dysfunctional, withdrawn and unable to invest or relate to life in a meaningful and integrated manner. In effect, there is a disturbance in 'life flow' or 'energy' which undermines spiritual integrity (Labun, 1988). McSherry (2006) suggests that the defining characteristics of spiritual distress centre upon a disturbance within the individual's belief and value system. Further, this disturbance may result from a range of aetiological factors, either pathophysiological or situational, such as disease, relational breakdown, loss, bereavement, regret, or loss of hope. Such disturbance may manifest in the form of uncertainty, ambivalence, a sense of emptiness or aloneness, anger, fear or a morbid preoccupation with suffering and death (McSherry, 2006, p.60). Dying persons may also encounter multiple losses often occurring simultaneously (Kennedy and Cheston, 2003, p.135), resulting in an overwhelming of available coping resources. Ellington et al. (2017, p.520) suggest that many cancer patients and their families experience associated spiritual uncertainty; such uncertainty is also characteristic of other terminal illnesses. Uncertainty occurs when individuals 'do not have schema to make sense of their experiences', particularly as a terminal diagnosis may be something only previously witnessed in others (Ellington et al., 2017, p.520). Unfamiliarity and uncertainty at the EOL may therefore cause a loss of control and associated spiritual distress. The role of the healthcare professional is then to assist such individuals in an exploration of the crisis they may be facing, so they can then attempt to rediscover meaning and value, allowing them once again to invest positively in life, whatever challenges they may be facing. This is the essence of spiritual care.

3.17 Spiritual Distress: My own definition

Using the definitions above and insights gained from them, I would like to offer the following definition of spiritual distress, constructed using key word definitions from the Oxford Dictionary on-line (Oxford English Dictionary, 2017). Using this approach, spiritual distress could be defined as:

> *An experience of significant distress [extreme anxiety, sorrow or mental pain] which overwhelms available spiritual coping resources: such distress is directly related to grief, loss [real or threatened] of relationship(s), disappointment, or other misfortune [either personal or to significant others] and is commonly localised [felt] in the thorax and/or viscera [gut].*
>
> *Spiritual distress is focused upon an outcome [or outcomes] that is uncertain, and which frequently poses an existential threat to the individual. Manifestations of spiritual distress are numerous and may include isolation, worry, nervousness or unease, fear, depression, regret, guilt, anger and loss of hope, meaning or control.*

My observation is that spiritual distress in EOL patients may be experienced both mentally and viscerally; any definition therefore needs to acknowledge both aspects. Unfortunately, this definition is again cumbersome for practitioners to utilise.

Spiritual distress may also result from deliberately withholding information from patients concerning their diagnosis. For example, Glaser et al. (2016) describe the paradigm of ‘awareness contexts’, which they define as ‘the total combination of what each interactant knows about the identity of the other and his[her] own identity in the eyes of the other’ (Glaser et al., 2016, p.670). The authors describe four types of context; ‘open’, ‘closed’, ‘suspicion’ and ‘pretence’. In three of these, deliberate attempts are made to disguise or withhold key information, including the likelihood of approaching death. Intrinsic to the paradigm is that the context as well as the language used often collude to deliberately avoid communicating to the patient that they are facing death. In this sense, ambiguity in relation to concepts such as spirituality can be useful and help avoid difficult conversations for the health professional. Timmermans (1994, p.325) identified three principal weaknesses in the theory of awareness contexts; 'the emphasis on rational negotiation at the expense of an emotional response to the terminal condition; the dominant medical perspective; and the conceptual problems of open awareness contexts in the age of informed consent'.

Hood Morris (1996) appears alone in warning against the assumption that manifestations of spiritual distress are always contrary to health or well-being, suggesting that crisis situations (such as a terminal diagnosis) which initiate reflection on purpose, personal limitations, the meaning of suffering and/or issues of control may potentially stimulate spiritual growth and greater spiritual awareness. Spiritual distress may therefore inhibit spiritual well-being or promote spiritual growth, depending upon the response of the individual.

Quinn (2020, p.62) suggests that in responding to patients' spiritual pain and distress, practitioners 'need to move beyond the structured process of clinical assessments to engage with patients' personal stories, which may reveal their deeper concerns and wishes'. Certainly, both analgesia and sedation alone cannot address spiritual distress and may only mask it (Johns, 2004).

3.18 Ambiguity in terminology

When reviewing relevant literature, evident is significant ambiguity in terminology regarding key concepts associated both with spiritual distress and terminal care. For example, the terms existential distress and psycho-existential distress are also used interchangeably with spiritual distress in numerous studies, with little attempt at definition or differentiation (e.g. Claessens et al., 2008). Cherny et al. (1994, p.57) describe existential distress as 'a multi-dimensional construct including personal identity, meaninglessness, hopelessness, and fear of death'. Kissane (2000, p.1022) suggests that the term refers to 'the psychological turmoil individuals may experience in the face of imminent death, which threaten individuals on a physical, personal, relational, spiritual, or religious level'. Latterly, Kissane (2012, p.1502) provided a typology of existential distress both to highlight its complexity and to guide therapeutic interventions which sought to reduce or alleviate such distress. Significant forms of existential distress/challenge include:

- Death anxiety.
- Loss and change.
- Freedom with choice.
- Dignity of the self.
- Fundamental aloneness.
- Altered quality of relationships.
- Meaning making.
- Coping with ‘mystery’.

In patients with terminal cancer, Breitbart et al. (2000) found that existential distress lead to increased levels of depression, hopelessness, and a desire for death to be hastened. This lack of differentiation is further highlighted by the work of Boston et al. (2011), who describe the ‘conceptual ambiguity’ of the term spirituality and identify fifty-six separate definitions of the term ‘existential suffering’. The authors also highlight that existential issues in palliative care contexts remain a widely used but ill-defined concept (Boston et al., 2011, p.612).

Paley (2008) further suggests that only the term ‘existential’ distress has credibility in nursing literature, because spirituality constitutes ‘a deeply artificial, shallow and unnecessary concept’ (Paley, 2008, p.18). It is evident that Paley writes from a reductionist, atheistic viewpoint, which rejects a tri-partite understanding of humanity and denies the existence of the spirit and therefore spirituality. For Paley, spiritual distress therefore constitutes a misnomer, and should instead be replaced with existential distress or ‘fear of annihilation’ which situate the experience wholly within a humanistic perspective.

Terminology associated with terminal care is also problematic, as highlighted by Kehl, (2006) and O’Connor, (2016). For example, there is currently lack of international agreement regarding terminology such as ‘end of life’, ‘palliative care’, ‘supportive care’ and ‘quality of life’. Also evident is that ‘terms such as good death, dying well, peaceful death, appropriate death, desired death, and dignified death are used interchangeably in some manuscripts and with different meanings in others' (Kehl, 2006, p. 277).

3.19 Practitioner death anxiety

The concept of death anxiety would appear relevant, as 'high levels of death anxiety among those working in the health care setting may negatively influence their attitudes and behaviour towards the dying patient and their family' (Boyle and Carter, 1998, p.38). Practitioner death anxiety has also been reported to negatively influence the quality of care provided to EOL patients (Brockopp et al., 1991; Santisteban et al., 2006; Braun et al., 2010). A recent Turkish study found the most significant factor in the delivery of spiritual care was the practitioner's own attitudes towards death (Akdeniz Kudubes et al., 2021).

Tillich (1952) described this phenomenon as a form of 'ontological anxiety'. However, evidence regarding death anxiety within current literature is lacking. Death anxiety has also principally been measured using self-reporting (Lehto and Stein, 2009, p.30); for example, by use of the 15-item Death Anxiety Scale (DAS) (Templer, 1970). Death anxiety has been defined as 'an unpleasant emotion of multidimensional concerns that is of an existential origin provoked on contemplation of death of self or others' (Nyatunga and de Vocht, 2006, p.413). The authors suggest that death anxiety can be felt when witnessing death and the dying experiences of patients as well as individuals known personally to practitioners. 'Death anxiety' has also been described as a feeling of dread, apprehension or solicitude (anxiety) when one thinks of the process of dying or ceasing to 'be' (Tomer and Eliason, 1996). The American handbook of nursing diagnoses defines death anxiety as 'the state in which an individual experiences apprehension, worry, or fear related to death and dying' (Carpentio-Moyet, 2008, p.39). In the American nursing outcomes classification guide, death anxiety is defined as 'a vague uneasy feeling of discomfort or dread generated by perceptions of a real or imagined threat to one's existence' (Moorhead et al., 2008, p.761). While generally used synonymously, the terms 'death anxiety' and 'fear of death' can also be distinguished. Momeyer (1988) suggests that death anxiety refers to anxiety which focuses upon annihilation of the individual, whereas fear of death is more concrete and focused upon the actual process of dying. In this sense 'fear has a clear object – an imminent threat, whereas anxiety does not. Anxiety is therefore linked to uncertainty, often leading to insecurity' (Nyatanga and de Vocht, 2006, p.411). Cicirelli (2006) further identified that a dread of annihilation broadly relates to a mental or spiritual awareness of the loss of existence, whereas fear of death related more to physical awareness of such loss.

Death anxiety has also been referred to as a pervasive fear of nonexistence, or as a fear of experiencing non-being (Christain, 1981). Yalom (1980), who also views anxiety and fear about death synonymously, defined death anxiety as 'a dread of death that resides in the unconscious, a dread that is formed early in life at a time prior to the development of precise conceptual formation, a dread that is terrible and inchoate and exists outside of language and image' (Yalom, 1980, p.189). In an American study, Lehto and Stein (2009) systematically reviewed literature sources (n=89) describing death anxiety during the period 1980–2007. Based on the attributes identified in their comprehensive review, death anxiety constitutes:

> a multidimensional construct related to fear of and anxiety related to the anticipation and awareness of the reality of dying and death that includes emotional, cognitive, and motivational components that vary by developmental stage and sociocultural life occurrences. Death anxiety encompasses both fear and anxiety emotional components and is not necessarily consciously manifested (Lehto and Stein, 2009, pp.31-2).

Six defining attributes of death anxiety were emotion, cognition, experiential, developmental, sociocultural shaping, and source(s) of motivation. Antecedents included stressful environments and the experience of unpredictable circumstances, diagnosis of a life-threatening illness or the experience of a life-threatening event, previous experience(s) with death and dying and the consequences of that experience. The authors also suggest that little systematic inquiry of death anxiety exists in current nursing literature (Lehto and Stein, 2009, p.23).

In an American based review (n=15) of quantitative studies covering the past twenty years, Peters et al. (2013, p.14) explored nurses' attitudes to death and whether caring for palliative patients created anxiety within practitioners, stating:

> Nurses are frequently exposed to dying patients and death in the course of their work, an experience which can make individuals conscious of their own mortality, often giving rise to anxiety and unease. Nurses who have a strong anxiety about death may be less comfortable providing nursing care for patients at the end of their life.

The authors further suggest that personal attitudes of nursing staff towards death and dying may influence the quality of care they provide within EOL contexts, as dealing with death can be both emotionally challenging and fear inducing, the management of which requires mature insight and appropriate skills. Younger nurses (i.e. average age less than thirty) in the reviewed studies also consistently reported a stronger fear of death and more negative attitudes towards caring at EOL. A similar finding was reported by Peters et al. (2013) who found that practitioner coping was enhanced by age and level of nursing experience. This may be because younger nurses are more likely to lack experience, mature self-awareness or skill in dealing with aspects of nursing care which are highly emotional.

Exposure to death has also been found to influence nurse perception(s) regarding death, whereby an increased consciousness of their own mortality can create both anxiety and/or unease (Payne et al., 1998). Neimeyer (1994) found that health professionals with high levels of death anxiety were more likely to utilise coping strategies which incorporated ‘avoidance’. Neimeyer (1994) also situated death anxiety within the ‘everyday’, rather than in acute situations where there were immediate threats to life. Braun et al. (2010) similarly found that personal attitudes toward death were associated with attitudes toward the care of dying patients, suggesting that some nurses may use avoidance to cope with their own personal fears of death. The authors highlighted inconsistencies between their own results and previous studies examining acceptance of death and attitudes toward care for dying patients, implying that culture and/or religion may influence the development of anxiety amongst practitioners. Components of this anxiety included anticipating one's own death, fear of the process of dying and fear regarding the death of significant others’. Payne et al. (1998) found that Accident and Emergency department nurses were more likely to avoid thinking about death than hospice nurses and showed a greater fear of death and less acceptance than hospice nurses. In contrast, hospice nurses appeared to display low levels of death anxiety, despite spending almost every day with dying patients. Accident and emergency nurses also reported that some of their most difficult times were spent with bereaved relatives. The author also highlighted that most previous research has related to emotions surrounding the death of the self rather than patients (Payne et al., 1997).

More recently, Keall et al. (2014) investigated facilitators, barriers and strategies identified by Australian palliative care nurses from different geographical and workplace settings in providing existential and spiritual care for patients with life-limiting illnesses. Principle barriers included lack of time, lack of skills, privacy and concerns for what might be uncovered, unresolved symptoms and differences in culture or belief. Strategies offered by participants included further education, being self-aware, ensuring care settings are conducive to in-depth conversations and interactions and documentation and/or interdisciplinary sharing for continuity of care (Keall et al., 2014, p.3197). Once again, time was a key factor and it is interesting to note the concerns of participants regarding 'what might be uncovered', which would appear to have resonances with practitioner death anxiety.

3.20 Taking a Spiritual history

As described earlier (see 3.9), integral to spiritual care is the identification of spiritual needs. Key to this process is the establishment of a therapeutic relationship and the ability of the practitioner to obtain a spiritual history. A spiritual history is undertaken to help illuminate those themes or needs 'pertinent to an individual's spirituality, serving as a broad, structured enquiry of a patient's beliefs and values as well as their ability to discover meaning and hope in the midst of their suffering' (Blaber et al., 2015, p. 434). Spiritual history taking uses 'a set of questions designed to invite patients to share their religious or spiritual beliefs to help identify spiritual issues. It is to be patient centred and guided by the extent to which the patient chooses to disclose his/her spiritual needs' (Borneman et al., 2010, p. 164). A spiritual history is normally taken as close to admission as possible, recognising that patients may be reluctant to share such information until some degree of trust has been established. A good spiritual history therefore involves far more than simply asking the individual patient/client if they follow any organised religion or belief. Instead, it requires sensitive inquiry regarding:

> the patient's beliefs and values, their ability to find meaning and hope in the midst of suffering, recognition of the role of spirituality or religion in the patient's life, the importance of ritual, identification of faith traditions, and evaluation of the impact of the patient's current illness on spiritual well-being (Borneman et al., 2010, p.164).

Problematic is that debilitating symptoms frequently associated with EOL may undermine attempts at assessment. There is also considerable ambiguity regarding assessment tools, as highlighted in section 3.19 below. Practitioners may also feel unprepared or equipped to carry out such assessments, particularly if they have never considered their own spirituality (Blaber et al., 2015).

3.21 Assessment tools

Over the past four decades, a multitude of tools have been developed to aid practitioners in the process of assessing the spiritual needs of patients. For example, Best et al. (2015) carried out a systematic literature search to identify all English-language studies published between 1992 and 2012 that focused on the assessment of suffering in cancer patients. The authors identified ninety articles which together described fifty-eight 'measures' or tools which appeared to assess either spiritual suffering or one of its synonyms or symptoms. Constructs examined by these 'measures' included:

- Suffering.
- Hopelessness/demoralisation.
- Hope.
- Meaning.
- Spiritual well-being.
- Quality of life where a spiritual/existential dimension was included.
- Distress in the palliative care setting and pain.
- Distress and/or struggle of a spiritual nature.

(Best et al., 2015, pp.1337-38).

In a recent Brazilian study, Lucchetti et al. (2013) also conducted a systematic review of spiritual assessment tools, identifying twenty-five instruments designed for use in either clinical or research environments. After evaluating the tools against sixteen criteria, the authors found that five instruments ranked highest in their analysis. These were the FICA (Puchalski and Romer, 2000), FAITH (Neely and Minford, 2009), SPIRITual (Maugans, 1996), HOPE (Anandarajah and Hight, 2001) and the RCP (Royal College of Psychiatrist) tools, though the authors also suggest that further work is required in terms of assessing the suitability of these tools for EOL contexts. Also, the RCP tool was developed specifically for psychiatric patients, whereas the other four originated from contexts related to either primary care or health education. In a UK study, Blaber et al. (2015) further consider these four tools (FICA, FAITH, SPIRITual and HOPE) and suggest that health care providers 'have a duty to identify what spiritual care should involve for each individual before them' (Blaber et al., 2015, p.434). Effective identification relies upon effective assessment. Further, routine systematic questioning is integral to history taking, a key component of patient assessment. Within palliative care, this form of questioning has been shown to reduce the potential for important symptoms to be overlooked (Ahmed et al., 2014), vigilance which should surely be extended to spiritual care. Blaber et al. (2015, p. 434) also suggest that the HOPE tool 'most comprehensively reflects the healthcare literature in exploring the various elements of spirituality known to be important to a person's wellbeing at the EOL, including terminal event planning'. Both the reliability and validity of each of these tools needs to be established through further research, particularly within EOL contexts. None were known to any study participants or utilised by them (the tools are summarised in Appendix 1).

Most assessment tools have also been developed in cultural settings outside of the UK and many appear to lack any attempt to measure efficacy. The lack of any effective 'gold standard measure of individualised suffering' also means that considerable work is needed if such assessment tools are to be validated such that they can be used clinically with confidence (Büchi et al., 2002, p.340). A further question concerns the applicability of assessment tools to a community setting. None of the published tools identified during my initial literature search were developed either in or for an exclusively UK community setting and are therefore unreported within this context.

In EOL patients, spiritual distress is also frequently combined with adverse physical symptoms. This combination can make significant demands upon available coping reserves, making assessment problematic. Suitable assessment tools by design therefore need to avoid being either lengthy or burdensome: both are likely to undermine the efficacy of the assessment process and possibly enhance patient distress. Also, 'most of the instruments are self-report questionnaires, designed to be completed by the patient' (Albers et al., 2010, p.21). For a significant percentage of EOL community patients, this is unrealistic, due to the stage of their illness and/or level of debilitation.

The experimental challenges posed by existing assessment tools is further complicated by a range of other practitioner variables, both situational and personal, which impact directly upon the assessment process. For example, in a Norwegian study of palliative care nurses (n=176), 'upbringing, personal history, and personal and professional experience' are all suggested to 'mark the nurse as a person' and therefore impinge upon the assessment process (Cone and Giske, 2017, p.3133). The authors further suggest that 'the nurse's own religiosity and spirituality were highly significant for both preparedness and importance of spiritual assessment' (Ibid). The way such assessments are performed is therefore likely to be influenced by the manner and level of expertise of the individual practitioner. Within acute clinical settings, assessment tools may also be overly cumbersome, time consuming and their abundance and lack of testing may cause further confusion for practising nurses (Timmins and Kelly, 2008). This would also appear true for palliative care settings. Henery (2003, p.556) suggests that 'attempts to measure and assess beliefs, values and lifestyles in the name of an objectified "spirituality" might only intensify the experience of alienation promoted by modern institutions rather than enhance holistic care'. The IPOS was utilised within Pilgrim's hospices (see section 6.6.4), although this is not a specific tool for the assessment of spiritual distress. Pertinent questions are therefore:

- Are there existing tools which could reliably be used within a community context?
- Are there existing tools that could reliably be adapted for community nurse?
- Could/should a bespoke tool be developed, which is specifically designed for community use?

None of the above questions were specific to this current study but each constitute important areas for further research.

3.22 Meaning making

Though not a specific research question for this study, how participants make specific conceptual meaning(s) regarding spiritual distress and the identification, assessment and alleviation of such distress are important associated areas of consideration. Problematic is there appears to be a dearth of literature that specifically addresses meaning making in relation to spiritual distress for either patients or practitioners within EOL contexts.

Meaning making is widely described as essential for subsequent adjustment to stressful life events (Gillies and Neimeyer, 2006). However, current literature on meaning making is largely theoretical, making practical application within nursing contexts problematic. Park (2010, p.262) highlights several criticisms of research within this area. These include:

- A failure to comprehensively examine meaning making, so making the drawing of conclusions problematic.
- Assessment time frames which are problematic (most studies are purely retrospective).
- A lack of standardised language and/or the use of language which is imprecise.
- A lack of participant awareness regarding global and situational meaning and of the process of meaning making.
- Problems in translation of rich theoretical conceptualisations into operational definitions which possess utility of practitioners.

Definitions of the terms meaning and meaning making, and the related term meaningfulness are also challenging ‘due to the complexity of the concepts and the multidisciplinary nature of this area of interest’ (Collie and Long, 2005, p.844). As Park (2010, p.267) states, ‘the translation of rich theoretical conceptualisations to operational definitions is perhaps the biggest limitation of current meaning research’. Not only may individuals lack awareness of or ability to report on the inner processes assumed to be occurring, but most studies of processes related to meaning making assessed a limited scope (i.e. only part of what might constitute meaning making) (Park, 2010). Further, meaning making in those facing death and experiencing debilitating symptoms such as pain or nausea and/or aspects of spiritual distress such as despair or a desire for reconciliation adds further complexity.

3.23 Situational and Global meaning

Within the context of aversive events, Park and Folkman (1997) helpfully differentiate between 'global meaning' (i.e. meaning of life in general, or the meaningfulness of life), situational meaning (i.e. meanings ascribed to particular events), and further describe meaning making as a 'process' rather than simply an 'entity' (Collie and Long, 2005). Park and Folkman (1997, p.116) further define global meaning as 'basic goals and fundamental assumptions, beliefs, and expectations about the world'. This includes assumptions regarding the self in relation to the external world, that facilitate order and purpose. Two decades later, Park (2010, p.258) further described Global meaning as referring to 'individuals general orienting systems, consisting of beliefs, goals, and subjective feelings' (Dittman-Kohli and Westerhof, 1999; Pargament, 2001).

Global beliefs therefore comprise 'broad views regarding justice, control, predictability, coherence, and so on, as well as individuals' self-views (Janoff-Bulman, 1992; Leary and Tangney, 2003; Koltko-Rivera, 2004) and 'form the core schemas' through which people interpret their experiences of the world (Park, 2010, p.258; Janoff-Bulman and Frantz, 1997; Mischel and Morf, 2003).

The term 'meaningfulness' frequently refers to 'global meaning that reflects a sense of purpose, in addition to an overall sense of value to life'. Definitions of global meaning that emphasise purpose also tend to focus on the person in relation to others or the world and may include spiritual and/or moral dimensions (Collie and Long, 2005, p.844). For example Frankl (1984), a psychiatrist known for his use of logotherapy ('meaning therapy') suggested that purpose and meaning in life derive from self-transcendence; 'consciously looking beyond the self and seizing opportunities to respond responsibly to life's moment-to-moment possibilities'. Frankl also viewed suffering as 'a primary life task full of potential for experiencing meaning', which he considered a matter of choice, decision, and moral responsibility. Meaning is therefore found by actualising the possibilities of life through creativity, a receptiveness to others and to the environment and by finding meaning in the attitude one takes when faced with an unchangeable situation (Collie and Long, 2005, p.845). Park (2012, pp.257-8) also identifies 'a set of essential tenets in relation to meaning making for which there is a surprisingly high degree of consensus'. These include:

- People possess orienting systems, referred to here as global meaning, that provide them with cognitive frameworks with which to interpret their experiences and with motivation such interpretation.
- When encountering situations that have the potential to challenge or stress their global meaning, individuals appraise the situations and assign meaning to them.
- The extent to which that appraised meaning is discrepant with their global meaning determines the extent to which they experience distress.
- The distress caused by discrepancy frequently initiates a process of meaning making.
- Through meaning-making efforts, individuals attempt to reduce the discrepancy between appraised and global meaning and restore a sense of the world as meaningful and their own lives as worthwhile.
- This process, when successful, leads to better adjustment to the stressful event.

(Greenberg, 1995; O'Connor, 2003; Lee et al., 2004; Collie and Long, 2005; Gillies and Neimeyer, 2006; Skaggs and Barron, 2006).

Within health-related contexts, situational meaning, in contrast, refers to personal perception(s) of specific events. Park and Folkman (1997, p.116) described situational meaning as 'the meaning that is formed in the interaction between a person's global meaning and the circumstances of a particular person-environment transaction'. Park (2010) later defined situational meaning as 'meaning in the context of a particular environmental encounter' (e.g. situation, personal threat). Situational meaning thus begins with the occurrence of a potentially stressful event and describes an ongoing set of processes and outcomes, including 'assignment of meaning to the event (appraised meaning), determination of discrepancies between appraised and global meaning, meaning making, meanings made, and adjustment to the event' (Collie and Long, 2005, p.845).

Lipowski (1983, p.1070) defined situational meaning within the context of illness as 'the subjective significance for the patient of all illness-related information that impinges on him or her'. Sources of information include 'bodily sensations, previous knowledge and beliefs about illness and messages from social environments, especially physicians' statements' (Ibid). For practitioners, situational meaning(s) also appear important. However, much remains to be clarified regarding how such meaning(s) then influences care within EOL contexts. It also remains to be demonstrated that individuals (both patients and practitioners) possess both the awareness and capability to describe their efforts to reduce ontological tension by 'assimilating or accommodating' situational and global meaning.

The specific emphases of different studies also vary significantly. Meaning making is typically described as occurring over time (Janoff-Bulman and Frantz, 1997; Updegraff et al., 2008) but frequently the time frame has not been clearly specified (Park, 2010). Few studies have tracked changes in appraised meaning of a highly stressful event over time, with those that have reporting conflicting findings (Park, 2010). Meaning making attempts also appear to diminish over time (Silver et al., 1983; Bonanno et al., 2004). Researchers have also argued that meaning making occurs not only intra-psychically but also interpersonally; talking with others and gaining their perspectives can facilitate (or impede) meaning making (Clark, 1993). Further, Lepore et al. (1996) found that meaning making was facilitated for those who were validated by others but inhibited if social constraints were present.

Culture can therefore influence both global and situational meaning, as may adverse symptoms, personal spirituality, religious beliefs and individual sources of hope and strength. For practitioners, meaning making may also require a willingness to engage in reflection (self and contextual), a process requiring emotional maturity, sufficient motivation and a readiness to confront issues which personally may be challenging. If these are lacking, it seems unlikely that the transformational potential of meaning making will be realised.

3.24 Summary

This review of nursing and related literature has attempted to situate spiritual distress within a wider context of spirituality, spiritual needs, and spiritual care, examine suffering and distress at the EOL, and explore definitions of spiritual distress, its identification, and assessment. The review has sought to identify key variables that may influence the experience of spiritual distress in EOL patients, examine relevant literature regarding spiritual history taking as part of initial nursing assessment protocols, and identify key challenges related to the use of assessment tools with patients who may be close to death. A brief consideration of conceptual meaning making for practitioners was also incorporated.

Evident is that key concepts forming the wider backdrop to spiritual distress display significant conceptual ambiguity and lack agreed international consensus. This is particularly apparent in relation to spirituality, spiritual needs and spiritual care, and the identification and alleviation of spiritual distress within community nursing contexts.

A lack of accessible and comprehensible assessment tools also appears to further hinder the assessment of spiritual needs, the delivery of spiritual care and the identification of spiritual distress in patients designated EOL. Until community nursing staff become aware of such tools and committed to their use, their impact upon patient care is likely to remain minimal.

There also appears to be a paucity of literature examining how meaning making occurs within EOL community-based contexts, both for practitioners and patients, and how this may influence patient care within such contexts.

4 Chapter 4: Research methods

This chapter describes the research methods used for data collection and data analysis.

4.1 Researcher background, beliefs and biases

I initially trained as a Registered General Nurse in London. Following registration, I specialised in Urological and Renal nursing before training as a nurse educator. I taught in both pre and post registration contexts, again in London. I then left the NHS to work as a lay pastor in Kent. Whilst working in a lay capacity, I undertook ordination training and was ordained as an Anglican priest in 1998. I served a curacy in Yorkshire before holding team vicar posts in both Stoke on Trent (Staffordshire) and later Tolworth (Surrey).

Whilst in Surrey I also trained as a couple counsellor, subsequently working both with ‘Relate’ and ‘Release’ (a small Christian counselling agency). After twenty years in church ministry, I took early retirement due to illness. Whilst recovering, I realised I had no wish to return to parish ministry and instead retrained as a community nurse with Kent Community Health Foundation Trust. Whilst working as a community nurse in Kent I quickly became involved in caring for patients who were designated EOL and dying at home. This led me to encounter the phenomenon currently known as spiritual distress. The experience raised significant questions and left me feeling uncomfortable about the way such patients were cared for and specifically how existential anxieties/concerns were assessed and managed within the wider context of community-based EOL care. It is from these concerns that this study emerged.

I am aware that my Christian faith and values combined with my own post-positivist, critical realist assumptions bring a degree of bias to this research, reflected in the way I approach the study, my assumptions regarding the knowledge obtained from participant interviews and the way that data has been utilised. I believe it is impossible for researchers to either completely ‘bracket’ or lay aside such biases, as they form part of one’s persona and way of thinking. Through regular supervision and the ongoing application of reflexivity throughout this study, my hope is that such biases were minimised.

4.2 Ethical Review

After initial consultation with the chair of the Canterbury Christchurch University (CCCU) ethics committee, a submission for ethical review of the study was made in September 2018. As the study did not involve patients, their families or any other participants deemed to be vulnerable the application was for CCCU proportionate review, in line with CCCU ethical guidelines. Further, as the study sought to recruit NHS nurses and to interview participants at their places of work on NHS premises, an additional application was made via the NHS Integrated Research Application System (IRAS) for NHS Health Research Association (HRA) review. Principle ethical concerns centred upon recruiting suitable participants, obtaining informed consent, maintaining the anonymity of participants, and ensuring none experienced any form of coercion to participate. As for any research study, beneficence and non-maleficence also remained integral considerations throughout. Permission for the study to proceed was obtained from the Pilgrim's hospices ethical committee in January 2019 and from the HRA in February 2019. Due to unforeseen administrative issues, it was not possible to obtain permission from Marie Curie (Kent). This would have allowed access to additional data but after nine months of attempting to gain access to Marie Curie nurses, the attempt was abandoned.

4.3 Psychological care of participants

Integral to ethical review of the proposed study from both CCCU and the HRA was a consideration of the psychological well-being of participants. Nursing staff within palliative contexts routinely experience situations which may be stressful, particularly if the nature of a patient's death has been personally challenging to the practitioner (e.g. younger patients with children, where the nurse practitioner is of a similar age and/or also a parent). Asking participants to review their experiences of caring for EOL patients who were manifesting spiritual distress could also potentially cause stress to the individual participant.

Robust support structures for practitioners were therefore important, as stated in both ethical applications. For example, all NHS community nurses work within team structures, which provide a significant level of informal support for team members. All KCHFT community nursing staff also have access to monthly, mandatory group supervision sessions, which provide opportunity to reflect on recent experiences within a safe and confidential setting. There is also opportunity to access personal counselling, using a local provider, should this be required.

Within the hospice setting, once again the team structure is very supportive, and constitutes a significant source of support. Group supervision sessions are also regularly scheduled for staff, and all Hospice staff have access to a local professional counselling service, should they require it.

Within both settings, nurse managers also provide a constant source of on-going support and are available to talk through difficult issues or significant emotions, should this be necessary, or as particular situations arise. Collectively, these support measures constitute a significant 'safety net' for practitioners, providing effective psychological care as and when it is needed.

Knowing that such measures were regularly utilised in both settings gave me confidence that participants were already well supported, should interviews cause significant stress or other negative emotions for participants.

No participants appeared to manifest any negative or adverse emotional reactions during interviews; in fact, a significant number of participants expressed their gratitude for being able to take part in the research and have opportunity to share their own stories and insights.

I believe that the support structures already in place within both practice settings, the individual interview environments, and the way interviews were carried out sought to ensure that participants were psychologically cared for and supported during the process of data collection.

4.4 Participants: population and sampling technique

Participants for this study were all band five or six community nurses who were registered with the Nursing and Midwifery Council of the UK. The term 'band' refers to NHS pay bands which are also adopted by other organisations such as hospices and care homes. The first group of participants were employed within Pilgrim's Hospices (Kent), which had three separate sites close to CCCU; these were situated in Canterbury, Ashford and Thanet. Each hospice offered in-patient care in combination with nursing support for patients still at home. The second group of participants were NHS nurses from KCHFT, a large primary health care trust situated within the southeast of England. Three NHS community nursing clusters (groups of geographically defined community nurses) were used for sampling, situated in Canterbury, Thanet and Aylesford.

My initial approach was to the Pilgrim's hospice and KCHFT research coordinators, who advised me regarding obtaining permission to approach registered nurses within each organisation. Such permissions were duly obtained. During February 2019 I attended the monthly nurse managers meeting at both locations and presented an outline of the research study, its central research questions and introduced the participant information materials. All nurse managers were willing to allow nursing staff to be approached and readily agreed to act as 'gate-keepers', which involved distributing participant information letters to all band 5 and 6 community nurses for whom they had direct line management responsibility. Potential participants received an introductory letter and information regarding how to contact me should they be willing to participate in the study. In this way, any sense of coercion was hopefully avoided (see Appendix 2 for copies of participant documentation). If participants chose to respond via e-mail, they were asked to utilise their secure workplace e-mail only. Participant anonymity was assured, and no mention made of where individual participants worked, except to designate participants as either Hospice or NHS practitioners.

The initial sampling technique involved Purposive (purposeful) or Criterion sampling: namely, explicitly selecting participants for interview who were likely to generate appropriate and useful data, and including sufficient participants to address the specified research questions (Green and Thorogood, 2014, p.121). Patton (2002) states that the power of purposive sampling lies in selecting 'information rich cases', which offer key insights concerning issues of central importance to the researcher (Patton, 2002, p.46). The selection of such 'information rich cases' allows the researcher to 'learn a great deal about matters of central importance to the purpose of the research' (Patton, 1990, p.169). This was my hope.

This approach contrasts with other sampling methods such as Representative or Quota sampling. The goal of representative sampling is to create sample data that 'mirror or represent other cases that we cannot directly examine'. The 'gold standard' is that of probability sampling, which seeks to create an 'accurate representative sample which possesses mathematically predictable errors' (Neuman, 2011, p.242). Two less demanding alternatives are convenience and quota sampling. Convenience sampling aims to obtain 'any cases in any manner that is convenient'. In contrast, quota sampling seeks to obtain a 'pre-set number of cases in several predetermined categories that are deemed to reflect the diversity of the population under study' (Neuman, 2011, p.267). In contrast, purposive sampling selects cases with a specific purpose in mind; in this case, to ascertain the perceptions of community nursing staff to the phenomenon of spiritual distress. Such cases are worthy of study because they provide detailed insight. They therefore possess a logic and power quite different from that of probability sampling (Emmel, 2014, p.38). Neither randomisation (seeking to ensure every member of a population has an equal chance of inclusion) nor representativeness (seeking to ensure a given sample share similar characteristics to a defined population) are relevant in selecting groups for purposeful sampling. Instead, this method of sampling actively seeks cases which give the findings of the research credibility with specific audiences (e.g. community nursing practitioners). Purposeful sampling is also congruent with the use of thematic analysis, an approach to data analysis which seeks to identify key themes within interview transcripts from a specific population of practitioners, chosen for their insights concerning issues of central importance (e.g. spiritual distress in EOL patients).

For this study, the specified criteria for participants constituted band 5 or 6 community nurses with a minimum of six months experience in caring for EOL community-based patients. Band 6 staff generally have greater seniority than band 5 five staff, and often additional management responsibility. Within community nursing, all community team leaders are designated as band 6. Sampling relied upon individual responses from the possible cohorts of community nurses within each of the six locations. The concept or experience under study comprised the unit of analysis; further, 'given that an individual person can generate hundreds or thousands of concepts, large samples are not necessarily needed to generate rich data sets' (Starks and Trinidad, 2007, p.1374). This study was also exploratory; there was no simple way to define sample size. After discussion with my supervisors, our initial aim was to recruit enough participants from each care setting to achieve a realistic saturation within the data corpus (see below).

4.5 Data saturation

Integral to grounded theory, data saturation is a useful term for indicating how the process of qualitative data collection is progressing. Categories of data are deemed saturated when 'gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories' (Charmaz, 2014, p.213). However, the legitimacy of saturation to indicate sampling adequacy has been questioned (O'Reilly and Parker, 2013). Evident is that data saturation now additionally refers to situations where data either tend towards repetition or fail to raise new questions (Hammarberg et al., 2016). Saturation appears a convincing concept but exhibits several practical weaknesses, especially when the number of emergent themes is potentially limitless (Green and Thorogood, 2014). Further, each participant is unique and therefore data are never truly saturated; there is always more to discover (Wray et al., 2007).

Central to qualitative research is gathering enough data to fully describe the phenomenon under study, rather than seeking to acquire a defined number of participants (Fossey et al., 2002). When 'homogeneous, purposive sampling is utilised to recruit participants with specified criteria, the threat of bias is irrelevant; participants are recruited and selected specifically because they can illuminate the phenomenon being studied' (Hammarberg et al., 2016, p.500). For this study, homogeneous, purposive sampling was utilised specifically for this reason. Participants were selected who were community based, and directly involved in the care of EOL patients, in the hope they could further 'illuminate' the phenomenon of spiritual distress by drawing upon their own experience.

The unquestioned acceptance of saturation may also become part of an 'institutional discourse that perpetuates unhelpful myths about optimal sampling and which simultaneously undermines the value of research not conforming to such expectations' (O'Reilly and Parker, 2013, p.195).

It was initially difficult to define exactly how many nurses would be required to achieve data saturation: a target of ten staff from each care setting seemed a realistic initial goal, but this number was open to modification and review as the study progressed. This target was also dependent upon the availability of time and resources and the availability/accessibility of participants. I was also aware that as a single researcher, analysing the data obtained from individual semi-structured interviews (i.e. transcribing and then utilising thematic analysis) required a significant time commitment. However, it was important that sufficient data be obtained and processed to ensure the research questions had been addressed. Green and Thorogood (2014) suggest that if a study is addressing a fairly specific research question or questions with a relatively homogeneous group of participants the experience of most qualitative researchers is that in interview based studies, little 'new' comes out of transcripts after approximately fifteen have been analysed (Green and Thorogood, 2014, p.122). Other researchers such as Guest et al. (2006) found similar results after approximately half of transcripts.

Data analysis was a novel experience. It was important to me that transcripts were analysed effectively, so that participant voices were accurately reflected within the analysis. For this reason, the concept of saturation was important, and I believe contributed to the overall reliability of data interpretation.

It was apparent that after analysis of the first six transcripts, similar themes were becoming evident. This was partly due to the interview structure (i.e. the questions used, and the order in which they were asked) but also related directly to the insights of individual participants. For example, participants struggled with definitions of key terms, demonstrated limited insight regarding spiritual distress, were generally unaware of specific assessment tools to help identify such distress and primarily utilised drug therapy as a primary intervention to help alleviate such distress. The dichotomy between resources for NHS and hospice based practitioners also quickly became apparent. Overall, a significant level of data saturation appeared evident after analysis of approximately half of participant interviews.

Ongoing discussion with my supervisors supported this assumption and thematic analysis of the remaining ten transcripts further demonstrated that data saturation appeared to have been reached, with no new novel themes becoming evident. Clearly, data can never be truly saturated, as the number of emergent themes is potentially limitless and additional insights for participants are always possible (Green and Thorogood., 2014). However, achieving an acceptable level of data saturation confirmed that analysis of the interview data had achieved the goal of providing a sufficient foundation upon which meaningful discussion regarding the data corpus could then progress.

4.6 Data collection procedure(s)

For both Pilgrim's hospice and KCHFT approximately sixty letters were distributed, resulting in responses from twenty-one staff (twelve PH; nine NHS). Each respondent was then contacted individually using secure e-mail to arrange a convenient date and time for interview in a suitable location where confidentiality could be guaranteed. At the start of each interview, participants were shown a copy of the original participant information letter, encouraged to ask any questions or clarify anything that was unclear, and then asked to sign a consent form. Copies of the documentation used are shown in Appendix 2. Interviews were recorded using a Sony digital ICD-PX470 recorder. At the first opportunity, digital recordings were transferred to a pass code protected laptop computer and uploaded to secure CCCU cloud storage. The original audio file was then deleted from the recorder. The average interview duration was approximately forty minutes. Interviews utilised a series of defined questions with prompts, to ensure that the central research questions of the study were addressed. These questions were developed in consultation with my supervisors and are shown in Appendix 3. Overall, interviewing participants was an enjoyable process, but I quickly realised my inexperience as an interviewer. Digital recordings were then individually transcribed and any information that might identify participants, service users, other staff or a specific organisation removed from the transcripts. The data would also be accessed only by myself and my supervisors, who oversaw the process. Once completed, written transcripts were then re-checked against the individual audio recordings, and any transcription errors corrected. It was interesting how many errors were discovered at this point, highlighting that transcription is a human, error laden process.

There are also several potential sources of bias in this study that require acknowledgement. Primarily, these relate to myself as researcher and include my own beliefs, previous experience, assumptions regarding spirituality, spiritual distress and the wider context of community nursing and the place of spiritual care within that context. The researcher's expectations, visible characteristics, race, gender, age, culture, personality and life experience can also affect the research process, particularly interviews. For example, categories of interview bias include:

- Errors by the respondent.
- Unintentional errors or interviewer sloppiness.
- Intentional subversion by the interviewer.
- Influence due to the interviewer's expectations.
- Failure of an interviewer to probe or to probe properly.
- Influence on participant answers due to the interviewer's appearance, tone, attitude or reactions.

(Neuman, 2011, p.347; Jacob and Furgerson, 2012).

I believe such sources of bias were minimised by ongoing supervision, which allowed regular opportunity to reflect upon how interviews were progressing and my role within them. Having a pre-determined outline of questions was also helpful and provided a useful framework for interviews. Transcription and the ongoing review of transcripts/transcript excerpts did not appear to reveal sloppiness or intentional subversion on my part as interviewer. I was also unaware of deliberate attempts to influence participants by my own appearance, tone or manner. All participants appeared comfortable during interviews and contributed willingly and without coercion. The issue of bias is further considered in 4.23.

4.7 GDPR considerations

All data storage demonstrated compliance with General Data Privacy Regulations (GDPR), the Data Protection Act 2018 and CCCU policies and procedures. Data was stored securely using CCCU One drive cloud storage. All participants were anonymised using appropriate descriptions (e.g. Participant 1, Participant 2) and no respondents are identified by name, age, or gender within the final thesis.

4.8 Semi-structured interviews

My goal was to access perceptions of community nurses regarding spiritual distress and its alleviation. Interviews therefore sought to access practitioners' insights concerning meaning(s) attached to spiritual distress, its identification and possible nursing interventions employed to address such distress. Semi-structured interviewing offered an effective method to achieve this goal, particularly as this style of interviewing can produce profoundly rich data sets. Encountering participants personally was also important to me; I believe this both values individual participants whilst facilitating access to data that may not be evident from other methods such as surveys, where it is often impossible to explore themes further or to clarify comments which appear unclear.

4.9 Semi-structured interviews and positionality

The use of semi-structured interviewing was underpinned by a series of assumptions/beliefs reflecting my own positionality as a researcher. Positionality describes both individual world view and the position adopted by individual researchers regarding a specific research task and its social/political context (Holmes, 2020; Rowe, 2014). Individual worldview incorporates assumptions regarding ontology, epistemology and both human nature and agency (i.e. assumptions regarding the way we interact with our environment and relate to it) (Holmes, 2020; Grix, 2019; Ormston et al., 2014). Such assumptions are directly influenced by individual values and beliefs, which in turn are shaped by issues such as religious faith, political views, gender, sexuality, ethnicity, social class and geographical location. (Savin-Baden and Major, 2013, p.71). My own positionality incorporates numerous assumptions/beliefs in relation to the use of semi-structured interviews, principally arising from my adoption of critical realism and post-positivism, and my Christian faith. These include:

- Participant data (i.e. knowledge) exists separately both from participant and researcher and therefore is accessible using appropriate (in this case qualitative) data collection methods. Also, semi-structured interviews function primarily by accessing knowledge rather than by knowledge creation.
- Participant perceptions/insights will always only constitute partial knowledge regarding a specific research focus. Further interviewing may provide additional insights which facilitate further modification of existing knowledge and/or its further development, or the discovery of new additional knowledge/meaning(s).

- Manifestations reflect (at least in part) the underlying causal mechanisms of spiritual distress. From a critical realist perspective, spiritual distress constitutes a causal mechanism, which then manifests empirically (i.e. in a manner that can be observed and potentially measured). In this way, the generative mechanisms of spiritual distress (e.g. fear of death; regret) directly impact the empirical.
- Generative mechanisms may be influenced by a variety of factors whose exact pattern of interaction is unknown, and which are not wholly accessible using a scientific method alone. Interviewing participants can only facilitate access to knowledge, which is partial and incomplete, as additional meaning always awaits discovery. 'Mystery' (the presence of more meaning than we can comprehend) is therefore a frequent companion within many research approaches.
- Credibility in qualitative research is determined by a combination of validity, generalisability, the factual nature of data and transparency of method.

Researcher positionality was also an important consideration both before and during the use of thematic analysis, as described in 4.13 below.

4.10 Semi-structured interviews: characteristics

Semi-structured interviewing is normally 'a one-to-one method of data collection that involves an interviewer and an interviewee discussing specific topics in depth, effectively 'a conversation with a purpose. The researcher's purpose is to gain insight into certain issues using a semi-structured interview guide' (Hennink et al., 2011, p.109). Such interviews are not a two-way dialogue; in effect, only the interviewee shares their story or experience whilst the interviewer attempts to elicit that story. For semi-structured interviews, the interviewer therefore asks pre-determined questions, attempting to encourage the interviewee to share their perspectives and experiences. It is evident that the interviewer and interviewee react not only to the questions being asked but also to each other's (perceived) appearance, identity and personality. The 'in depth aspect of the method is important as it reinforces the purpose of gaining a detailed insight into the research issues from the perspective of the study participants themselves' (Hennink et al., 2011, p.109).

Semi-structured interviewing is often described as a form of conversation, though there are obvious differences between normal conversation and interviews of this type, including individual objectives and the roles of the researcher and participant (Rubin and Rubin, 2012). There is also debate concerning if new knowledge is constructed in the interview or if the interview is simply a tool to discover new knowledge regarding pre-existing phenomena. Kvale and Brinkman (2009) utilise the metaphor of the interviewer as either a miner or a traveller. Using the mining metaphor, the interview provides the context for the interviewer to effectively acquire ('mine') the participant's pre-existing knowledge or views (Ritchie et al. 2014, p.179). This metaphor situates within the positivist or post-positivist paradigm, viewing knowledge as 'given' or awaiting discovery. As Kvale and Brinkman state:

> Knowledge is understood as buried metal and the interviewer is a miner who unearths the valuable metal. The knowledge is waiting in the subject's interior to be uncovered, uncontaminated by the miner. The interviewer digs nuggets of knowledge out of a subject's pure experiences, unpolluted by any leading questions (Kvale and Brinkmann, 2009, p.48).

In contrast, the traveller metaphor views knowledge as something which does not already exist, but which is created and negotiated within the interview process. The researcher is therefore an active player in the development of both data and meaning. As Kvale and Brinkman (2009) describe:

> The interviewer-traveller, in line with the original Latin meaning of conversation as 'wandering together with', walks along with the local inhabitants, asking questions and encouraging them to tell their own stories of their lived world. The journey may not only lead to new knowledge; the traveller may change as well. The journey might instigate a process of reflection that leads the traveller to new ways of self-understanding (Kvale and Brinkmann, 2009, p.48).

I would suggest the interview process falls somewhere in between these two perspectives. New knowledge awaits discovery, but the complexity of the human individual and the nature of subjective experience mean that in-depth interviewing is likely to access only part of the participants experience and the meanings attached to that experience. Maintaining a healthy humility within the context of any preferred research paradigm is also useful, particularly as some aspects of experience may in effect remain intangible and therefore beyond the capability of the researcher or research method to accurately objectify and describe..

My own view is that knowledge within the context of interviewing is neither solely constructed nor often fully discoverable. In-depth interviews may, however, be both interactional and transformative, for both researcher and participant. As Gubrium and Holstein (2011) suggest: ‘No matter how hard interviewers try to restrain their presence in the interview exchange and no matter how forthright interviewees are in offering their views, [interviews] are interactional accomplishments rather than neutral communicative grounds‘ (Gubrium and Holstein, 2011, p.150). Certainly, this was my experience. However, participants appeared to feel valued and shared their perspectives freely. Interviews were therefore personally satisfying though frequently frustrating.

A further metaphor which appears to capture this ‘in-between’ position is that of ‘Treasure hunter’, an approach which is specifically focused, requires discipline, method, a designated search area and a defined search strategy. Treasure hunting places great value on what is being sought and realises that the process requires persistence and subtlety, compared to the more brutal and mechanistic approach of mining, which may prove destructive to that which is sought. Whatever metaphor is adopted, the in-depth interview provides a potentially rich source of study data, if employed effectively.

The perspective of knowledge as something created within the setting of an individual interview has also led some authors to raise concerns regarding the stability, reliability and validity of interview data (Ritchie et al., 2014, p.179). For example, post-modernist researchers question the stability of interview data, and refute the notion that there is an individual ‘self’ who can be interviewed, suggesting instead that the interview is effectively a performance of one or ‘a number of selves’ and the data obtained merely a representation of that single interview (Ritchie et al., 2014, p.180). Meaning in interviewing is also potentially problematic. Central is the presumption that ‘interviewer and respondent share the same meanings of terms employed in the interview questions and answers’; however, ‘the possibility that interviewer and respondent may not be sharing the same meaning systems and hence imply different things in their use of words is simply sidestepped in structured interview research' (Bryman, 2012, p.228). In contrast, many current authors take a 'broadly pragmatic view', acknowledging that while interviews involve the discovery of knowledge in a specific interaction, they still view the interview as meaningful beyond its immediate context (Rubin and Rubin, 2012; Kvale and Brinkman, 2009). This summarises my own position.

It is also important to acknowledge that the research interview involves interaction between participant and researcher which is likely to 'shape the form and features of the data generated'. As Ritchie et al. (2014, p.180) state:

> adopting an extreme postmodern [constructionist] position on this issue appears to deny the possibility of participants being able to share their experiences and views with researchers meaningfully at all. Interview data remains an important way in which to better understand other people's lives and holds value beyond the context of the immediate research interaction. Unlike documents or observations, [interview data] includes the participant's explicit interpretations and understanding of events.

To obtain insight into the interpretations and understanding of participants regarding spiritual distress in EOL patients was the primary motivation for my use of interviewing. It was also my hope that my previous experience from nurse education, parish ministry and couple counselling would all positively influence the establishment of rapport with participants, the interview process and the quality of the data obtained. In each of these roles, I had gained experience of utilising one to one interaction with others to help gain insight into individual perceptions, and to facilitate a process of change where this was appropriate and there existed a suitable motivation on the part of the individual concerned.

For example, in nurse education, integral to the role of personal academic tutor was regular reflective conversations with students, usually at the end of specific theoretical modules or at the end of clinical placements. The purpose of these conversations was to enable the student to reflect on what they had recently learnt, both in the classroom and clinical practice, in terms of new knowledge and skills.

In parish ministry, I spent a significant amount of time with parishioners in focused personal conversation (‘spiritual direction’), assisting individuals to reflect on their experience of faith, helping clarify potential difficulties, identifying areas for spiritual growth, and seeking to facilitate such growth. Once again, the perceptions of the individual were paramount, and provided an essential starting point for such conversations.

Within couple counselling, the use of questioning and reflection provided specific tools to help couples identify specific problems and perceptions, to explore possible solutions, and where suitable motivation existed, facilitate a process of change in which specific issues were addressed.

In each of these previous roles, the establishment of rapport was crucial to the efficacy of the individual conversations. I believe this experience enabled me to similarly establish rapport with participants, to provide a comfortable and appropriate interview environment, and to gain insight into the perceptions of participants in a way that facilitated the collection of data of sufficient quality to enable the identification of key themes via subsequent thematic analysis.

For this study, interviews were underpinned by an ‘empathically neutral position’ and structured using the six stage framework described by Yeo et al. (2012, p.189), aiming to achieve both breadth and depth of coverage in relation to the research focus of the study. Interviews also provide opportunity to clarify meaning if required and to observe and note body language and non-verbal cues (Sturges and Hanrahan, 2004). Interviews utilised a pre-determined interview guide which sought first to examine the wider backdrop to spiritual distress before proceeding to explore the individual perceptions of participants regarding the research questions specific to the study. The interview framework is described below.

Stage 1: arrival and introductions

- Establish an initial rapport.
- ‘Host’ the interaction by taking responsibility for making it friendly and positive.

Hosting was achieved by first ensuring the interview location was comfortable, quiet and free from interruption. All interviews took place at the participants place of work, in a room chosen by the participant and in which they felt at ease. In the hospice setting, this tended to be an office or interview room located away from the in-patient unit. For NHS participants, interviews utilised an office at the team base. Participants were welcomed and given time to 'transition' into the interview space. Each was offered a suitable form of refreshment (water, tea or coffee) and opportunity taken to begin to establish trust and rapport.

Stage 2: introducing the research

- Seeking informed consent: research aims, objectives, voluntary, confidential.
- Scope of the interview: but the participant is in control of what they disclose.
- No right or wrong answers, hearing their perspective in their own words.

A short summary of the study was provided, and opportunity given for questions. The confidential nature of the interview was also re-stated, and participants reassured that there were no right or wrong answers. What was important was their own views, expressed in their own words. It was also re-stated that interviews were being recorded for later transcription and analysis. Participants were then asked to sign a consent form signifying their willingness to take part in the interview. Participants appeared to appreciate the opportunity to ask questions and frequently commented on their interest in the study and its relevance/connection to their own practice.

Stage 3: beginning the interview

- Contextual background information: for reference in interview and to set the tone.

Once participants were visibly at ease and had no further questions, the interview began, using the pre-determined interview guide. This initially explored perceptions regarding spirituality, spiritual care, spiritual needs and spiritual distress, providing the initial framework upon which interviews were then constructed.

Stage 4: during the interview

- Breadth and depth of coverage.

Interviews then proceeded to explore participant perceptions regarding the research questions outlined earlier. These questions provided further structure for interviews, but also allowed considerable scope for additional exploration of additional issues shared by participants. For example, many participants were unable to provide a concise definition for spiritual distress but could identify specific manifestations that might suggest that distress was present. Exploring such manifestations was productive. Such exploration was key because it 'both holds and allows the elucidation of meaning' expressed by participants. To ensure as much as possible that such meaning(s) were captured, interviews were digitally recorded (Yeo et al., 2014, p.184).

Stage 5: ending the interview

- Give some advance notice.
- End on a positive note: suggestions and recommendations.

Advance notice was given that interviews were concluding, and all participants given opportunity to ask further questions or to make any additional comments, particularly if they felt they had not had opportunity to do this. It was important to me as interviewer that no-one left the interview room without having been given adequate time and opportunity to allow their individual voice to be heard.

Stage 6: after the interview

- Thank participants for their contribution.
- How the information will be treated and used.
- Be prepared to stay to help the change of mode back to the everyday.
- Listen out for 'doorstep' data.

All participants were thanked at the conclusion of the interview and given opportunity to share what else they were due to be doing that day, so facilitating transition back to their own work context. I found repeatedly that participants enjoyed talking informally once interviews had formally concluded, but at no time felt that important issues had been missed. At this point, I also reiterated how the interview data would be stored and analysed. All participants were subsequently e-mailed to formally thank them for their participation.

4.11 Interviewing: personal reflections

Interviewing participants had significant resonances with my previous experience as a counsellor. For example, welcoming participants into the interview room, helping them feel at ease, creating rapport, asking focused questions, allowing time for responses and exploring responses/significant themes all felt very familiar. All participants appeared motivated and willing to participate; the majority expressed both their interest in the research focus and a desire to know more about spiritual distress and ways in which this form of distress could be alleviated. Each had also taken the time to contact me personally to express their willingness to be interviewed and to contribute to the study.

Overall, interviews appeared to progress smoothly, with no interviews suffering significant disruption due to external factors such as noise. Participants appeared physically comfortable, and no participants expressed non-verbal cues to suggest they were experiencing undue stress because of the questions they were being asked. No recordings were disrupted by failure of the digital recording device, such as excessive external noise or other interruptions.

Criteria used for judging the effectiveness of interviews originated from my previous counselling experience, ongoing consultation with my supervisors, and insights from the work of Kvale and Brinkmann (2009). These criteria included:

- Did the participant appear comfortable?
- Was rapport created, so encouraging the sharing of individual perceptions?
- Did the interviewer say significantly less than the participant?
- Were silences used to allow participants adequate time for reflection?
- Was the style of questioning creative and non-threatening?
- Were the perceptions of participants valued?
- Were participants allowed sufficient time to express their views?

Participants appeared comfortable throughout interviews, and freely shared their individual perceptions. From transcripts, it is evident that I spoke significantly less than participants, and silences were used repeatedly to allow participants time both for reflection and to express their views (as evidenced by the presence of frequent pauses throughout the transcripts). Time was also taken at the end of interviews to ensure that participants had no further insights they wished to share. As an interviewer, I also predominantly tried to use open questions (e.g. 'how would you define spiritual distress?'; 'could you tell me more about?'; 'what would you say the term spiritual need refers to?'). This strategy appeared to work well, and it was evident that participants shared freely about their perceptions and experiences.

On reflection, I am aware that some questions asked to participants may have appeared 'leading'. I believe the use of such questions resulted from my own naiveite as a researcher; however, at no time did I sense that participants were pressured or manipulated to provide pre-determined answers to questions, or that participants were in any way undermined by the questions used or the way in which questions were asked. I am also aware that not giving any leading cues (verbal or non-verbal) within an interview setting is virtually impossible (Silverman, 2011). Certainly, all perceptions shared by participants were valued.

Questions that participants found particularly difficult to answer where those that dealt with definitions; for example, most were unable to provide any kind of workable definition of spiritual care, spiritual needs, spirituality or spiritual distress. Struggles with definition were often accompanied by participants sighing, looking at the ceiling and the use of phrases such as "I don't know or "that's hard" or "I've never really thought about that". These phrases were often accompanied by periods of silence of varying length. During interviews, I dealt with such silences by allowing the participant time to think, by verbally encouraging them not to feel hurried to respond, and by stating that other participants had also struggled with these questions, so reassuring them their struggles were not unique. This seemed to work well, and no participants expressed a desire that individual interviews be terminated prematurely.

A strategy I also adopted intuitively during the first interview was that of the 'imaginary white board'. It was only after my primary supervisor commented that I realised I had utilised this in most of the subsequent interviews; it had just felt very natural and appeared to assist participants, particularly when trying to explore key definitions. The strategy involved asking participants to picture an imaginary whiteboard somewhere on the wall, and then ask them what they would write on it when asked to define specific terms (e.g. spiritual needs; spiritual distress). I also frequently found myself handing an imaginary pen to participants, which they could use for writing on the board. I believe this helped participants in several ways. First, it communicated to participants that I valued their insights and perceptions and wanted to hear their insights. Second, it helped maintain rapport and helped prevent participants feeling unduly pressured or rushed which was important to me. Thirdly, it creatively utilised prolonged silences where participants were struggling to articulate their views regarding key definitions or perceptions. The strategy is likely to have particularly suited participants who were visual learners, though I had no way on knowing if participants routinely adopted this style of learning. However, all participants with which I employed this strategy appeared to find it helpful and willingly used it during interviews.

The process of transcription also clearly contains potential sources of error. For example, does transcription of a verbal recording or indeed the recording itself reveal everything from interviews? In terms of communication, approximately 55% is non-verbal (Stickley, 2011; Thompson, 2011), encompassing posture, facial expression, gestures and tone of voice. Of these, only tone of voice is directly accessible from a digital recording, but without associated non-verbal cues and can therefore easily be misinterpreted. However, data saturation appeared to confirm that interview data was valid (i.e., had successfully captured participant responses to interview questions) and that perceptions which participants had shared were accessible to thematic analysis.

Transcription therefore constitutes ‘a key phase of data analysis, as an acknowledged and integral part of [my] data interpretation’ (Bird, 2005, p.247). Evident is that ‘each researcher makes choices about whether to transcribe, what to transcribe, and how to represent the record in text’ (Lapadat and Lindsay, 1999, p.66). Transcription therefore constitutes an interpretative act, whereby meanings are created, rather than simply a mechanical act of transferring spoken sounds to an appropriate form of storage.

Digital recordings were transferred from the digital recorder to a lap top computer, and then transcription software utilised to obtain transcripts of interviews. Although the software displayed limited efficacy, it successfully transcribed substantial portions of each interview, significantly reducing the overall time required for transcription. It also meant that transcription required a substantial degree of reading and re-reading, which provided familiarity with the interview data on my part. Once transcribed, completed transcripts were then compared to the individual interview recordings, to ensure accuracy. Verbal expressions such as ‘ums’ and ‘ahs’ and significant pauses were also deliberately included in transcripts, rather than being removed by a process of editing, as these allow the transcript data to be read as the participant presented it, so representing an accurate textual record of all participant responses. An example of a transcript excerpt is shown below (I: Interviewer; P: Participant):

I. What’s your understanding of spirituality?

P. For me, spirituality isn't necessarily about religion.

I. Right.

P. Erm [pauses]; you can have somebody who is spiritual but doesn't follow any religion.

I. Sure.

P. Erm, but on the flip side, they could be very religious and attend church two, three times a week, or whatever. I think it's whatever the patient [pauses]; how anything that they do to help them psychologically, to get through something. So, they could, erm, [pauses]; could be self-help books, it could be, could be religion, it could be a meditation for spirituality, you know; anything that helps them in their mind, I think; to me anyway.

4.12 Thematic analysis

Data were analysed using Thematic analysis, as described by Braun and Clarke (2006). Thorne (2000) identifies data analysis as the most complex phase of qualitative research, though often receiving only superficial discussion in relevant literature. Thematic analysis is ‘a widely used qualitative analytic method, within and beyond psychology’ which offers ‘an accessible and flexible approach to analysing qualitative data’ (Braun and Clark, 2006). Though qualitative approaches are incredibly diverse, complex and nuanced, ‘thematising meanings’ or thematic coding constitutes one of the few shared generic skills employed across qualitative analysis (Holloway and Todres, 2003, p.346-7). This form of analysis aims to generate ‘codes’, i.e., ‘words or phrases that symbolically assign a summative, salient, essence capturing and/or evocative attribute for a portion of language based or visual data' (Saldana, 2016, p.4). Thematic coding is often described as a process performed within 'major' analytic traditions, (such as grounded theory, or conversational analysis), rather than a specific approach in its own right (Ryan and Bernard, 2000; Holloway and Todres, 2003). In contrast, other authors argue that thematic analysis should be considered a research methodology which stands alone (Thorne, 2000; Braun and Clarke, 2006; Nowell et al., 2017). This reflects my own view. Thematic analysis displays considerable flexibility, and offers a methodology independent of theory and epistemology, which can be applied across a range of approaches (Braun and Clarke, 2006, p.78). Although often implicitly 'framed' as a realist/experiential method (Roulston, 2001), thematic analysis is compatible with both realist and constructionist approaches.

As Braun and Clarke (2006) suggest; 'It can be seen as a very poorly 'branded' method, in that it does not appear to exist as a 'named' analysis in the same way that other methodologies do (e.g., narrative analysis, grounded theory)' (Braun and Clarke, 2006, p. 80). Clarity is also lacking regarding how researchers can rigorously apply the method (Nowell et al., 2017). Research studies also frequently describe themes either 'emerging' from the given data or being 'discovered' within the data. Braun and Clarke (2006) suggest both activities constitute passive descriptions of data analysis, which deny the very active role the researcher always plays in the identification and selection of patterns/themes and reporting them to a given audience (Taylor and Ussher, 2001). As Ely et al. (1997) state:

> The language of 'themes emerging': can be misinterpreted to mean that themes 'reside' in the data, and if we just look hard enough, they will 'emerge' like Venus on the half shell. If themes reside anywhere, they reside in our heads from our thinking about our data and creating links as we understand them (Ely et al., 1997, pp.205-6).

As thematic analysis does not require the detailed theoretical or technical knowledge of approaches such as phenomenology or grounded theory, it offers a more accessible form of analysis, particularly so for early-stage qualitative researchers. This was a primary reason for my choosing this form of analysis. Further, thematic analysis is particularly suited to applied research within a healthcare context and accessible for practitioners seeking ‘actionable intelligence’ to influence current practice:

> Thematic analysis offers a really useful qualitative approach for those doing more applied research, which some health research is, or when doing research that steps outside of academia, such as into the policy or practice arenas. Thematic analysis offers a toolkit for researchers who want to do robust and even sophisticated analyses of qualitative data, but yet focus and present them in a way which is readily accessible to those who aren’t part of academic communities (Braun and Clarke, 2014, p.2).

Findings should therefore demonstrate both utility and accessibility to practitioners operating outside of academic communities. This was important to me as researcher.

4.13 Thematic analysis and researcher positionality

Researcher positionality is commonly considered in broad terms, based predominantly upon the researcher’s ontological and epistemic position (see 2.3-2.7). However, positionality may also be considered from the perspective of insider/outsider positioning.

Researcher positionality (i.e. the issue of insider and outsider researcher) is important when utilising thematic analysis. For this study, I was very aware of my own position as an insider researcher (i.e. working as a community nurse within KCHFT at the time of data collection).

Brannick and Coglan (2007) refer to a range of challenges faced by those considering research within their own organisation, including ‘pre-understanding’ and ‘role duality’. ‘Pre-understanding refers to people’s knowledge, insights and experience before they engage in a research programme’ (Gummesson, 2000, p.57). Such knowledge and insights apply not only to theoretical knowledge but also to the researcher’s own lived experience of the organisation in which the study is situated, therefore extending researcher reflexivity to explicitly include lived experiences (Brannick and Coglan, 2007). Relevant issues include:

- Are insider researchers better positioned to elucidate meanings in events with which they are already familiar?
- Will insider researchers seek out participants who are most like them, and therefore introduce bias into the data collection process?

- What are the advantages and disadvantages of occupying a familiar role within a particular social setting?

For example, when interviewing, insider researchers already know how the organisation works, are familiar with internal jargon, can draw on their own experiences when asking questions, and are more able to follow up on participant replies, facilitating the collection of richer data. Conversely, as interviewer, insider researchers may assume too much and therefore fail to probe as much as an outsider, or someone who had no experience of the participants specific work role, or the wider organisation. Insider researchers may also assume they know the answer to specific questions, therefore avoiding exposing their thinking to alternative explanations, and therefore potentially missing participant insights (Brannick and Coghlan, 2007).

Insider researchers may also experience both role and value conflicts from attempting to sustain both organisational and research roles simultaneously (Bryman, 2012). For example, insider researchers may be perceived as spying or breaking peer norms, resulting in the researcher being viewed with suspicion by participants, who then choose to limit their replies to interview questions, potentially undermining the reliability of the data obtained.

The potential for bias may further influence the objectivity of studies carried out by insider researchers. For example, an insider researcher may have a similar background to at least some participants, which may influence the interpretation of data and how such data is subsequently coded. A researcher may also be influenced by past experiences regarding the focus of their research as compared to an outsider researcher, who may have no prior background information or experience of the specific phenomenon providing the focus for the study. However, simply because a person occupies a particular role within an organisation does not mean they will have the same views as other individuals who share similar roles.

My hope is that reflexivity combined with ongoing supervision during the processes of research design, data collection, and subsequent thematic analysis of data helped to minimise such influences and to ensure the process of thematic analysis was sufficiently robust to draw reliable conclusions from participant responses.

4.14 Identification of themes

Central to thematic analysis is the identification of 'themes' within a given data set. A theme 'captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set (Braun and Clarke, 2006, p.82). In qualitative research, there are no defined rules as to what percentage of a given data set is required to display a given theme for that theme to be deemed present (i.e. 'prevalence'). For example, prevalence could relate to how many times a given theme occurred in each individual interview transcript. Or it could be counted in terms of the number of research participants who articulated the theme. Or it could be counted in terms of each individual occurrence of the theme across the entire data set. Prevalence can also mean how much data individual themes are deemed to 'capture' within individual data items or across the data set as a whole.

Determining what a theme is, and whether that individual theme is present within the data set is therefore a judgement made by the individual researcher. There is also no right or wrong method for determining prevalence. What is important is that there is consistency within any given analysis. For this study, prevalence related to the number of participants who articulated a particular theme.

4.15 Prevalence and 'quantitizing' in qualitative research

The use of numbers in qualitative research is also controversial as many qualitative researchers reject the use of numerical data, assuming it to be incompatible with constructionist approaches. Such assumptions are based on the belief that utilising numerical data assumes the existence of 'a single, objective reality' that can be identified, analysed and used to reach generalisable conclusions' (Maxwell, 2010). Despite this, prominent qualitative researchers have supported the inclusion of numerical data in qualitative research practices (Miles and Huberman, 1984; Schwandt, 2007). For example, Schwandt (2007, p.251) states that 'qualitative studies can and often do make use of quantitative data'. Further, as a qualitative approach 'Critical realism affirms a role for quantification alongside other practices' (Jones, 2011, p.202). Decades earlier, Becker (1970) argued that qualitative researchers frequently make quantitative claims in 'verbal form', using terms such as 'many', 'often', 'typically', and ‘sometimes’. Becker (1970) also argued that numbers increase the precision of such claims and coined the term ‘quasi statistics’ for simple counts of things to support the use of such terminology, stating ‘One of the greatest faults in most observational case studies has been their failure to make explicit the quasi-statistical basis of their conclusions’ (Becker, 1970, pp. 81-82). Similarly, Sandelowski et al. (2009, p.210) state that ‘quantitizing’ qualitative data aims ‘to facilitate pattern recognition or otherwise to extract meaning from qualitative data, account for all data, document analytic moves, and verify interpretations’; the authors further argue that such ‘quantitizing’ ‘allows analysts to discern and to show regularities or peculiarities in qualitative data they might not otherwise see…or to determine that a pattern or idiosyncrasy they thought was there is not’ (Ibid). This reflects my own view; I do not believe that representing the prevalence of key themes numerically across the data set conflicts with my own position as a critical realist, post-positivist researcher, nor with the adoption of a qualitative approach per se. Numerical representation also enhances the extraction of meaning from participant responses, helps differentiate between hospice and NHS participants, and adds to the plausibility of the story told by the data.

Further, the importance or ‘keyness’ of a theme is not necessarily dependent on measures which are quantifiable. More important is whether that theme captures something important in relation to the overall research question(s) and whether themes were generated for a deductive or inductive analytic strategy (Collins and Stockton, 2018).

4.16 Thematic analysis and theoretical frameworks

As thematic analysis is not ‘wedded’ to any pre-existing theoretical framework, it can be used within a range of frameworks (although not all). Thematic analysis can function as an essentialist or realist method, which aims to report experiences, meanings and the reality of participants, or employed as a constructionist method, aiming to examine the ways in which events, realities, meanings and experiences are the effects of a range of discourses operating within society. It can also be a ‘contextualist’ method, effectively situated between essentialism (‘the doctrine that essence is prior to existence’ (Oxford Dictionary online)) and constructionism and characterised by theoretical frameworks such as critical realism, which acknowledge both the role of individual experience and social context(s) in the development of meaning, whilst maintaining a focus upon realities distinct and separate from the individual (Braun and Clarke, 2006). Congruence with my own epistemic and ontological positions also underpinned my choice of this form of analysis. Thematic analysis is therefore 'relatively unique among qualitative analytic methods in that it only provides a method for data analysis; it does not prescribe methods of data collection, theoretical positions, epistemological or ontological frameworks' (Braun and Clarke, 2013, p.178). A key strength of thematic analysis is therefore its inherent flexibility: it be used to answer almost any type of research question (except for questions about language practice) and utilised to analyse almost any kind of data.

4.17 Coding of data

In my approach to coding, I also sought to apply the wisdom of Miles and Huberman (1994, p.70), who suggest that researchers 'dissect them [in this case, textual data] meaningfully, while keeping the relations between the parts intact', recognising that a text without a context is always a pretext. Interview transcripts were read and re-read prior to coding. Coding then involved a process of highlighting sections of individual transcripts (phrases, sentences or sections of text) and then applying specific labels or 'codes' to describe their content, whether this referred to participant perceptions (e.g., definitions of specific concepts) or specific areas of practice (e.g., interventions for spiritual distress). Codes were generated and applied to specific areas identified from transcripts that related directly to the research questions of the study, or that helped provide a backdrop to participant responses. In this way, a code effectively becomes a named repository for specific interview data describing a particular aspect of participant perception or practice.

Codes were then reviewed, and specific themes identified within each code. For example, within the code 'Identification of spiritual distress', themes included patient withdrawal from staff and/or family, regret, and anger. Within the code 'Interventions for spiritual distress', key themes included use of medication, talking with patients, and use of talking therapies.

Individual themes were then reviewed, to ensure they were accurate representations of participant responses, and the name used for each theme was succinct and easily understandable. This approach reflects that of Braun and Clarke (2006; 2014), as outlined in 4.22 below. Themes were collated and saved using NVivo.

4.18 Description within a given data set

The type of analysis and the claims a researcher makes in relation to a given data set are important components of any research study. For example, a researcher may wish to provide a rich, thematic description of an entire data set, so giving the reader a sense of the important themes contained within the data. In this case, the researcher would identify, code and analyse themes which provide an accurate reflection of the content of the entire data set. This approach may lose a degree of depth and complexity when used for a short dissertation or journal article, but overall, aims to provide a rich description of themes present within a given data set. This method can be particularly useful when a researcher is attempting to investigate a poorly researched area, or is working with participants whose views on the research topic are not know (Braun and Clarke, 2006, p. 83). For this study, providing a rich, thematic description that identified the important themes contained within the data set was a central aim of data analysis.

Thematic analysis can also be used to provide a more detailed and 'nuanced' account either of a particular theme or group of themes within a data set. This 'semantic' approach could relate to a specific question or area of interest within the data. Thematic analysis could also attempt to identify 'latent' themes, evident across the whole of the data set.

4.19 Inductive versus theoretical thematic analysis

Themes or patterns within a given data set can be identified using two primary approaches. The first is 'inductive' and uses a 'bottom up' approach. Using this approach, themes are identified based on what is in the data. For example, if the data have been collected using face to face interviews, the themes identified may bear little relationship to the specific questions asked of the participants, nor the researcher's theoretical interest within a given area. Inductive analysis therefore codes data, without trying to situate it within a pre-existing coding frame, or the researcher's preconceptions, in terms of analysis.

In contrast, 'theoretical' thematic analysis is driven by the researcher's theoretical or analytic interest within a given area of study and is therefore more explicitly analyst driven. Here, the researcher uses the data to explore specified theoretical ideas. This form of thematic analysis tends to provide a less 'rich' description of the overall data, and more detailed analysis of a specific aspect (or aspects) of the data. Using a theoretical approach, researchers can also code for a specific research question (or questions), in contrast to allowing specific research questions to evolve through the coding process, as in inductive thematic analysis. For this study, a predominantly theoretical approach was taken, which attempted to relate themes to the specific research questions of the study.

Whichever approach is taken, thematic analysis is therefore data driven. However, as stated earlier, in the context of 'bracketing', it is unrealistic to assume that researchers can free themselves from their theoretical and epistemological assumptions. For this reason, data are rarely coded free of epistemological influence.

4.20 Semantic or latent themes

Thematic analysis typically focuses upon one level. Using a semantic approach, themes are identified within the 'explicit or surface meanings of the data' (Braun and Clarke, 2006, p. 84). This form of analysis does not look for further themes or meaning beyond what a participant has said or written. Ideally, the analytic process involves a progression from description, where data have been organised to show patterns in semantic content, and summarised, to interpretation, where there is an attempt to theorise the significance of the patterns and their broader meanings and implications (Patton, 1990).

In contrast, latent thematic analysis attempts to identify and examine underlying ideas, assumptions and ideologies (or paradigms) that may be shaping or informing meaning(s) expressed in the data. If a given data set could be likened to a mountain, semantic analysis would seek to describe the surface features of the mountain, in terms of its form and meaning. A latent approach to analysis would seek to identify those specific components which give the mountain its form and meaning. For latent thematic analysis, development of themes therefore involves interpretation. As this was an exploratory study, data analysis utilised a semantic approach, which sought to identify themes within the 'surface meanings' of the interview data.

4.21 Epistemology and thematic analysis

Thematic analysis can be utilised within both realist and constructionist frameworks. As stated earlier, epistemology guides what an individual researcher can say about their data and informs how meaning is theorised. Important is the concept of 'rigour': 'devising a systematic method whose assumptions are congruent with the way one conceptualises the subject matter' (Reicher and Taylor, 2005, p. 549). With an essentialist/realist approach, it is possible to 'theorise motivations and meanings in a straightforward way, because a simple, largely unidirectional relationship is assumed between meaning and experience and language (language reflects and enables us to articulate meaning and experience)' (Braun and Clarke, 2006, p.44). Utilising the framework of critical realism, this reflects my own position.

In contrast, from a constructionist perspective, meaning and experience are socially produced and reproduced, rather than residing within individuals (Ryan, 2017). Therefore, 'thematic analysis conducted within a constructionist framework cannot and does not seek to focus on motivation or individual psychologies, but instead seeks to theorise the sociocultural contexts and structural conditions that enable the individual accounts that are provided' (Braun and Clarke, 2006, p. 44).

4.22 Phases of Thematic analysis

Thematic analysis involves:

> a constant moving back and forward between the entire data set, the coded extracts of data that you are analysing, and the analysis of the data that you are producing. Writing is an integral part of analysis, and should begin in phase one, with the jotting down of ideas and potential coding schemes, and continue right through the entire coding/analysis process (Braun and Clarke, 2006, p. 86).

Braun and Clarke outline a six-stage framework for thematic analysis. This framework was utilised in the present study and included:

Phase 1: Familiarisation with the data.

Phase 2: Generating initial codes.

Phase 3: Searching for themes.

Phase 4: Reviewing themes.

Phase 5: Defining and naming themes.

Phase 6: Producing the report.

A brief description of each of these phases follows.

4.22.1 Phase 1: Data familiarisation

To gain familiarity, a researcher is required to immerse themselves in the data; both in terms of its depth and breadth. Immersion therefore involves 'repeated reading' of the data in an active way. Integral to this process is actively searching for meanings and patterns. This phase effectively provides the foundation upon which all other analysis rests.

Authors such as Green and Thorogood (2014) suggest that the process of transcription of recorded interview data is an excellent way to begin the process of familiarisation, allowing the researcher to gain ' a feel for the data: the range of accounts generated, how participants talk about issues, recurrent topics and broad typologies of experiences, events or views' (Green and Thorogood, 2014, p.210). Bird (2005) argues that transcription should be seen 'as a key phase of data analysis within interpretative qualitative methodology' (Bird, 2005, p.227). The concept of transcription therefore becomes 'a key phase of data analysis, as an acknowledged and integral part of [my] data interpretation' (Bird, 2005, p.247). This perspective recognises transcription as an interpretative act, where meanings are created, rather than simply a mechanical act of putting spoken sounds on paper: 'each researcher makes choices about whether to transcribe, what to transcribe, and how to represent the record in text' (Lapadat and Lindsay, 1999, p.66).

The term 'accurate' in relation to transcripts can be problematic, as there is considerable debate amongst qualitative researchers as to what constitutes an accurate transcript. Better, is to aim for a 'good enough transcript' (Braun and Clarke, 2013, p. 162). This reflects my own approach. A transcript of audio data is also not an exact copy, a facsimile, but rather a representation. Just as an audio recording of an interview is not the same as the actual interview experience, so a transcript is not the same as the audio recording from which it originated. This makes the transcript two-steps removed from the actual interview experience and with each step, information may be lost or changed. The transcript is therefore the product of a specific interaction between the recording and the transcriber, who listens to the recording and actively makes choices about what to preserve and how to represent what they hear within the recording (Braun and Clarke, 2013, p. 162).

4.22.2 Phase 2: Generating initial codes

Phase two involves the researcher generating an initial list of ideas concerning what is contained within the data and what may be of interest about them. This phase then involves the production of codes from the data, features (semantic or latent) that appear of interest. This coding process forms a vital part of the analysis, allowing the data to be organised into meaningful sections or groups (Tuckett, 2005). The identification of themes then allows the researcher to begin interpretative analysis of the data. Coding will also depend, to a degree, on whether the themes are more 'data-driven' or 'theory-driven'. As stated earlier, if thematic analysis is more theory-driven, the researcher may approach the data with specific questions in mind, around which, the data is then coded; this approach was adopted for the present study.

The following guidelines for coding were utilised in data analysis:

- Code for as many potential themes/patterns as possible, within the time limits available.
- Code extracts inclusively, using small amounts of the surrounding data, if possible, to provide a context for each data extract (Bryman, 2012).
- Data extracts can be coded, uncoded, coded once, or coded many times, as relevant.
- Retain data extracts that appear to depart from the dominant story contained in the analysis.

4.22.3 Phase 3: Searching for themes

This phase begins when all data have been initially coded and collated. The phase re-focuses the analysis at the broader level of themes, rather than codes, and involves sorting the different codes into potential themes, and collating all the relevant coded data extracts within the identified themes. Essentially, codes are analysed, and a consideration made of how different codes may combine to form an overarching theme or themes. This phase therefore seeks to identify the relationship between codes, themes and different levels of themes, such as main overarching themes and sub-themes within those main themes. For example, having coded the data in relation to participant perceptions regarding spiritual distress, specific themes were then identified concerning definitions of spiritual distress, identification of spiritual distress, and specific interventions utilised for the alleviation of such distress. Within each of these key themes, numerous sub-themes were evident, which were then considered further within the process of data analysis.

4.22.4 Phase 4: Reviewing themes

Phase 4 begins when the researcher has developed a set of 'candidate themes' and involves the refinement of those themes. Data within themes should clearly 'cohere' together meaningfully, and there should be clear and identifiable distinctions between themes, so that themes are easily identifiable. This phase involves firstly reviewing the coded data extracts to see if they form a coherent pattern, with the aim of clearly identifying those themes which are present. If this pattern is initially unclear, further review is required until thematic clarity is achieved. Braun and Clarke (2006) liken this phase to editing written work. It is possible to endlessly edit sentences and paragraphs, but eventually the process fails to generate new insights, and instead may create unnecessary refinements (Braun and Clarke, 2006, p.80).

4.22.5 Phase 5: Defining and naming themes

This phase begins when a satisfactory thematic map of the data has been established. In effect, those themes which are to be presented within the final analysis are defined and refined. Braun and Clarke (2006) define these two terms as 'identifying the 'essence' of what each theme is about (as well as the themes overall) and determining what aspect of the data each theme 'captures' (Braun and Clarke, 2006, p.92). This means returning to the collated data extracts for each theme, and organising them into 'a coherent and internally consistent account, with accompanying narrative' (Braun and Clarke, 2006, p.92). Each theme is considered individually, but also in relation to the other highlighted themes. At this stage, sub-themes may also be evident. These are essentially themes within a theme and can be helpful in giving structure to large and complex themes, as well as for demonstrating possible hierarchies of meaning within the data. By the end of this phase, it is important that themes are clearly identified, and the breadth and content of each theme can be succinctly described.

4.22.6 Phase 6: Producing the report

Once themes have been fully identified, phase six involves the final analysis and write up of the results of the thematic analysis. This write up aims to 'tell the complicated story of your data in a way that convinces the reader of the merit and validity of your analysis'. It is important that the analysis provides a concise , coherent, logical, non-repetitive and interesting account of the story the data tell – within and across themes' (Braun and Clarke, 2006, p.93). Any write up must provide sufficient evidence, in terms of data extracts, of those themes deemed to be present within the data. Extracts also need to be 'embedded' within an analytic narrative that compellingly illustrates the story the researcher is telling about their data. This narrative must go beyond mere description and instead, make an argument that relates to the original research question(s).

Effective thematic analysis therefore strives to ensure that all aspects of the theme cohere around a central idea or concept, or relate to the specific research questions of a study, and provides adequate examples from the data for the analysis to be convincing to someone who has not read the entire data set (Braun and Clarke, 2006, pp.94-5). This avoids the pitfall of what Bryman (2012) has described as 'anecdotalism'. As Bryman (2012) states: 'the widespread use of brief sequences of conversation, snippets from interview transcripts, and accounts of encounters between people provides little sense of the prevalence of whatever such items of evidence are supposed to indicate' and also 'little guidance as to the prevalence of the issue to which the anecdote refers' (Bryman, 2012, p. 624). The researcher also needs to ensure that their interpretations and analysis are consistent with the data extracts presented. This was a key aim of data analysis.

Braun and Clarke (2006, p.96) provide a fifteen-point checklist to help ensure effective thematic analysis. The checklist is shown in Table 2 below.

Table 2: A fifteen-point checklist for effective thematic analysis

Process	No.	Criteria
Transcription	1	The data has been transcribed to an appropriate level of detail and the transcripts have been checked against the recording for 'accuracy'.
Coding	2	Each data theme has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (anecdotalism) but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent and distinctive.
Analysis	7	Data have been analysed – interpreted, made sense of – rather than just paraphrased or described.
	8	Analysis and data match each other – the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organised story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim to do, and what you show you have done – i.e. described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is positioned as *active* in the research process; themes do not just 'emerge'.

4.23 Rigour within qualitative research

Rigour refers to the quality of being thorough and careful (Oxford Dictionary online). Within qualitative research, rigour describes the criteria for trustworthiness of data collection, analysis, and interpretation (Prion and Adamson, 2014, p.e107). Terminology associated with rigour commonly includes validity, reliability and generalisability, though researchers have differing views on whether such terms should be applied to qualitative research. For example, although embracing the 'core principles of reliability and validity', authors such as Neuman (2012, p.214) suggest these terms are inappropriate for qualitative approaches, because of their close association with quantitative measurement and significantly different epistemological and ontological assumptions. However, despite differing views amongst researchers, it is evident that within qualitative research the terms reliability, validity and generalisability are widely accepted (Brewer, 2000; Hammersley and Atkinson, 2007), even though their use appears similar to that of quantitative research (Bryman, 2012). Validity has also been described as an 'overused term' which seeks to encompass a wide canvas. For example, the terms 'face, content, measurement, criterion, concurrent, predictive, construct and convergent' each attempt to describe different types of validity (Newman, 2011, p.211). The position and role of the researcher are also likely to influence objectivity within a particular study, its findings and the interpretations of those findings (Mason, 2002; Lewis et al., 2014). Accuracy and authenticity in qualitative research are strengthened by utilising rich and detailed data extracts that reflect both the language and meanings assigned by the participants and which allow participant voices to be heard (Brewer, 2000; Lewis et al., 2014). Reliability refers to dependability or consistency. In qualitative studies this principally means 'being thorough, careful and honest in carrying out the research' (Robson, 2002, p.176), particularly as qualitative approaches strive for consistency in observation. Problematic with reliability in qualitative contexts is that this form of research often attempts to study processes that lack consistency over time. Further, qualitative approaches value the changing or developing interaction between researcher and subject, frequently consider a range of data sources and may employ multiple measurement methods.

Important is that ‘we do not become locked into the quantitative-positivist ideas of replication, equivalence, and subpopulation reliability’ (Newman, 2012, p.214). It is also important to note that qualitative research approaches are unique, and frequently attempt to obtain the perceptions of participants regarding specific concepts or phenomena. The inherent subjectivity in qualitative approaches means that participant responses are individualised and therefore replication, equivalence and reliability are viewed in a different way to that of quantitative approaches (Bryman, 2012). Qualitative research also attempts to describe phenomena or individual perceptions in detail, without considering questions of causality or attempting to demonstrate clear relationships between variables. For example, it is unlikely that an individual participant would provide the same answers within a semi-structured interview should the interview be repeated, even if the same questioning framework were used (Bryman, 2012; Kvale and Brinkmann, 2009). Data collection is therefore uniquely interactive, whereby researchers operate in ‘an evolving setting whose context dictates using a unique mix of measures that cannot be repeated’. Such diversity helps illuminate ‘different facets or dimensions of the subject matter’ (Newman, 2012, p.214). These ‘measures’ include variables such as the interview context, time of day, length of interview, the nature of the participant-interviewer interaction, and the motivation of both participant and interviewer, none of which can be exactly replicated.

In qualitative research, the term ‘neutrality’ is also used to imply that inquiry is free of bias or separate from the individual researcher’s perspectives, background, position or previous experience. It is virtually impossible to wholly eliminate such factors totally from research approaches; instead, awareness of such variables combined with reflexivity attempt to minimise such biases and maintain sufficient neutrality on the part of the researcher, helping to ensure validity and reliability in the data obtained.

Maximising rigour

To maximise rigour (trustworthiness), this study utilised the evaluation criteria of Lincoln and Guba (1986). Clearly, rigour is essential if findings are to be deemed credible. The following components are integral to trustworthiness:

- Credibility: confidence in the 'truth' of the findings.
- Transferability: can the research findings be applied to other relevant contexts? Also, can the findings be generalised from the representative sample within the study to a wider population?
- Dependability: are the findings consistent and could they be repeated?
- Confirmability: do the findings display neutrality on the part of the researcher? Are they shaped by the respondents and not researcher bias, motivation, or interest?

These components are considered below.

4.24 Credibility

Key to establishing credibility is seeking to ensure that the voice of participants is accurately represented, the methods used appropriate for the aims of the study and that the findings and 'story' of the study are believable. Integral to credibility are both reflection (the act of reflecting) and reflexivity (the condition or state of being reflective). Reflexivity is important in seeking to minimise bias throughout the research process. As Davis (2020, p.43) states: 'Reflexivity is not just a cursory explanation, but an in-depth scrutiny of the researcher's role in the construction of new knowledge, how the researcher arrives at conclusions and how the resulting knowledge can shape the world. As such, it is not a destination, but a pursuit'. The following strategies sought to promote validity and minimise bias within findings:

- The study is not sponsored, eliminating external pressures to elucidate designated findings.
- Participants were recruited from contexts representative of community nursing staff who cared for EOL patients as part of their normal, daily practice.
- Gate-keepers (service managers) contacted nursing staff on my behalf, to prevent any sense of coercion to participate.
- Interviews took place within participant's normal places of work, to minimise inconvenience, maximise their sense of ease and encourage sharing of perceptions.

- In the absence of co-researchers, the role of my supervisors was to critically question the validity of the study. Both supervisors were encouraged to challenge my decisions and assumptions throughout the process of data collection and analysis.
- Interview questions were first discussed with my supervisors, to enhance both structure and effectiveness of participant interviews.
- Within interviews, I sought to use open, indirect questions, to avoid leading participants and to encourage freedom in responses.
- I also sought to maintain neutrality as an interviewer, resisting the temptation to imply that there were specific answers deemed correct for questions and which I was looking for; in effect, displaying confirmation bias. As far as I am aware, I was not attempting to support hypotheses I had already formulated.
- All interviews were digitally recorded, and interviews were transcribed within forty-eight hours of occurrence, keeping each interview current in memory whilst transcription was taking place. Interviews were also reviewed in detail, so facilitating accuracy in transcription.
- The study deliberately uses a substantial number of interview excerpts to allow participant voices to be heard, allowing the reader to draw their own conclusions as to whether the story presented is believable.
- I am aware that at times, my passion concerning the subject was evident during some of my replies during interviews. However, at no time did I feel this had affected interviews adversely. My observation was that when I did reply in this way, participants responded very positively, often displaying enhanced levels of animation.
- Thematic analysis sought to be open and comprehensive, without falling into ‘anecdotalism’. This was assisted by regular conversations within supervision sessions, in which I discussed both data collection and data analysis with my supervisor(s).
- The structure of the questionnaire meant all participants were presented with the same narrative, though interviews were also semi-structured, allowing participants freedom to contribute additional insights as they wished.

- I do not believe that my personal gender, culture, professional or personal background have negatively influenced either my choice of methodology nor the collection or analysis of data. However, my naiveite and lack of experience as a researcher may potentially have influenced all of these. I believe this was offset by effective and ongoing supervision throughout the research process.
- I also do not believe that my ethnic and professional background negatively influenced my relationship with individual participants. During interviews all participants appeared at ease and willing to share their views concerning the topics discussed. As a male, I am also used to interacting with predominantly female nursing colleagues.
- I believe that my role as an active NHS community nurse at the time of data collection gave me credibility amongst participants, which encouraged them to share their own experiences. Further, my own professional/personal history did not appear to significantly trigger any negative emotions for participants, nor a reluctance to share their own insights.

Research can also be affected by characteristics of the participants, such as memory, knowledge, motivation and personality (Neuman and Robson, 2007). I would hope that the sample size and relative homogeneity of participants helped minimise potential error or bias in responses.

I am also aware that my own personal and professional history may have influenced participant responses. However, I would argue that such influence is likely to have been minimal, particularly as interviews were the first time I had met any of the participants and there was no previous reference to my personal history within previous participant documentation. My previous role as an NHS community nurse also appeared to facilitate the establishment of rapport with many participants, although this may also have caused a degree of positive bias in responses. However, this is speculation, rather than fact, and it is impossible to know to what degree my own professional history and experience influenced the responses of participants during interviews. Achieving apparent data saturation also suggests that the data was credible, and that significant bias in responses had been avoided.

All participants were also white British, which is my own ethnicity. I hope this further eliminated the likelihood of participants experiencing any sense of discomfort resulting from possible cultural misunderstanding or misinterpretation, which may have influenced responses during interviews.

It could further be argued that the care of EOL patients within palliative, community-based contexts demonstrates a high degree of uniformity within the U.K, regardless of practitioner ethnicity, particularly as all nursing staff are accountable to the same NMC code of practice. This code applies to all practitioners, irrespective of their place of work and individual ethnic background. However, it would be useful to ascertain the views, perceptions and experiences of practitioners of additional ethnicities in future studies.

4.25 Transferability

Transferability denotes the degree to which findings can be generalised from a representative sample to a whole population (Lincoln and Guba, 1986). Further, because qualitative research involves the 'intensive study of a small group, or of individuals sharing certain characteristics, qualitative findings tend to be oriented to the contextual uniqueness and significance of the aspect of the social world being studied' (Bryman, 2012, p. 392). Although this research aimed to explore perceptions of community staff from two different practice settings, it was not attempting to apply these findings to a wider population, nor assume that the findings would be representative of nurses who were not community-based or providing palliative care. However, transferability is evident when research findings from a smaller group have resonance or applicability to a broader group, beyond those that participated (Ritchie et al., 2014). My hope is that this study's findings will profoundly resonate with community-based practitioners caring for EOL patients. Spiritual distress, however, is not unique to community contexts, and my aim is that the insights of participants will both inform and influence practitioners working within other contexts. The degree to which each is achieved will depend on the dissemination strategy utilised once the study is completed, and the individual motivations of practitioners across a range of contexts.

4.26 Dependability

Dependability refers to the presence of an accessible audit framework or checking process of methods (Lincoln and Guba, 1986). The research framework and methods utilised for this study have already been described in detail and I believe exhibit both transparency and integrity. Also, as mentioned previously, there were several potential sources of bias in this study that required acknowledgement. As described in section 4.1, these relate to myself as researcher and include my own beliefs, previous experience, assumptions regarding spirituality, spiritual distress, the wider context of community nursing, and the practice of spiritual care within that context. The researcher's expectations, visible characteristics, race, gender, age, culture, personality and life experience can also affect the research process, particularly interviews. For example, categories of interview bias include:

- Errors by the respondent.
- Unintentional errors or interviewer sloppiness.
- Intentional subversion by the interviewer.
- Influence due to the interviewer's expectations.
- Failure of an interviewer to probe or to probe properly.
- Influence on participant answers due to the interviewer's appearance, tone, attitude or reactions.

(Neuman, 2011, p.347; Jacob and Furgerson, 2012).

An awareness of such influences can help 'sensitise' the researcher to both events and participants integral to the study and provide a useful resource for reflexivity (Rubin and Rubin, 2012). This assumption was in part addressed by acknowledging and reflecting upon my own biases throughout the research process, as identified earlier. A further issue particularly related to interviews is that of persuasiveness: the capability of a person or argument to convince or persuade someone to accept a desired or predetermined way of thinking (Stewart and Cash, 2008). This capability can influence dependability, either during recruitment of participants or during interviewing. I believe dependability was enhanced both by the use of gate-keepers in recruitment and by a process of ongoing reflection during interviews, seeking to ensure that my own persona and manner of questioning was not attempting to unduly lead or influence participants in their responses. It would be unrealistic to assume there was no influence at all; however, ongoing awareness of this possibility hopefully meant that any such influence was recognised and therefore did not constitute a significant source of bias, or negative influence.

4.27 Conformability

Conformability illustrates that research data are clearly linked to stated sources, thus establishing that interpretations and conclusions are credible (Lincoln and Guba, 1986). To achieve this, I have repeatedly sought to demonstrate how I arrived at my findings and to evidence that my own biases did not significantly influence either data collection or data analysis. The use of NVivo also facilitated the analysis of transcript data, ensuring that participant voices were valued and heard. The initial literature review and the use of six data collection sites also contribute to comprehensiveness, transferability and authority.

4.28 Reporting findings

Reporting the findings of qualitative research presents several challenges. For example, transcribing large amounts of interview data and then presenting it in a way that preserves its integrity, subtlety and inherent complexity requires considerable skill and insight on the part of the researcher. Reporting findings is also a dynamic, iterative, reflective process (Marvasti, 2011; White et al., 2014). There are also no standardised frameworks for the presentation of qualitative research findings, which will usually be influenced both by the study design and personal preferences of the researcher.

For this study, findings are presented using the codes and themes identified from the transcribed interview data. Data extracts from interviews are then used to illustrate these themes and to help contextualise the rich (‘thick’) descriptions offered by participants. The use of verbatim quotes throughout aims to illustrate the themes which underpin the core concepts, allows participant voices to be heard within the context of the analysis, and seeks to address the specific research questions of the study.

4.29 Participant location

The location and number of participants is shown below.

Pilgrim’s hospices

- Hospice 1: (3)
- Hospice 2: (5)
- Hospice 3: (3)

KCHFT

- Community setting 1: (5)
- Community setting 2: (1)
- Community setting 3: (4)

Recruiting participants from Pilgrim’s hospices was markedly easier than recruiting participants from KCHFT. For example, interviews with several NHS participants had to be repeatedly re-scheduled, due to participant workload pressures. However, this did not appear to adversely influence data collection. During the recruitment process, I visited nurse managers responsible for four separate KCHFT community nursing clusters, based in Kent.

Despite distributing nearly sixty participant invitation letters across these sites, only nine KCHFT community nurses responded. This was disappointing, but understandable. As a former NHS community nurse, I am very aware of the significant workload pressures experienced by community staff; such demands may help explain why recruitment of participants from KCHFT was particularly challenging.

4.30 Years since qualification

The time participants had been involved in nursing practice since qualification ranged from a minimum of one year to a maximum of forty-five years, with an average of twenty years. This was an experienced group of nurses. The breakdown is shown in Table 3 below:

Table 3: Participants: years since qualification

Time (years)	KCHFT	PH	Total
< 10	2	3	5
10-19	4	3	7
20-29	2	1	3
30-39	1	3	4
≥ 40	1	1	2

For NHS participants, the number of years since qualification varied between a minimum of six years and a maximum of forty-five years. The average was twenty years.

For hospice-based participants, the number of years since qualification varied between a minimum of one year and a maximum of forty-nine years. The average was twenty-three years.

4.31 Time (years) involved in caring for community-based EOL patients

The time participants had been involved in the care of EOL community-based patients varied from a minimum of one year to a maximum of thirty-one years, with an average of ten years. The number of years NHS participants had been involved in community-based EOL care varied between two and thirty years, with an average of fourteen years.

For hospice-based participants, experience of community-based EOL care varied between one and thirty-one years, with an average of ten years. The breakdown is shown in Table 4 below:

Table 4: Participants: time (years) involved in caring for EOL community-based patients

Time (years)	KCHFT	PH	Total
< 10	4	7	11
10-19	3	4	7
20-29	1	-	1
> 30	1	1	2

Participants therefore had considerable palliative care experience. All participants identified as white British in terms of ethnicity and two identified as male in terms of gender. This reflects national trends, where the percentage of male nursing staff has remained unchanged at approximately eleven percent for many years (Williams, 2017; NMC, 2019).

The lack of ethnic diversity constitutes a limitation to the study in terms of reproducibility, and for NHS participants does not reflect present day NHS staffing. This may have resulted from several factors, including the overall ethnic staffing profile of both organisations, the six data collection sites all being in West Kent rather than in a city such as London, which has a much greater mixed ethnicity, or another area of the UK, for example the midlands or the north of England. This may also reflect that community-based EOL care in Kent predominately attracts nurses who are white British in origin.

However, my observation whilst visiting the potential data collection sites was that ethnic diversity amongst community nursing staff appeared to be minimal. This trend was also evident within my own community nursing team. Sampling may also have been influenced using 'gate-keepers'. To avoid any sense of coercion, invitation letters to potential participants had been distributed by nurse managers, so avoiding any initial contact with myself as researcher. There was no way of knowing whether this distribution had been a random process to all eligible staff for which the individual manager had responsibility, or if this process had been more selective. How closely participants reflected the overall ethnic diversity within both organisations was also unclear.

4.32 Reasons for choosing a community context involving EOL care

Individual motivation amongst participants for choosing a community context which involved caring for EOL patients varied, but not significantly. Eighteen participants reported they had a previous interest in the care of EOL community-based patients. Of these, six were NHS staff and twelve were based within Pilgrim's hospices. Of the eighteen, three (all NHS) stated they were aware that caring for EOL patients was integral to their role and three (again, all NHS) stated that they had not specifically chosen community nursing because of an interest in caring for EOL patients. One hospice nurse described how they had chosen the hospice context both because of a desire to develop effective therapeutic relationships with patients and because of their own personal experience of a loved one receiving hospice care some years before. This experience had clearly been important. Another hospice nurse described how they had decided to work with cancer patients at the age of six, and within hospice care at the age of ten, after observing their grandfather die of cancer at home. Of the eighteen participants who had an interest in EOL community-based care, one NHS nurse reported that their own personal faith had also contributed to their decision, and two hospice-based nurses described how they chose the hospice context because they had a desire to establish what they saw as effective therapeutic relationships with patients, viewing the hospice as a suitable context to facilitate this. This was clearly a group of nurses who were highly motivated towards caring for EOL patients, who viewed this aspect of care as integral to their role. Most participants had also deliberately chosen a work context involving the care of EOL patients.

4.33 Participant interviews

Twenty-one semi-structured interviews were undertaken, the average length of which was approximately thirty-five minutes. The semi-structured interviews employed for data collection utilised a series of sequential questions/prompts to provide interview structure. This resulted in the transcripts having the form of an individualised ‘sequential narrative’ (Mason, 2002). The questions/prompts used for interviews are shown in Appendix 3. Data obtained following thematic analysis of participant interviews are summarised in chapter 5. Relevant excerpts from interview transcripts are reproduced in chapter 6, to illustrate specific findings.

5 Chapter 5: Data

5.1 Data Analysis

Interview transcripts were analysed using the programme NVivo, a specific computer aided qualitative data analysis (CAQDAS) programme suitable for researchers new to qualitative analysis. Mason (2002) describes how CAQDAS both facilitates and enhances the indexing and retrieval process during analysis and enables a much larger number of categories to be indexed efficiently than could be undertaken by hand, using paper copies of data. However, although CAQDAS can potentially both enhance and speed up data retrieval, it can also mean that indexing takes on a more prominent role than planned, as so much more is possible than with purely manual systems. Interview transcripts are first uploaded and stored within NVivo. The programme then facilitates analysis of transcripts, via the generation of specific nodes or codes.

5.1.1 Data presentation

Initial analysis of interview transcripts identified sixty codes relevant to the overall study. These are shown in Fig 6 below. Table 5 then displays these codes in relation to prevalence across the data set.

These codes and their associated themes were then linked to the specific research questions of the study, using both diagrams and tables. For each question, diagrams provide a visual summary of specific themes, and tables are then used to illustrate prevalence of each theme.

Fig 6: Codes applied to interview transcript data

Codes applied to interview transcript data.

- Spiritual needs (definition).
- Spiritual needs (initial assessment).
- Spiritual needs (ongoing assessment).
- Spiritual distress (definition).
- Spiritual distress (identification).
- Spiritual distress (assessment).
- Spiritual distress (interventions).
- Efficacy of interventions.
- Therapeutic relationships.
- Training needs.
- Time pressure (lack of time).
- Patient referred too late.
- Time (having sufficient time).
- Staff support.
- Communication.
- Managing difficult symptoms.
- Availability of resources.
- Emotional cost to staff.
- Family related issues.
- Medication related issues.
- Team support.

- Assessment tools for spiritual needs.
- Staff symbolising impending death.
- Spirituality and religion (difference).
- Practitioner identifying with patient's situation or age.
- Helping patients remain at home.
- Initially fearful of EOL care.
- Loss and grief.
- Practitioner anxiety.
- Practitioner death anxiety.
- Reluctant to share faith with patients.
- Access to CPD.
- Avoiding burnout.
- Avoiding burnout
- Carer distress.
- Continuity of care.
- Distraction strategies.
- Ethical issues.
- Excessive paperwork.
- Financial stress (patients).

- Focus on measurement rather than caring.
- Holistic care.
- Human spirit as energy.
- Impaired thinking (practitioner).
- Restricting patient choice.
- Lack of information.
- Loss of hope (patient).
- Loss of hospice chapel.
- Personal faith provides support.
- Phone conversations difficult.
- Practitioner feelings of helplessness.
- Religious needs.
- Spiritual pain.
- Staff self-care.
- Task orientated working undermined EOL care.
- Telephone assessment.
- Travel related issues.
- Unrealistic patient or family expectations.
- Criticism for finishing late.

Table 5: Codes applied to interview transcript data

Code	Responses	KCHFT	PH
Time caring for EOL patients	21	9	12
Why a context involving EOL patients	21	9	12
Spirituality (definition)	21	9	12
Spiritual care (definition)	21	9	12
Spiritual needs (definition)	21	9	12
Spiritual needs (initial assessment)	21	9	12
Spiritual needs (ongoing assessment)	21	9	12
Spiritual distress (definition)	21	9	12
Spiritual distress (identification)	21	9	12
Spiritual distress (assessment)	21	9	12
Spiritual distress (interventions)	21	9	12
Efficacy of interventions	21	9	12
Therapeutic relationship(s)	15	5	10
Difficult conversations	11	6	5
Training needs	10	5	5

Time pressures (lack of time)	9	7	2
Patient referred too late	9	7	2
Time (having sufficient time)	8	-	8
Staff support	6	1	5
Communication	6	6	-
Managing difficult symptoms	6	1	5
Availability of resources	6	4	2
Emotional cost to staff	5	4	1
Family related issues	5	5	-
Medication related issues	5	3	2
Team support	5	-	5
Assessment tools for spiritual needs	5	2	3
Staff symbolising impending death	4	1	3
Spirituality and religion (difference)	3	2	1
Practitioner identifying with patient’s situation or age	3	-	3
Helping patients remain at home	2	1	1
Initially fearful of EOL care	2	2	-

Loss and grief	2	-	2
Practitioner anxiety	2	1	1
Practitioner death anxiety	2	-	2
Reluctant to share faith with patients	2	2	1
Access to CPD	1	-	1
Avoiding burnout	1	-	1
Carer distress	1	-	1
Continuity of care	1	-	1
Distraction strategies	1	1	-
Ethical issues	1	1	-
Excessive paperwork	1	1	-
Financial stress (patients)	1	1	-
Focus on measurement rather than caring	1	-	1
Holistic care	1	-	1
Human spirit as energy	1	-	1
Impaired thinking (practitioner)	1	-	1
Restricting patient choice	1	-	1
Lack of information	1	1	-

Loss of hope (patient)	1	-	1
Loss of hospice chapel	1	-	1
Personal faith provides support	1	1	-
Phone conversations difficult	1	-	1
Practitioner feelings of helplessness	1	-	1
Religious needs	1	1	-
Spiritual pain	1	-	1
Staff self-care	1	-	1
Task orientated working undermined EOL care	1	-	1
Telephone assessment	1	-	1
Travel related issues	1	1	-
Unrealistic patient or family expectations	1	1	-
Criticism for finishing late	1	1	-

The most prevalent codes related to the sequential narrative of the interviews. For example, all participants were asked how long they had been involved in the care of EOL patients within a community context. Participants were also asked to define spirituality, spiritual care, spiritual needs and how spiritual needs were assessed both initially and as an integral aspect of on-going patient care. Regarding spiritual distress, participants were asked about definition, identification, interventions they had used to alleviate such distress, whether the efficacy of those interventions had been measured and if so, how. Outside of the sequential interview questions, the most prevalent theme was the nurse-patient therapeutic relationship, which was mentioned by fifteen participants (5 NHS, 10 PH). Eleven participants mentioned difficult conversations (6 NHS, 5 PH). These were either with patients, loved ones or both. Training needs were mentioned by ten participants (5 NHS, 5PH), all of which highlighted that further training regarding spiritual distress would be useful. Time was a key aspect of three themes. First, in the context of time pressure, where nine participants (7 NHS, 2 PH) identified this as a key factor preventing them from engaging more effectively with spiritual distress. In contrast, seven hospice-based participants stated that for them, time was not an issue, as they felt they had enough time to effectively deal with their individual caseloads. A further time related issue identified by nine participants (7 NHS, 2 PH) was that of patients being referred too late, making it either difficult or impossible to establish any kind of therapeutic relationship with patients, as the patient was either too ill or already unconscious. Communication was identified by six NHS participants and six participants (1 NHS, 5 PH) identified attempting to manage difficult patient symptoms associated with EOL. Two other codes highlighted by six participants were staff support (1 NHS, 5 PH) and available resources (4 NHS, 2 PH). Five participants respectively identified the emotional cost to staff associated with EOL care (4 NHS, 1 PH), family related issues (5 NHS), medication related issues (3 NHS, 2 PH) and team support (5 PH). Other less prevalent codes are summarised in Table 14. Twenty-seven codes related to a single participant, though it is important to note that all codes identified from interview data were significant to those participants.

Codes were then categorised in relation to the research questions of the study, as shown below.

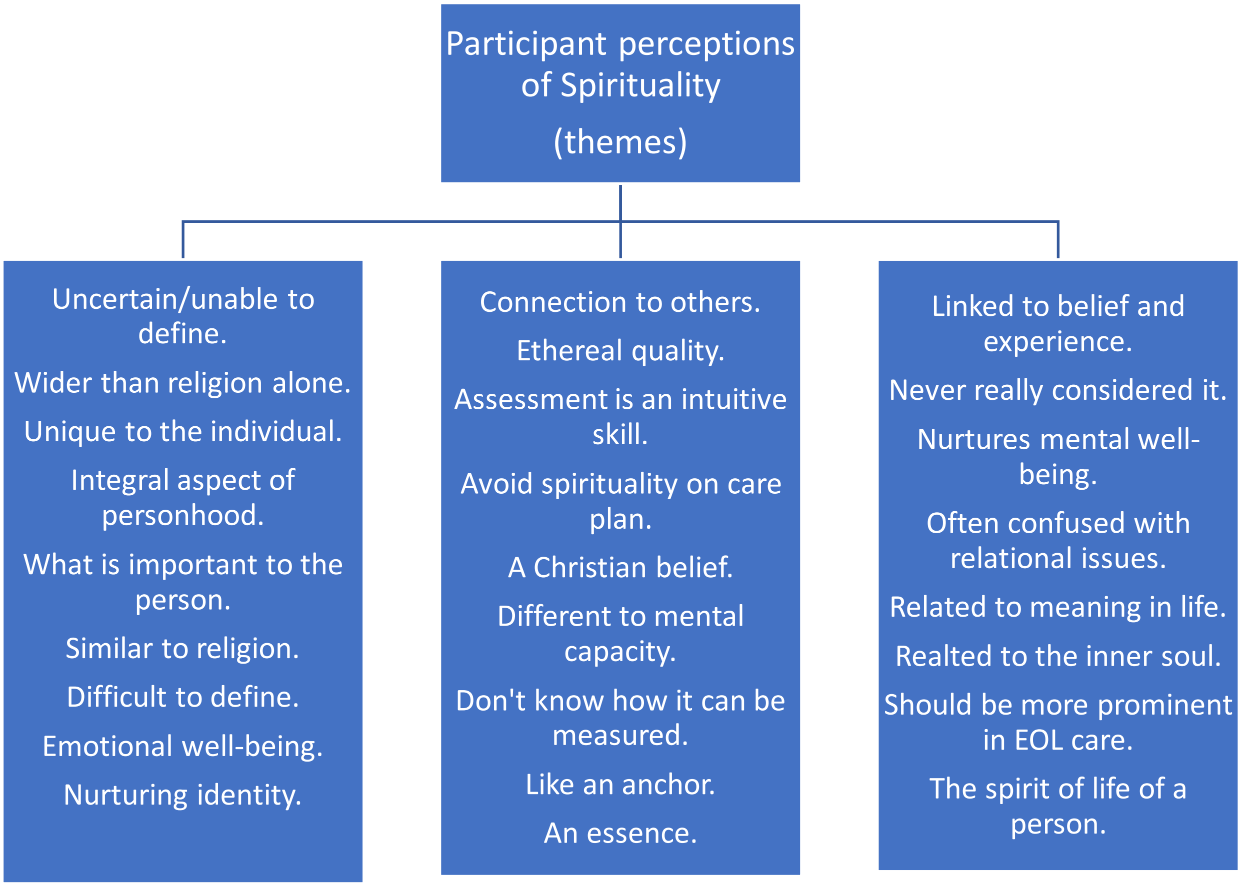
5.2 Codes pertaining to research question 1

Research question 1 attempts to ascertain the perceptions of participants regarding spirituality, spiritual care and spiritual needs. Each is considered below.

5.2.1 Spirituality: participant perceptions

Analysis of interview data concerning participant definitions for spirituality identified twenty-six themes. These are summarised in Fig 7 below.

Fig 7: Participant perceptions of spirituality: themes



A further breakdown of themes in terms of prevalence is shown in Table 6.

Table 6: Participant perceptions of spirituality: themes

Theme	Respondents	KCHFT	PH
Uncertain/unable to define	7	3	4
Wider than religion alone	7	2	5
Unique to the individual	6	2	4
Integral aspect of personhood	5	3	2
What is important to the person	5	1	4
Similar to religion	4	1	3
Difficult to define	3	1	2
Emotional well-being	2	-	2
Nurturing identity	2	1	1
Connection to others	2	2	-
Ethereal quality	1	1	-
Assessment is an intuitive skill	1	1	-
Avoid spirituality on care plan	1	1	-
Christian belief	1	1	-
Different to mental capacity	1	1	-
Don’t know how it can be measured.	1	1	-
Like an anchor	1	-	1

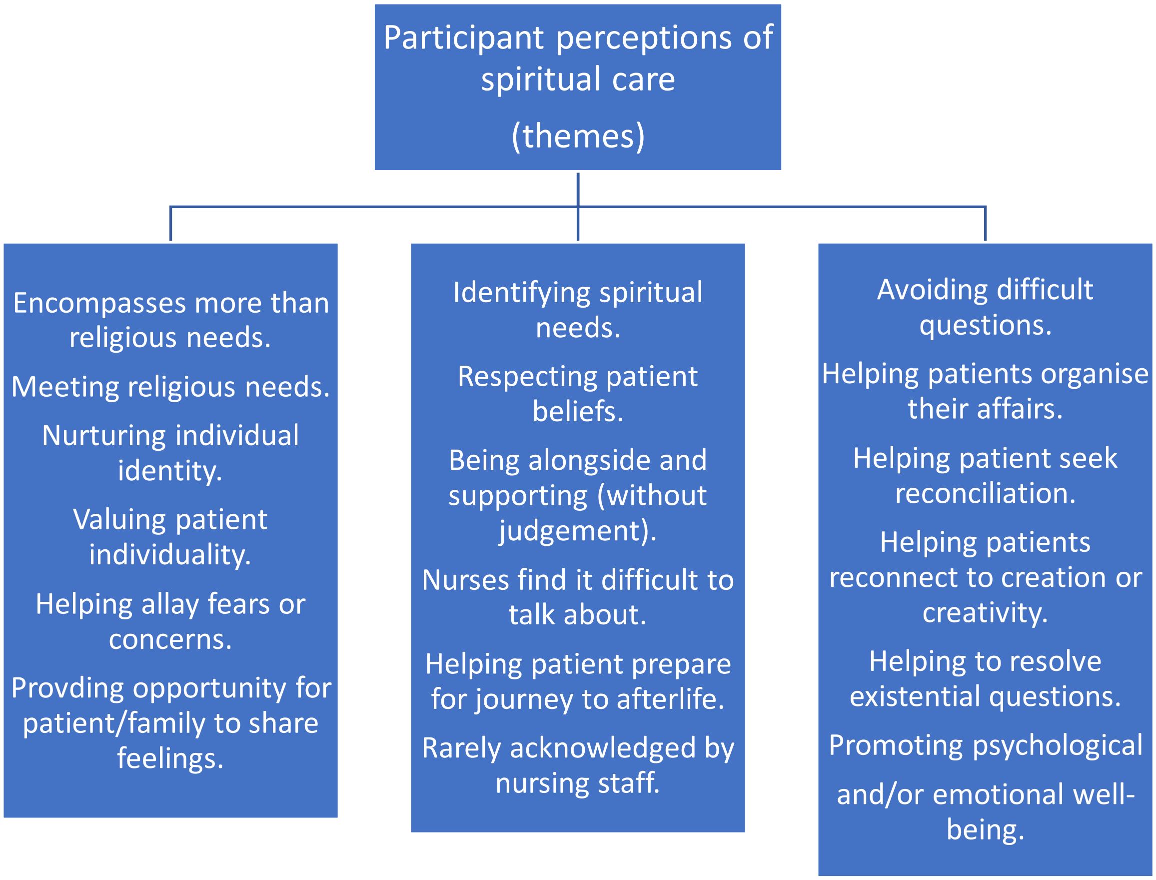
An essence	1	1	-
Linked to belief and experience	1	1	-
Never really considered it	1	1	-
Nurtures mental well-being	1	1	-
Often confused with relational issues	1	-	1
Related to meaning in life	1	-	1
Related to the inner soul	1	-	1
Should be more prominent in EOL care	1	-	1
The spirit or life of the person	1	1	-

Participants found attempting to define spirituality difficult. No participant was able to offer a concise definition of the term and over half of the associated themes were identified only by a single participant, reflecting the wide variation in views. One third of participants (3 NHS, 4 PH) were unable to offer a definition of spirituality and/or were uncertain as to what the term represented. One third (2 NHS, 5 PH) stated that spirituality was wider than religion alone, six participants (2 NHS, 4 PH) stated spirituality was unique to the individual and five participants (3 NHS, 2 PH) stated that it was an integral aspect of personhood. Five participants (1 NHS, 4 PH) described the term as referring to what was important to the individual and four participants stated that spirituality was similar to religion. Three participants (1 NHS, 2 PH) stated that spirituality was difficult to define. Two NHS participants identified connection to others as integral to spirituality. All remaining themes were identified by a single participant.

5.2.2 Spiritual care: participant perceptions

During interviews, participants found it difficult to articulate exactly what was meant by spiritual care or to identify specific nursing interventions integral to this aspect of care. Nineteen themes were described by participants. These are summarised in Fig 8 below.

Fig 8: Participant perceptions of spiritual care: themes



A further breakdown of themes in terms of prevalence is shown in Table 7.

Table 7: Participant perceptions of spiritual care: themes

Theme	Responses	NHS	PH
Encompasses more than religious needs	8	2	6
Meeting religious needs	7	3	4
Nurturing individual identity	6	1	5
Valuing patient individuality	5	2	3
Helping allay fears or concerns	4	-	4
Difficult to define	4	2	2
Providing opportunity for patient/family to share feelings	3	2	1
Identifying spiritual needs	3	1	2
Respecting patient beliefs	3	2	1
Being alongside and supporting (without judgement)	2	1	1
Nurses find it difficult to talk about	2	1	1
Helping patient prepare for journey to afterlife	2	2	-
Rarely acknowledged by nursing staff.	2	2	-
Avoiding difficult questions	1	1	-
Helping patients organise their affairs	1	1	-
Helping patient seek reconciliation	1	-	1

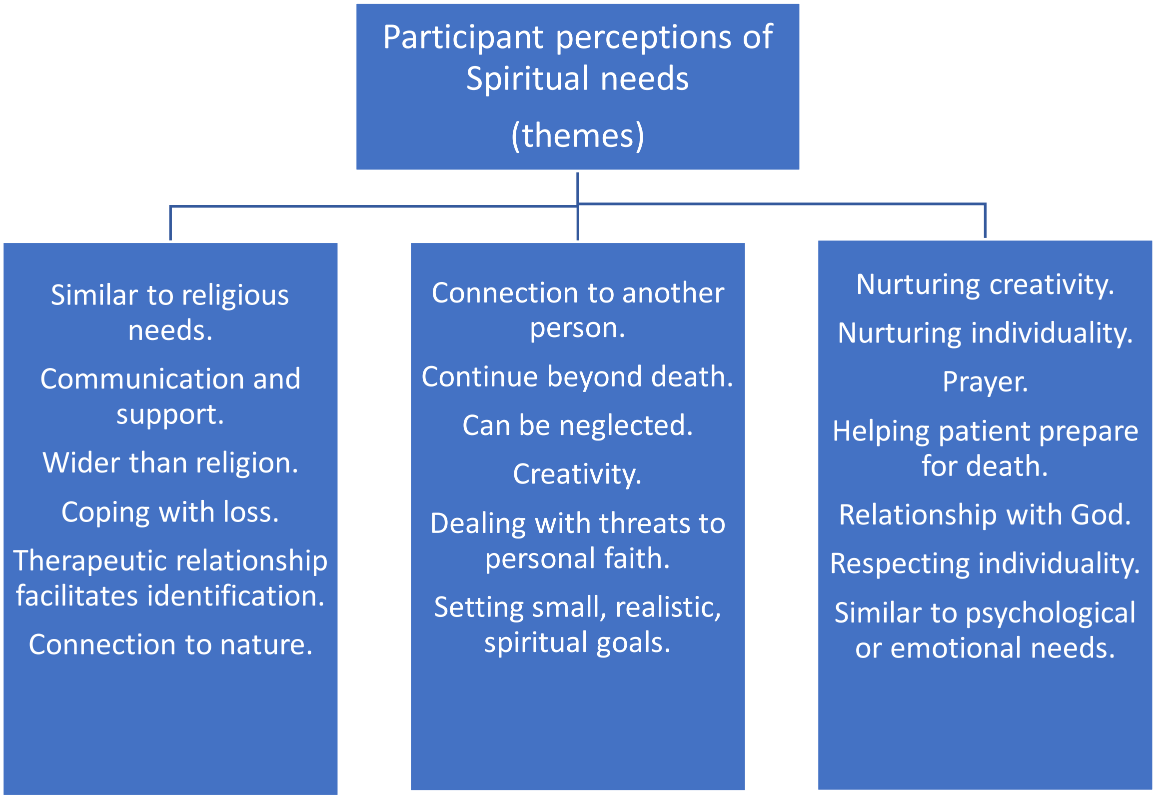
Helping patients reconnect to creation or creativity	1	1	-
Helping to resolve existential questions	1	1	-
Promoting psychological and emotional well-being	1	-	1

The most prominent theme represented was that spiritual care encompassed more than just religious needs. This was stated by eight participants (2 NHS, 6 PH). In contrast, seven participants (3 NHS, 4 PH) stated that spiritual care principally involved meeting religious needs alone and six participants (1 NHS, 5 PH) identified nurturing the individual identity of patients as key. Five participants (2 NHS, 3 PH) also identified valuing patient individuality as integral to spiritual care. Four hospice-based participants stated that spiritual care involved helping allay patient or family fears or concerns and four participants (2 NHS, 2 PH) expressed the view that the term was hard to define. All themes are summarised in Table 7.

5.2.3 Spiritual needs: participant perceptions

Nineteen themes were identified from interview transcripts concerning participant perceptions of spiritual needs. These are summarised in Fig 9.

Fig 9: Participant perceptions of spiritual needs: themes



A further breakdown of themes in terms of prevalence is shown in Table 8.

Table 8: Participant perceptions of spiritual needs: themes

Theme	Responses	KCHFT	PH
Similar to religious needs	5	4	1
Communication and support	5	2	3
Wider than religion	3	1	2
Coping with loss	2	-	2
Therapeutic relationship aids identification.	2	1	1
Connection to nature	1	1	-
Connection to another person	1	1	-
Continue beyond death	1	1	-
Can be neglected	1	1	-
Creativity	1	1	-
Dealing with threats to personal faith	1	-	1
Setting small, realistic, spiritual goals	1	-	1
Nurturing creativity	1	1	-
Nurturing individuality	1	-	1
Prayer	1	1	-
Helping prepare for death	1	-	1
Relationship with God	1	-	1
Respecting individuality	1	1	-

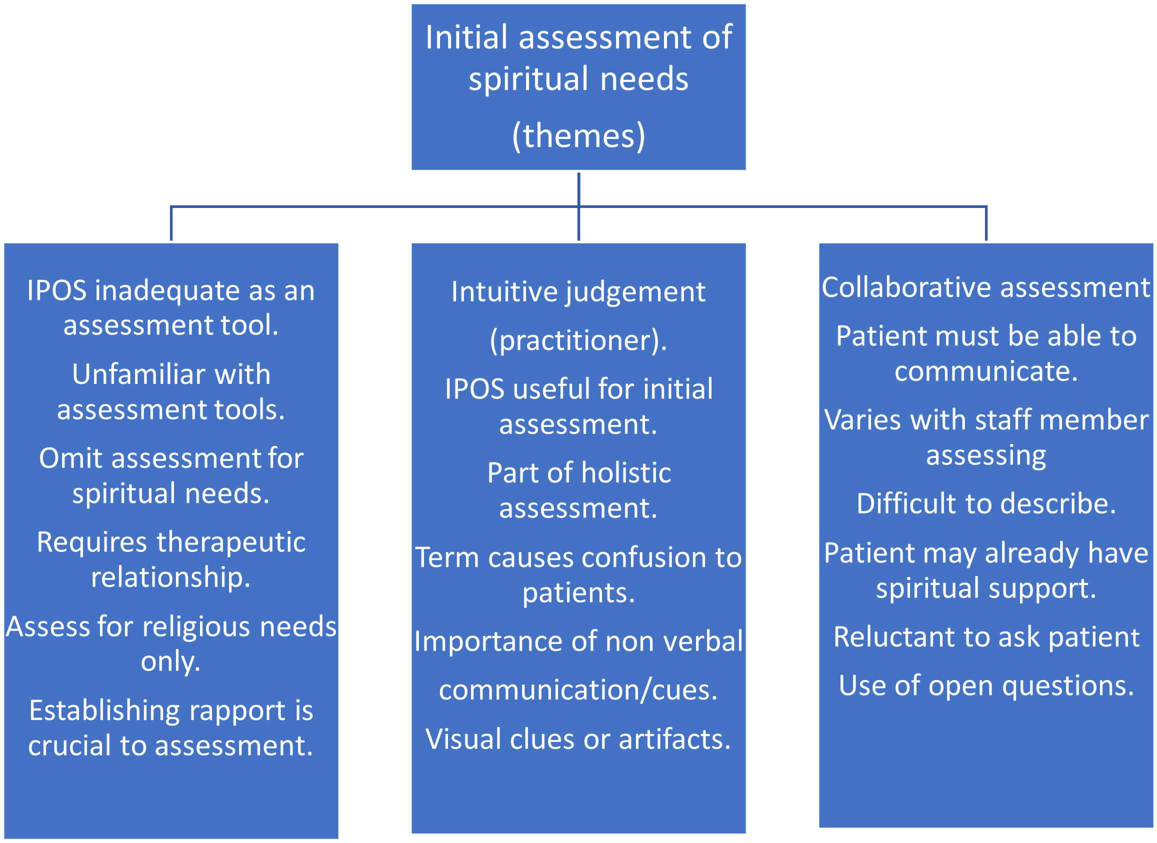
Similar to Psychological or emotional needs	1	-	1

The most prominent themes identified by participants were that spiritual needs are similar to religious needs (4 NHS, 1 PH), and communication and support both characterise spiritual needs (2 NHS, 3 PH). Three participants stated that spiritual needs were wider than religious needs alone (1 NHS, 2 PH). Two hospice-based participants stated that coping with loss was an important spiritual need and two participants (1 NHS, 1 PH) stated that the therapeutic relationship between patient and nurse provided a context within which spiritual needs could be identified. All remaining themes were identified by a single participant.

5.2.4 Spiritual needs: initial assessment (themes)

Nineteen themes were identified from interview transcripts concerning the initial assessment of spiritual needs. These are summarised in Fig 10.

Fig 10: Initial assessment of spiritual needs: themes



A further breakdown of themes in terms of prevalence is shown in Table 9.

Table 9: Initial assessment of Spiritual needs: themes

Theme	Responses	KCHFT	PH
IPOS inadequate as an assessment tool	8	-	8
Unfamiliar with assessment tools	8	5	3
Omit assessment for spiritual needs.	4	3	1
Requires therapeutic relationship	4	2	2
Assess for religious needs only	3	2	1
Establishing rapport is crucial to assessment	3	2	1
Intuitive judgement (practitioner)	2	1	1
IPOS useful for initial assessment	2	-	2
Part of holistic assessment	2	1	1
Term causes confusion to patients	2	2	-
Use of non-verbal communication/cues	2	1	1
Visual clues or artifacts evident	2	2	-
Collaborative assessment	1	-	1
Patient must be able to communicate	1	1	-
Varies with staff member assessing	1	1	-
Difficult to describe	1	1	-

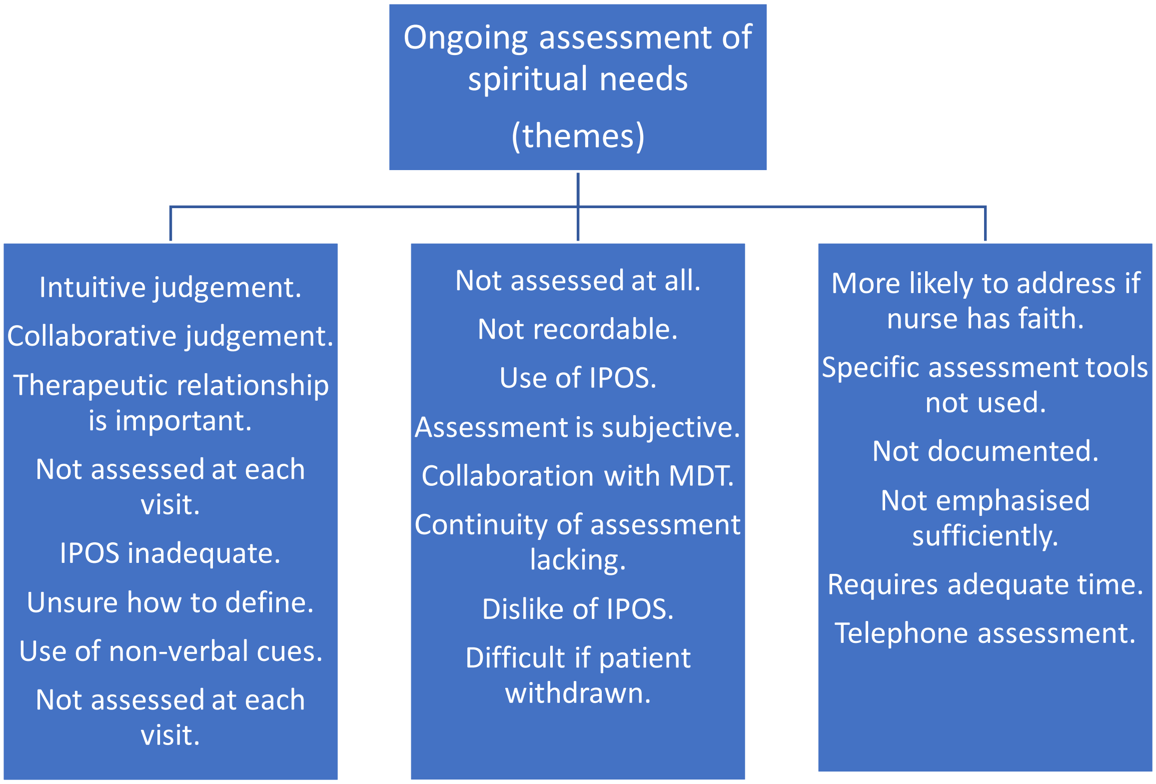
Patient may already have spiritual support	1	-	1
Reluctant to ask patient	1	1	-
Use of open questions	1	-	1

It is evident from interview data that participants struggled to articulate a definition for the term spiritual needs. Likewise, describing how an initial assessment of spiritual needs was undertaken also proved problematic for participants. Individual responses also reflected a lack of uniformity within practice. The two most prominent responses related to the IPOS assessment tool, and unfamiliarity with assessment tools for spiritual needs. Eight hospice-based participants stated that the IPOS was inadequate for the initial assessment of spiritual needs. Eight participants (5 NHS, 3 PH) stated they were unfamiliar with the use of assessment tools for spiritual needs and four participants (3 NHS, 1 PH) did not assess for spiritual needs at all. Four participants highlighted establishing a therapeutic relationship with a patient as integral to assessment and three participants (2 NHS, 1 PH) assessed for religious needs alone. All themes are summarised in Table 9.

5.2.5 Spiritual needs: ongoing assessment (themes)

Initial data analysis concerning the ongoing assessment of spiritual needs identified twenty-two themes. These are summarised in Fig 11.

Fig 11: Ongoing assessment of spiritual needs: themes



A further breakdown of themes in terms of prevalence is shown in Table 10.

Table 10: Ongoing assessment of Spiritual needs: themes

Theme	Responses	KCHFT	PH
Intuitive judgement	12	5	7
Collaborative judgement	4	2	2
Therapeutic relationship is important	4	1	3
Not assessed at each visit	3	3	-
IPOS inadequate	3	-	3
Unsure how to define	3	2	1
Use of non-verbal cues	3	2	1
Not assessed at all	2	2	-
Not recordable	2	2	-
Use of IPOS	2	-	2
Assessment is subjective	1	-	1
Collaboration with MDT	1	-	1
Continuity of assessment lacking	1	1	-
Dislike of IPOS	1	-	1
Difficult if patient withdrawn	1	-	1

More likely to address if nurse has faith	1	1	-
Specific assessment tools not used	1	1	-
Not documented	1	-	1
Not emphasised sufficiently	1	1	-
Requires adequate time	1	-	1
Telephone assessment	1	-	1

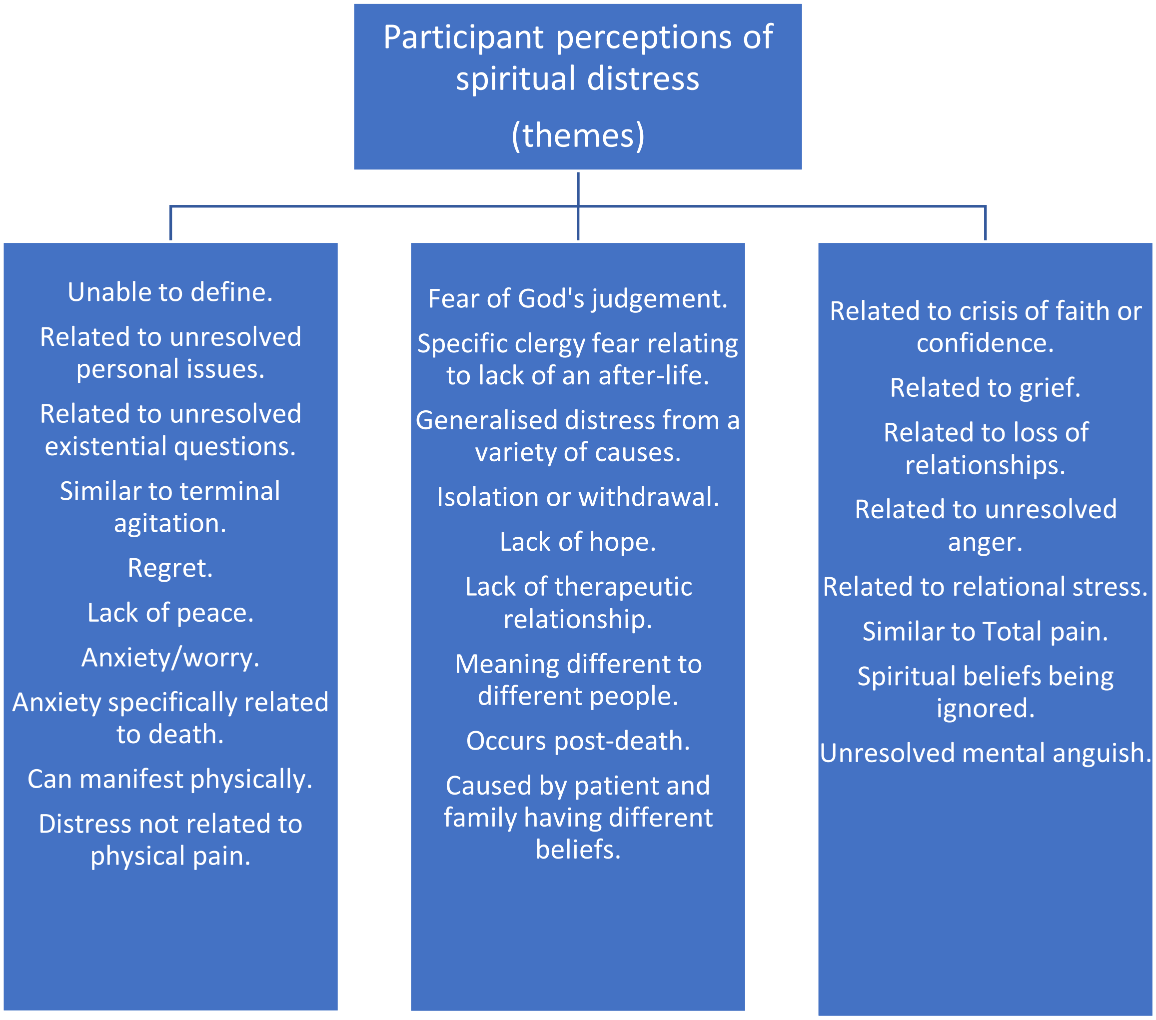
Evident was that the ongoing assessment of spiritual needs was problematic. Over half of participants (5 NHS, 7 PH) stated that ongoing assessment was an intuitive judgement alone, which did not involve the use of specific assessment tools. Four participants (2 NHS, 2 PH) described that collaborative assessment with colleagues aided assessment. Four participants (1 NHS, 3 PH) also highlighted the importance of a therapeutic relationship to the ongoing assessment of spiritual needs. Three hospice-based participants described the IPOS assessment tool as inadequate; three NHS participants did not assess spiritual needs at each visit and three participants (2 NHS, 1 PH) relied on the use of non-verbal cues alone. Three participants (2 NHS, 1 PH) were unsure if the on-going assessment of spiritual needs was possible. All themes are summarised in Table 10.

5.3 Codes pertaining to research question 2

5.3.1 Spiritual distress: participant perceptions (themes)

During interviews practitioners struggled to define spiritual distress. No participants were able to provide a succinct definition of spiritual distress, and all participants perceived spiritual distress negatively. Ten participants specifically stated they could not provide any kind of definition for spiritual distress and/or suggested it was impossible to define. Twenty-seven themes were evident in participant responses. These are summarised in Fig 12.

Fig 12: Participant perceptions of spiritual distress



Participant perceptions of spiritual distress

(themes)

- Unable to define.
- Related to unresolved personal issues.
- Related to unresolved existential questions.
- Similar to terminal agitation.
- Regret.
- Lack of peace.
- Anxiety/worry.
- Anxiety specifically related to death.
- Can manifest physically.
- Distress not related to physical pain.

- Fear of God's judgement.
- Specific clergy fear relating to lack of an after-life.
- Generalised distress from a variety of causes.
- Isolation or withdrawal.
- Lack of hope.
- Lack of therapeutic relationship.
- Meaning different to different people.
- Occurs post-death.
- Caused by patient and family having different beliefs.

- Related to crisis of faith or confidence.
- Related to grief.
- Related to loss of relationships.
- Related to unresolved anger.
- Related to relational stress.
- Similar to Total pain.
- Spiritual beliefs being ignored.
- Unresolved mental anguish.

A further breakdown of themes in terms of prevalence is shown in Table 11.

Table 11: Participant perceptions of spiritual distress: themes

Theme	Responses	KCHFT	PH
Unable to define	10	3	7
Related to unresolved issues	2	-	2
Related to unresolved existential questions	3	2	1
Similar to Terminal agitation	2	1	1
Regret	3	2	1
Lack of peace/not at ease	2	2	-
Anxiety/worry	2	1	1
Anxiety specifically related to death	1	-	1
Can manifest physically	1	-	1
Distress not related to physical pain	1	-	1
Fear of God's judgement	1	-	1
Specific clergy fear relating to lack of an afterlife	1	-	1
Generalised distress from a variety of causes	1	-	1
Isolation or withdrawal	1	1	-
Lack of hope	1	1	-
Lack of therapeutic relationship	1	1	-
Meaning different to different people	1	-	1

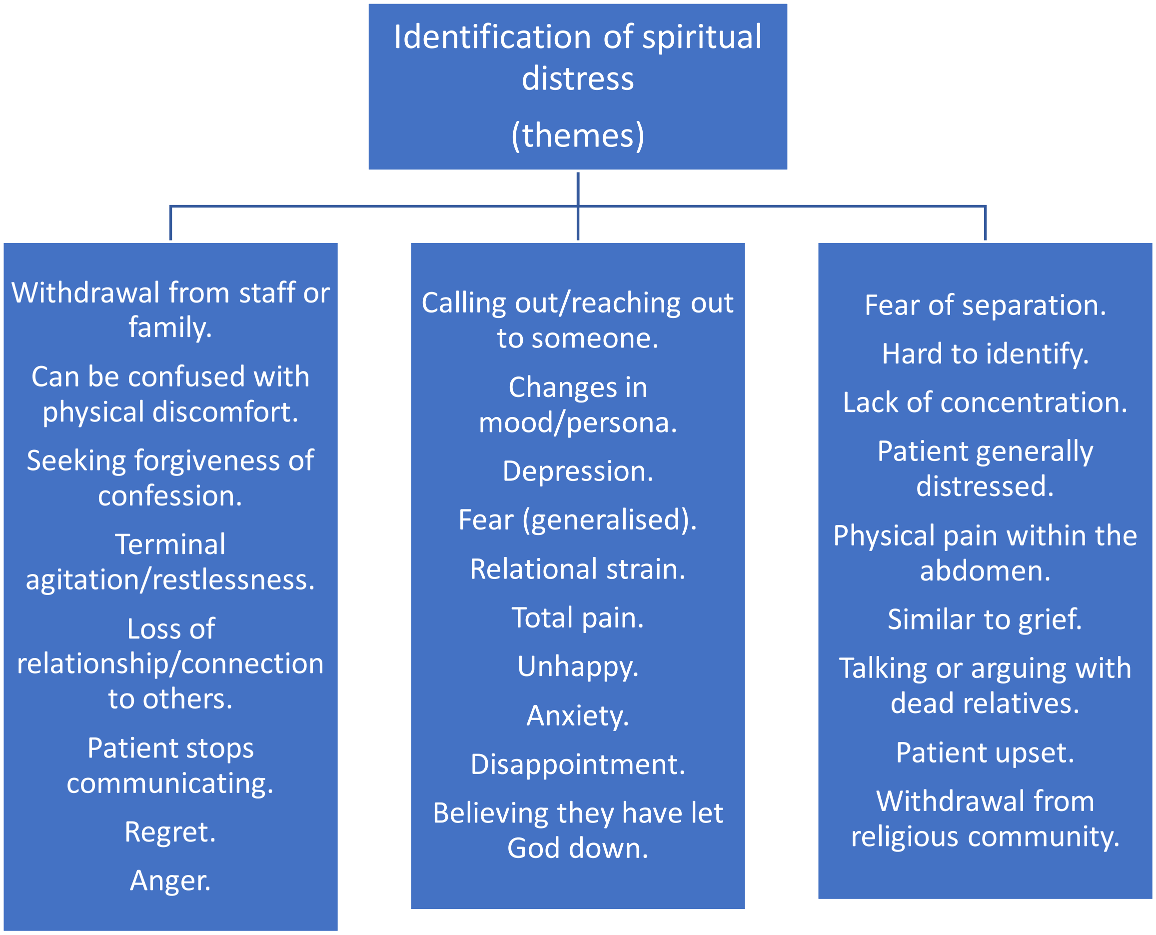
Occurs post-death	1	1	-
Patient and family having different beliefs	1	1	-
Related to crisis of faith or confidence	1	-	1
Related to grief	1	1	-
Related to loss of relationships	1	-	1
Related to unresolved anger	1	1	-
Relational stress	1	-	1
Similar to Total pain	1	-	1
Spiritual beliefs being ignored	1	1	-
Unresolved mental anguish	1	1	-

5.4 Codes pertaining to research question 3 (identification and assessment of spiritual distress).

5.4.1 Spiritual distress: identification (themes)

During interviews participants described multiple manifestations that would lead them to suspect an individual patient was suffering spiritual distress. Key themes regarding identification of spiritual distress are summarised in Fig 13.

Fig 13: Identification of spiritual distress: themes



A further breakdown of themes in terms of prevalence is shown in Table 12.

Table 12: Identification of spiritual distress: themes

Theme	Responses	KCHFT	PH
Withdrawal from staff or family	8	2	6
Can be confused with physical discomfort	4	4	-
Seeking forgiveness or confession	4	2	2
Terminal agitation/restlessness	4	2	2
Loss of relationship/connection to others	3	1	2
Patient stops communicating	3	3	-
Regret	3	-	3
Anger	2	-	2
Calling out/reaching out to someone	2	1	1
Changes in mood or persona	2	-	2
Depression	2	1	1
Fear (generalised)	2	-	2
Relational strain	2	-	2
Total pain	2	-	2
Unhappy	2	-	2
Anxiety	1	1	-
Disappointment	1	-	12
Believing they have let God down	1	-	1

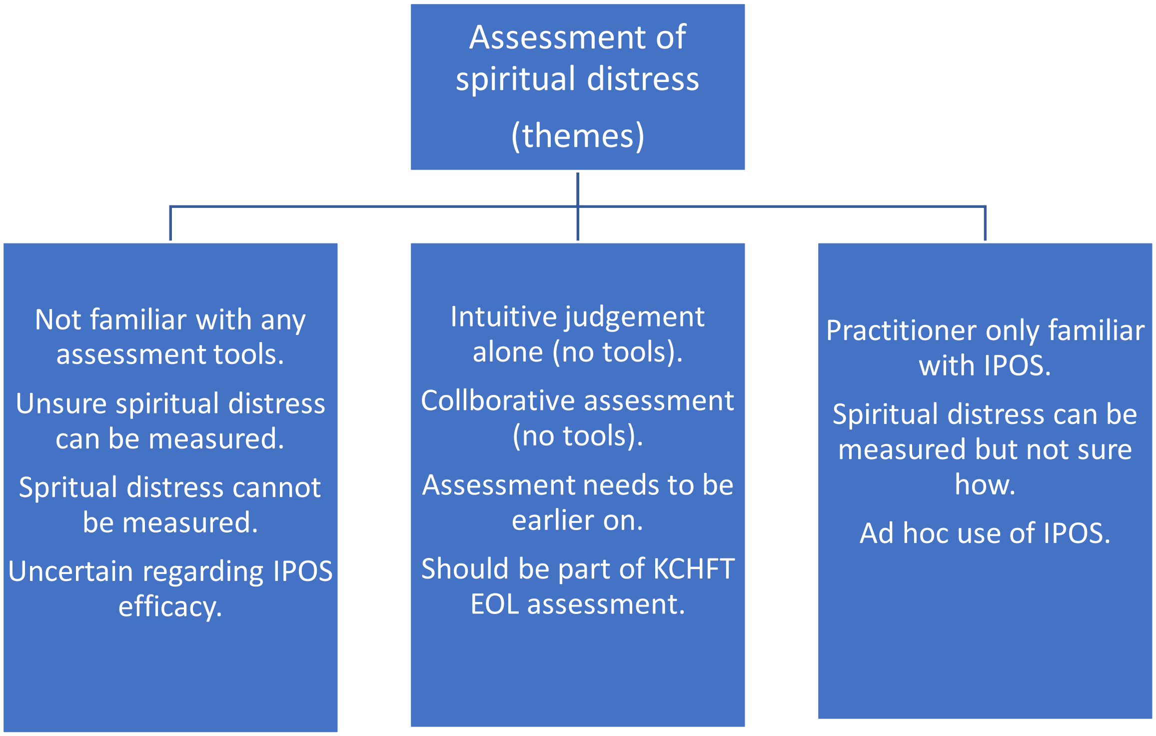
Fear of separation	1	-	1
Hard to identify	1	1	-
Lack of concentration	1	-	1
Patient generally distressed	1	1	-
Physical pain within the abdomen	1	1	-
Similar to grief	1	1	-
Talking or arguing with dead relatives	1	1	-
Patient upset	1	1	-
Withdrawal from religious community	1	-	1

The most prominent manifestations all related to communication. Most common was patient withdrawal, as identified by eight participants (2 NHS, 6PH). Four participants (all NHS) expressed the view that spiritual distress could easily be confused with distress resulting from physical causes, such as urinary retention or pain. Four participants identified patients seeking forgiveness or confession (2 NHS, 2 PH) and four (2 NHS, 2 PH) suggested terminal agitation or restlessness. Three participants identified loss of relationship or connection (1 NHS, 2 PH), patients who stopped communicating (3 NHS) and patient regret (3 PH). A range of emotional manifestations were also identified by participants, for example anger (2 PH), depression (1 NHS, 1 PH), fear (2 PH), unhappiness (2 PH), anxiety (1 NHS) and general distress (1 NHS). One NHS participant likened spiritual distress to grief, suggesting this could similarly manifest in a variety of ways and one hospice-participant identified withdrawal from a religious community. All themes are summarised in Table 12.

5.4.2 Spiritual distress: assessment (themes)

A range of descriptors were used by participants when attempting to describe spiritual distress (5.3). Also evident during interviews was that many participants struggled to articulate either a description or definition of spiritual distress. This struggle was similarly evident when participants were asked about assessment of spiritual distress and specifically if they utilised specified assessment tools to either aid identification or quantify the degree of distress present. Eleven themes were identified, as shown in Fig 14.

Fig 14: Assessment of spiritual distress: themes



A further breakdown of themes in terms of prevalence is shown in Table 13.

Table 13: Assessment of spiritual distress: themes

Themes	Responses	KCHFT	PH
Not familiar with any assessment tools	18	9	10
Unsure SD can be measured	11	5	6
SD cannot be measured	4	1	3
Uncertain regarding IPOS efficacy	2	-	2
Intuitive judgement alone (no tools)	2	-	2
Collaborative assessment (no tools)	2	1	1
Assessment needs to be early on	2	1	1
Should be part of KCHFT EOL assessment	1	1	-
Practitioner only familiar with IPOS	1	-	1
SD can be measured: but not sure how	1	1	-
Ad hoc use of IPOS	1	-	1

SD: Spiritual distress.

IPOS: Integrated Palliative Care Outcome questions. This is an assessment tool used in Pilgrim's hospices (see discussion section).

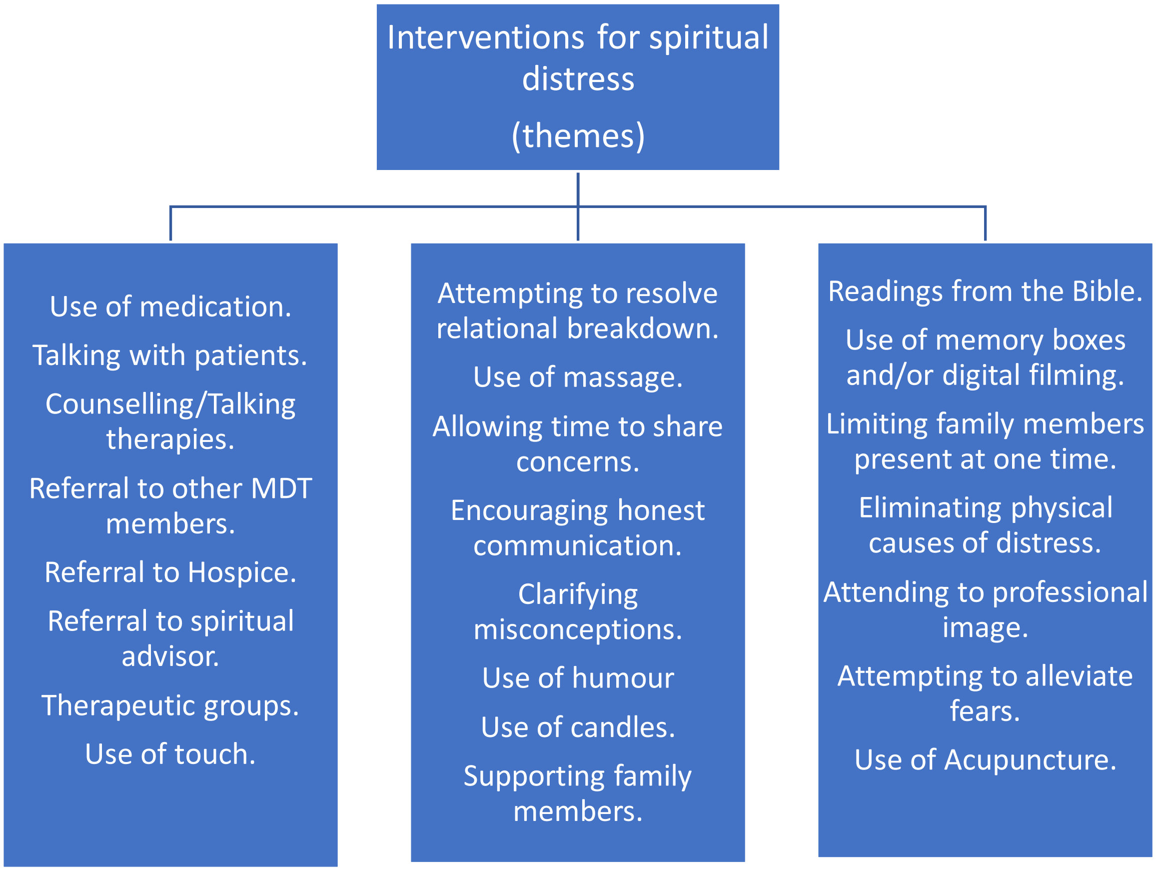
The two most significant participant responses were unfamiliarity with assessment tools and uncertainty as to whether spiritual distress can be measured or quantified. Eighteen participants (9 NHS, 10 PH) stated they were unaware of any specific assessment tools for spiritual distress. Eleven participants (5 NHS, 6 PH) expressed uncertainty as to whether spiritual distress could be assessed and four participants (1 NHS, 3 PH) stated that, in their view, it was impossible to objectively measure spiritual distress. Two hospice-based participants stated that their assessment of spiritual distress was purely intuitive and did not utilise tools. Two other participants (1 NHS, 1 PH) felt that assessment was undertaken in collaboration with others at patient handovers but did not utilise tools. Two hospice-based participants referred to the IPOS assessment tool. One stated that, in her experience, the IPOS was used somewhat ad hoc, and data from it was rarely reviewed. The other stated that the IPOS was the only tool they were familiar with, though they were uncertain as to its efficacy. Two other hospice participants also stated they were uncertain regarding the efficacy of the IPOS. All themes are summarised in Table 13.

5.5 Codes pertaining to research questions 4 and 5

5.5.1 Spiritual distress: interventions/management (themes)

Participants utilised a variety of interventions to help alleviate spiritual distress in EOL patients. Twenty-three separate interventions were identified by participants. These are summarised in Fig 15.

Fig 15: Interventions for spiritual distress: themes



A further breakdown of themes in terms of prevalence is shown in Table 14.

Table 14: Interventions for spiritual distress: themes

Themes	Responses	KCHFT	PH
Use of medication	17	7	10
Talking with patients	13	5	8
Counselling/Talking therapies	10	3	7
Referral to other MDT members	7	-	7
Referral to hospice	5	2	3
Referral to spiritual advisor	4	3	1
Therapeutic groups	3	-	3
Use of touch	2	-	2
Attempting to resolve relational breakdown	2	2	-
Use of massage	2	1	1
Allowing time to share concerns	2	2	-
Encouraging honest communication	2	1	1
Clarifying misconceptions	2	1	1
Use of humour	1	1	-
Use of candles	1	-	1
Supporting family members	1	1	-
Readings from the Bible	1	1	-
Use of memory boxes and/or digital filming	1	-	1

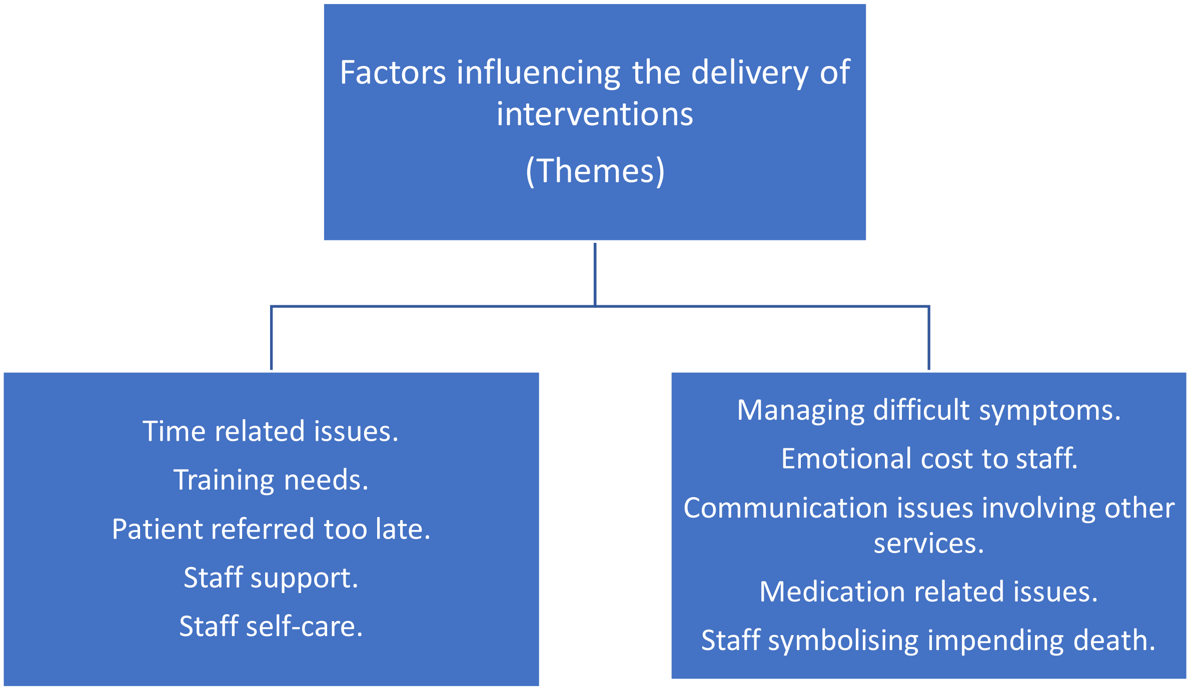
Limiting family members present at one time	1	1	-
Eliminating physical causes of distress	1	1	-
Attending to professional image	1	1	1
Attempting to alleviate fears	1	1	-
Use of Acupuncture	1	-	1

The use of medication was the most common intervention, mentioned by seventeen participants (7 NHS, 10 PH). Views on both the appropriateness of medication usage and the type of medication that should be administered differed amongst participants, as did opinions regarding the appropriateness of syringe driver usage. Thirteen participants (5 NHS, 8 PH) highlighted talking within the context of the nurse-patient therapeutic relationship as key to alleviating spiritual distress. Counselling or specific talking therapies were mentioned by ten participants (3 NHS, 7 PH) and seven participants (all hospice nurses) described referral to the multi-disciplinary team (MDT) as important, for example, to occupational therapy, social worker or spiritual lead (Pilgrim's hospices no longer use the term 'Chaplain', having replaced this with 'spiritual lead'). Five participants described referral to the hospice as a specific intervention (2 NHS, 3 PH). The use of complementary therapies was identified by five participants (1 NHS, 4 PH) and four participants (3 NHS, 1 PH) highlighted referral to a specific spiritual advisor. All themes are summarised in Table 14.

5.5.2 Factors influencing the delivery of interventions

Participants identified numerous factors that influenced the delivery of specific interventions for spiritual distress. Ten themes were evident from interview data. These are summarised in Fig 16.

Fig 16: Factors influencing the delivery of interventions: themes



A further breakdown of themes in terms of prevalence is shown in Table 15.

Table 15: Factors influencing delivery of interventions

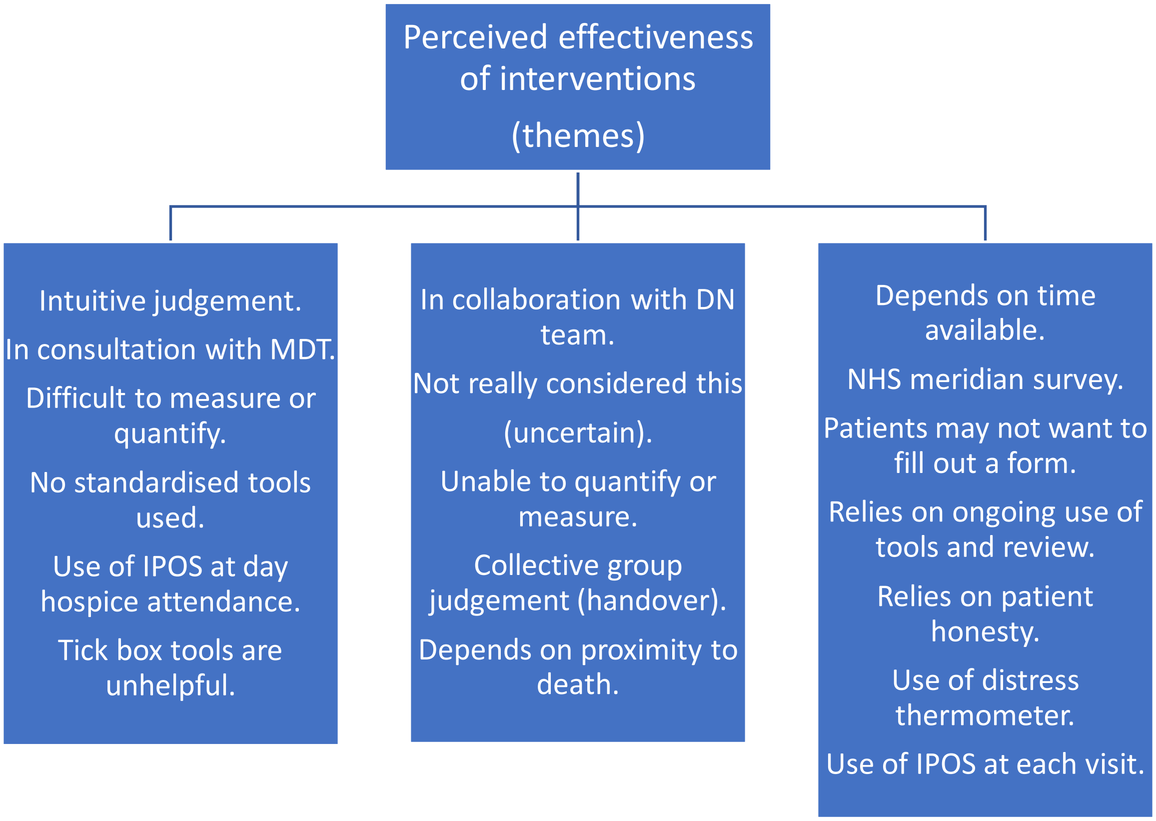
Theme	Responses	NHS	PH
Time related issues	17	7	10
Training needs	10	5	5
Patient referred too late (very close to death)	9	7	2
Staff support	7	1	6
Staff self-care	6	1	5
Managing difficult symptoms	6	1	5
Emotional cost to staff	5	4	1
Communication issues involving other services	5	5	-
Medication related issues	5	4	1
Staff symbolising impending death	4	1	3

Time related issues and training needs were the most prominent themes, followed by the lateness of patient referral. For NHS participants, this frequently resulted in patients who were either semi-conscious or indeed unconscious, making assessment of possible distress virtually impossible and negating the possibility or need for interventions.

5.5.3 Spiritual distress: perceived effectiveness of interventions (themes)

Attempts to measure effectiveness of interventions utilised to help alleviate spiritual distress varied. Eighteen themes were identified from interview transcripts. These are summarised in Fig 17.

Fig 17: Perceived effectiveness of interventions: themes



A further breakdown of themes in terms of prevalence is shown in Table 16.

Table 16: Perceived effectiveness of interventions: themes

Theme	Responses	KCHFT	PH
Intuitive judgement	9	2	7
In consultation with MDT	7	-	7
Difficult to measure or quantify	3	-	3
No standardised tools utilised	3	2	1
Use of IPOS at day hospice attendance	3	-	3
Tick box tools unhelpful	2	1	1
In collaboration with DN team	2	2	-
Not really considered this (uncertain)	2	2	-
Unable to quantify or measure	2	1	1
Collective group judgement (handover)	1	1	-
Depends on proximity to death	1	1	-
Depends on time available	1	1	-
NHS Meridian survey	1	1	-
Patients may not want to fill out a form	1	1	-
Relies on ongoing use of tools and review	1	-	1
Relies on patient honesty	1	-	1

Use of distress thermometer	1	-	1
Use of IPOS at each visit	1	-	1

The most prominent response from practitioners was that of intuitive judgement, as mentioned by nine participants (2 NHS, 7 PH). This did not involve the use of any specific tools, or any other means to objectify the process of assessment. All themes are summarised in Table 16.

5.6 Additional codes

Analysis of interview data identified a number of additional codes relevant to the overall study. These are categorised below as follows:

- Practitioner related codes (5.6.1-12).
- Care related codes (5.6.13-18).
- Patient related codes (5.6.19-20).

5.6.1 Therapeutic relationships

The nurse-patient therapeutic relationship was mentioned by two thirds of participants. Fifteen themes were evident, as summarised in Table 17.

Table 17: Therapeutic relationships: themes

Theme	Respondents	KCHFT	PH
Requires time to establish	6	2	4
Facilitates identification of patient needs	5	1	4
Facilitates effective communication with patient	4	1	3
Trust is an integral component	2	-	2
Enhances quality of patient assessment	2	1	1

Provides opportunity to get to know patient	2	2	-
Allows significant issues to be addressed	1	1	-
Enhanced by continuity of care	1	1	-
Facilitates effective communication with family	1	1	-
Facilitates effective family support	1	1	-
Facilitates identification of spiritual distress	1	-	1
Need not require spoken words	1	-	1
Requires more than a single visit	1	1	-
Right practitioner important	1	-	1
Involves walking alongside	1	-	1

The most prominent sub-theme was that therapeutic relationships require time to become established, as mentioned by six participants (2 NHS, 4 PH). Five participants (1 NHS, 4 PH) stated that therapeutic relationships facilitated the ongoing identification of patient needs and four participants (1 NHS, 3 PH) highlighted the need for effective nurse-patient communication in establishing such relationships. Two hospice-based participants stated that trust was integral to any therapeutic relationship, two participants (1 NHS, 1 PH) stated that therapeutic relationships enhanced the quality of patient assessment and two NHS participants stated that therapeutic relationships provided the opportunity to get to know patients well. All remaining themes related to a single participant.

5.6.2 Difficult conversations

Difficult conversations with patients and/or family members were mentioned by over half of participants. Seventeen themes were identified, as shown in Table 18.

Table 18: Difficult conversations: themes

Theme	Respondents	KCHFT	PH
Patient avoiding conversations regarding prognosis	5	4	1
Prognosis related conversations	4	2	2
Conversations relating to DNAR	3	1	2
Relatives avoiding conversations regarding prognosis	3	2	1
Communication that is supportive and helps relieve distress	1	1	-
Communication compromised as patient very ill	1	1	-
Dealing with difficult questions	1	1	-
Challenging denial	1	1	-
Deliberately changing subject	1	1	-
Having to tell patient or family that he/she is dying	1	1	-
Hospice image only associated with death	1	-	1
Maintaining professionalism	1	-	1
Personal experience of bereavement helpful		-	1

Phone conversations particularly difficult	1	-	1
Fearful of talking to patient about death	1	1	-
Telling the truth	1	1	-
Professional language aids avoidance of difficult conversations	1	1	-

The most prominent theme identified from interview transcripts was that of situations where patients deliberately choose to avoid conversations regarding their prognosis. This was identified by five participants (4 NHS, 1 PH). Conversations relating to patient prognosis were also difficult, as identified by four participants (2 NHS, 2 PH). Three participants identified conversations relating to do not attempt resuscitation (DNAR) advanced care planning (1 NHS, 2 PH) and three participants (2 NHS, 1 PH) identified the sub-theme of relatives avoiding conversations regarding the prognosis of the patient. All remaining themes were identified by a single participant.

5.6.3 Training needs

Training needs were identified by ten participants. Nine themes were evident within interview transcripts, as shown in Table 19.

Table 19: Training needs: themes

Theme	Participants	KCHFT	PH
Staff development issue	10	5	5
Time pressures can undermine staff development	3	2	1
Limited understanding of spiritual distress amongst practitioners	2	2	-

Nurse training issue	2	2	-
Lack of definition of spirituality affects nursing practice	1	1	-
Lack of knowledge regarding spirituality Amongst practitioners	1	1	-
More understanding will aid patient assessment.	1	1	-
Spirituality ignored in EOL training.	1	1	-
Use of spiritual lead (hospice)	1	-	1

The need for ongoing staff development was the most prevalent theme, as identified by ten participants (5 NHS, 5 PH). Three participants (2 NHS, 1 PH) stated that workload or time pressures can undermine staff development and two NHS participants stated there was a need for more comprehensive student nurse training regarding spirituality and EOL care. Two NHS participants also stated there was a lack of understanding amongst practitioners regarding spiritual distress. All remaining themes were identified by a single participant.

5.6.4 Time related issues

Time was an interesting issue, which participants viewed both positively and negatively. Analysis of interview transcripts revealed twenty-one themes relating to time. These are shown in Table 20.

Table 20: Time related issues: themes

Theme	Responses	KCHFT	PH
Insufficient time to manage caseload	9	7	2
Sufficient time to manage caseload	8	-	8
Workload or caseload unrealistic	6	4	2

Criticised for finishing late	2	2	-
Frustration	2	2	-
More time would allow engagement with spiritual distress	2	2	-
Workload increases time consciousness	2	2	-
Changed job due to time pressures	1	1	-
Community nurses lack sufficient time	1	-	1
Limited time with patients, due to workload	1	-	1
Feel like you are failing patients	1	1	-
Having more time is an unrealistic goal	1	1	-
Lack of thanks	1	1	-
Work additional hours without recognition	1	-	1
Insufficient time to assimilate information	1	1	-
Providing care out of my own time	1	1	-
Needing time to de-stress	1	1	-
Relegates spirituality as a priority	1	-	1
Undermines holistic assessment	1	-	1
Work-life balance disrupted	1	-	1
Workload prevents seeing ill patients quickly	1	-	1

Would love to spend more time with EOL patients	1	1	-

The most prominent sub-theme was having insufficient time. Nine participants (7 NHS, 2PH) stated they repeatedly felt there was insufficient time to fulfil their caseload. In contrast, eight hospice-based participants described having enough time to fulfil their role. This was the second most prominent theme. No NHS participants shared this view. In contrast, six participants (4 NHS, 2 PH) described their workload or caseload as unrealistic. Four sub-themes were described by two NHS participants. These were: being criticised for finishing late; experiencing frustration due to a lack of available time; having more time would allow greater engagement with spiritual distress; and workload pressures increase time consciousness. All remaining themes were identified by a single participant.

5.6.5 Staff support

Staff support was identified by ten participants. Eleven themes were evident within interview transcripts. These are shown in Table 21.

Table 21: Staff support: themes

Theme	Participants	KCHFT	PH
Nursing colleagues as source of support and advice	6	1	5
Hospice staff support structures good	3	-	3
MDT as source of support and advice	2	-	2
Being kind to colleagues	1	-	1
Professional relationships can affect patient care	1	-	1
No chaplaincy support for staff	1	1	-

Compassionate care for staff lacking	1	1	-
No opportunity to share concerns	1	1	-
Not enough staff to facilitate support	1	1	-
Support inadequate	1	1	-
Organisation perceived as unkind	1	1	-

The most prominent sub-theme related to colleagues providing a resource for advice and support (1 NHS, 5 PH). Three hospice participants identified hospice support structures as good, and two hospice participants identified the MDT as an effective resource for support. All remaining themes were identified by a single participant.

5.6.6 Communication

Communication (both with patients and other practitioners/MDT members) was identified by six participants. Eleven themes were evident within interview transcripts. These are shown in Table 22.

Table 22: Communication: themes

Theme	Participants	KCHFT	PH
Inadequate patient handover from other services	3	3	-
Multiple services hinders communication	2	2	-
Acting as a go-between	1	1	-
Dependant on GP practice	1	1	-
Excellent communication from other services	1	1	-

Loss of MDT hinders communication	1	1	-
Loss of rapport with GPs	1	1	-
Need for frank conversation	1	1	-
Need for sensitivity in communication	1	1	-
Building trust hindered by late referral	1	1	-
Practitioner confident regarding communication skills	1	1	-

Of note is that none of the participant responses relating to communication came from hospice-based participants. The most prominent themes related to the inadequate handover of patient information from other services, such as GP’s and hospitals, and the view that involvement of multiple services hinders effective communication. All remaining themes were identified by a single participant.

5.6.7 Emotional cost of caring

The emotional cost of caring was identified by five participants. Seven themes were evident within interview transcripts. These are shown in Table 23.

Table 23: The emotional cost of caring: themes

Theme	Participants	KCHFT	PH
Caring can trigger personal issues relating to practitioner	2	1	1
Building rapport with patients	1	1	-
Developing coping resources over time	1	-	1

Maintaining professional persona	1	1	-
Difficult conversations	1	-	1
Practitioner vulnerability	1	1	-
Seeing patients or family members upset	1	1	-

The most prominent theme was that of patient care triggering personal issues related to the individual practitioner. This was identified by two participants (1 NHS, 1 PH). All remaining themes were identified by a single participant.

5.6.8 Practitioner anxiety

Practitioner anxiety was identified by two participants (1 NHS, 1 PH). Five themes were evident within interview transcripts. These are shown in Table 24.

Table 24: Practitioner anxiety: themes

Theme	Participants	KCHFT	PH
Advice being ignored	1	-	1
Fear of helplessness	1	-	1
May affect younger nurses more	1	1	-
Advisory role rather than ‘hands on’	1	-	1
Patient/family anxiety creating practitioner anxiety	1	-	1

All themes were identified by a single participant.

5.6.9 Practitioner death anxiety

Practitioner death anxiety was mentioned by two hospice-based participants. Five themes were evident within interview transcripts. These are shown in Table 25.

Table 25: Practitioner death anxiety: themes

Theme	Participants	KCHFT	PH
Death seen as failure	1	-	1
Self-protection (practitioner)	1	-	1
Avoiding patient fears about dying	1	-	1
Hard to talk about with patients that have young families	1	-	1
Patient's fear harder to deal with than physical symptoms	1	-	1

All themes were identified by a single participant.

5.6.10 Loss and grief

Loss and/or grief was identified by two hospice participants. Four themes were evident within interview transcripts. These are shown in Table 26.

Table 26: Loss and grief: themes

Theme	Participants	KCHFT	PH
Bereavement can be a lengthy process	1	-	1
Moving on and denial	1	-	1
Sense of loss	1	-	1
A good death	1	-	1

All themes were identified by a single participant.

5.6.11 Practitioner initially fearful of EOL care

Being initially fearful of EOL care was mentioned by two NHS participants. Four themes were evident within interview transcripts. These are shown in Table 27.

Table 27: Practitioner initially fearful of EOL care: themes

Theme	Participants	KCHFT	PH
Emotional environment requiring sensitivity	1	1	-
Families require experienced nurses	1	1	-
Fear linked to initial lack of knowledge	1	1	-
Support/experience important	1	1	-

All themes were identified by a single participant.

5.6.12 Practitioner reluctant to share faith with patients

A reluctance to share personal faith with patients was described by two NHS participants. Two themes were evident within interview transcripts. These are shown in Table 28.

Table 28: Practitioner reluctant to share personal faith: themes

Theme	Participants	KCHFT	PH
Frightened to share personal faith	1	1	-
Lack of freedom to speak about faith within an NHS setting	1	1	-

Each theme was identified by a single participant.

5.6.13 Patient referred too late

Patients being referred too late (i.e. too close to death) was identified by nine participants. Twelve themes were evident within interview transcripts. These are shown in Table 29.

Table 29: Patients referred too late (too close to death): themes

Theme	Responses	KCHFT	PH
Therapeutic relationship prevented	5	4	1
Denies opportunity to get to know patient	3	3	-
Undermines establishing trust with family	3	3	-
Poor communication from GP or hospice	3	3	-
Prevents delivery of effective spiritual care	2	2	-
Can create problems with medication availability	1	1	-
Little meaningful patient interaction	1	1	-
Patient dies before relationship can be established	1	-	1
Patient too ill for meaningful conversation	1	1	-
Undermines effective patient assessment	1	1	-
Undermines holistic care	1	1	-
Undermines referral to spiritual advisor	1	1	-

Most themes were relational in nature. The most prominent theme, identified by five participants (4 NHS, 1 PH), was that late referral prevents the establishment of the nurse-patient therapeutic relationship. Three NHS participants stated that late referral meant that opportunity to get to know the patient was lost; establishing trust with the family was made more difficult and that late referral was a result of poor communication from either GP or hospice. Two NHS participants stated that late referral prevented the delivery of effective spiritual care. All remaining themes were identified by a single participant.

5.6.14 Managing difficult symptoms

Managing difficult symptoms in a community setting was identified by six participants. Six themes were evident within interview transcripts. These are shown in Table 30.

Table 30: Managing difficult symptoms: themes

Theme	Participants	KCHFT	PH
Unable to fully manage patient symptoms	2	-	2
Can be more challenging in younger patients	1	-	1
Important that patients are symptom free, if possible	1	-	1
Need to seek advice from colleagues	1	-	1
Stat injections and the use of syringe drivers	1	1	-
Working alone in the community is challenging	1	-	1

The most prominent theme was that of being unable to fully manage challenging symptoms, as identified by two hospice-based participants. All remaining themes were identified by a single participant.

5.6.15 Resource availability

Resource availability was identified by six participants. Six themes were evident within interview transcripts. These are shown in Table 31.

Table 31: Resource availability: themes

Theme	Participants	KCHFT	PH
Insufficient staff (GPs and nurses)	4	2	2
Community referral route for spiritual needs would be useful	1	1	-
Difficulties in accessing equipment	1	1	-
Syringe driver availability limited	1	1	-
Patient refusing equipment	1	1	-
Social services support variable	1	1	-

The most prominent theme was that of insufficient staffing, which was identified by four participants (2 NHS, 2 PH). All remaining themes were identified by a single participant.

5.6.16 Medication related issues

Issues related to medication were identified by five participants. Eight themes were evident within interview transcripts. These are shown in Table 32.

Table 32: Medication related issues: themes

Theme	Participants	KCHFT	PH
Problems with obtaining EOL medications	2	2	-
Patients having to wait for medications	2	2	-
Insufficient information regarding patient	1	1	-
Medication only suppresses distress	1	1	-

Medication viewed by family as euthanasia	1	1	-
Patient and family attitudes important	1	1	-
Relationship with NHS colleagues fragmented	1	-	1
Symptoms can be controlled without Syringe driver	1	1	-

The two most prominent themes were each identified by two NHS participants. These were problems with obtaining EOL medications and patients having to wait for medications. All remaining themes were identified by a single participant.

5.6.17 Challenges relating to patient age

Challenges relating to patient age were mentioned by three hospice-based participants. Five themes were evident within interview transcripts. These are shown in Table 33.

Table 33: Challenges relating to patient age: themes

Theme	Participants	KCHFT	PH
Can create a barrier between nurse and patient	1	-	1
Hard seeing young children visiting	1	-	1
Practitioner identifying with patient's situation	1	-	1
Seeing elderly parents at beside is hard	1	-	1
Younger patients appear more agitated	1	-	1

All themes were identified by a single participant.

5.6.18 Helping patients remain at home

Helping patients remain at home was identified by two hospice-based participants. Three themes were evident within interview transcripts. These are shown in Table 34.

Table 34: Helping patients remain at home: themes

Sub-Theme	Participants	KCHFT	PH
Can be challenging to meet their needs	1	-	1
Lack of social care leads to hospice admission	1	-	1
Requires supportive family situation	1	-	1

All themes were identified by a single participant.

5.6.19 Family related issues

Issues specifically related to families were identified by five participants. Eight themes were evident within interview transcripts. These are shown in Table 35.

Table 35: Family related issues: themes.

Theme	Participants	KCHFT	PH
Family members trying to dictate care of patient	2	2	-
Need for open communication	2	2	-
Pressure from families not to discuss prognosis with patient	1	1	-
Families trying to tell us our job	1	1	-
Contacting the DN team	1	1	-
Supporting family members	1	1	-

Syringe driver causing distress to families	1	1	-
Therapeutic relationship important	1	1	-

All themes within this category were identified by NHS participants. Most prominent themes were family members attempting to dictate care for patients and the need for open and honest communication. Each was identified by two participants. All remaining themes were identified by a single participant.

5.6.20 Staff symbolising impending death

Staff symbolising the impending death of the patient was identified by four participants. Three themes were evident within interview transcripts. These are shown in Table 36.

Table 36: Staff symbolising impending death: themes

Theme	Participants	KCHFT	PH
Hospice staff associated with death	3	-	3
Hospice staff only want to talk about dying	1	-	1
Hospice viewed as a death sentence	1	-	1

The most prominent theme was patients associating the physical presence of hospice nurses with impending death, rather than as a resource for support. This was identified by three hospice-based participants. Other themes were identified by a single hospice participant.

5.6.21 Themes identified by a single participant alone

Twenty-seven themes were identified by a single participant alone. These could be grouped into four broad areas:

- Patient related themes
- Family related themes
- Practitioner related themes
- Organisational themes

These themes are shown in Tables 37-40 below.

Table 37: Patient related themes identified by a single participant

Theme	KCHFT	PH
Continuity of care	-	1
Distraction strategies	1	-
Financial stress	1	-
Human spirit as energy	1	-
Restricting patient choice	-	1
Loss of hope	-	1
Religious needs	1	-
Spiritual pain	-	1

Table 38: Family/carer related themes identified by a single participant

Theme	KCHFT	PH
Carer distress		1
Lack of information	1	-
Unrealistic patient or family expectations	1	-

Table 39: Practitioner related themes identified by a single participant

Theme	KCHFT	PH
Access to CPD	-	1
Avoiding burnout	-	1
Ethical issues	1	-
Excessive paperwork	1	-
Focus on measurement rather than caring	-	1
Holistic care	-	1
Impaired thinking	-	1

Personal faith provides support	1	-
Phone conversations difficult	-	1
Practitioner feelings of helplessness	-	1
Staff self-care	-	1
Task oriented working undermined EOL care	-	1
Telephone assessment	-	1
Travel related issues	1	-
Criticism for finishing late	1	-

Table 40: Organisational themes identified by a single participant

Theme	KCHFT	PH
Loss of hospice chapel	-	1

5.7 Summary

Thematic analysis of interview data revealed a rich data set, which related directly to the research questions of the study. Participant responses also identified a number of associated themes integral to the care of EOL patients experiencing spiritual distress. The study's findings are discussed further in chapter 6.

6 Chapter 6: Discussion

This chapter attempts to relate the findings of the study to the research questions below and the literature review described in Chapter 3. The most prevalent themes identified in participant interviews reflect the sequential narrative contained within interview transcripts.

6.1 Research questions

The specific research questions for this study were:

1. How are the terms spirituality, spiritual care and spiritual needs perceived by community nurses within the different care settings?
2. How is spiritual distress perceived by community nurses within the different care settings?
3. How is spiritual distress identified by community nurses in the different care settings?
4. What specific interventions (forms of practice) are utilised by community nurses in the different care settings to help alleviate spiritual distress?
5. Is there any commonality of practice between the different care settings?

The use of specific research questions to define both the boundaries of the study and the research focus reflects my own post-positivist approach. This contrasts with more subjectivist or constructionist approaches, where research questions can appear more fluid and may further evolve as the study progresses.

6.2 Critical realism in qualitative data analysis

The use of critical realism in qualitative research is underpinned by a series of assumptions. These include:

- What is observed by participants (surface phenomena) in their practice is assumed to relate directly to specific generative mechanisms (which may not be directly obvious).
- Research methods employed, such as semi-structured interviews, are likely to access some but not all of participant knowledge regarding specific phenomena. However, the data obtained represents knowledge which is separate from the participant, and which is not socially constructed.

- Ontologically, reality is viewed as something that exists independently of those who observe it, but it is only accessible though the perceptions and interpretations of individuals. Interviews provide a method of accessing such knowledge.
- Deeper layers of ontology possess reality because their effects can be observed. Bhaskar (1997) refers to this observation as ‘emergence’: surface phenomena are influenced by and have their foundation in hidden sub structures but cannot be completely explained by them.
- Knowledge of these stratified layers of reality is always partial, incomplete and eminently revisable in the light of new research. The element of mystery also remains because generative mechanisms may never be fully explainable. Any research approach utilising critical realism therefore also requires humility on the part of the researcher.

Critical realist research also requires ‘an intensive study, with a limited number of cases, where the researcher systematically analyses the interplay between the ontological layers’ (Bygstad et al., 2016, p. 85). This approach reflects that causal mechanisms arise from structures and actors that are not directly observable (though the effects of such mechanisms are). Data collection and analysis therefore provided opportunity to make inferences relating to the identification of those mechanisms responsible for observed phenomena.

Critical realism also assumes that reality is ‘an open system’ and therefore beyond our ability to control directly (Stutchberry, 2021; Scott, 2005). Data analysis also utilised a stratified ontology, which assumed that participant observations and perceptions represented both empirical and actual realities, which in turn provided access to possible underlying causal mechanisms. Data analysis therefore assumed that reality can be approached in terms of the three conceptual layers integral to critical realist understanding: the empirical (observable and measurable); the actual (accessible here through semi-structured interviews); and the real (the underlying causal mechanisms which give rise to participant observations and perceptions (Stutchberry, 2012). Linkage (or relationship) between these conceptual layers was also assumed in the process of data analysis. In this way, analysis provides opportunity to make inferences, based on evidence, that identify the mechanisms (e.g. despair, regret etc.) which produce the observed events (e.g. withdrawal, lack of communication, anxiety, a desire to seek forgiveness etc.) seen in EOL patients experiencing spiritual distress.

Events are observed at the empirical level using two types of data: extensive (e.g., statistical data dealing with widespread trends) and intensive (e.g., in-depth interpretive data, obtained here through participant interviews). Data analysis began with the search for demi-regularities or 'semi-predictable patterns' present within the data at the empirical level (Fletcher, 2016). Predictability is always partial with social systems, as these constitute 'open systems' in which multiple occurrences and events overlap and interact (Danermark et al., 2002). Critical realism therefore looks for tendencies, rather than laws, evident in trends or patterns within the data corpus (Danermark, 2002, p.70). Demi-regularities are then identified using qualitative coding (Fletcher, 2016). Such organisational codes effectively function as 'topic based bins' into which information is then sorted (Maxwell, 2012; Fletcher, 2017). A flexible approach to coding was also employed, particularly initially, to try to avoid 'preconceptions of what to expect' which may then distort the process of interpreting 'what is "really" happening there' (Saldana, 2013, p. 146). Also, ontological assumptions integral to critical realism (i.e. there is a 'real' world that is theory -laden, rather than theory-determined) require that all explanations of reality arising from participants, theorists and scientists are treated as fallible (Bhaskar, 1979; Fletcher, 2016). Further, scientific explanations are not always deemed more accurate than experiential explanations; all are potentially fallible, and participants' experiences and explanations of phenomena such as spiritual distress may prove most accurate in explaining the reality (Fletcher, 2017). Critical realism therefore treats 'the ideas and meanings held by individuals – their concepts, beliefs, feelings, intentions and so on – as equally real to physical objects and processes' (Maxwell, 2012, p.v111). Critical realism also views the perceptions of participants as knowledge distinct and separate from the individual, which can be accessed using semi-structured interviewing and subsequent coding and thematic analysis.

6.3 Initial codes

Interview transcripts were coded as described in 4.17 and analysed using the programme NVivo, as described in 5.1. Participants were initially asked to define spirituality, spiritual care, spiritual needs, and how spiritual needs were assessed, both initially and as a continuing aspect of patient care. Uncertainty was evident in the responses of many participants regarding definitions; a tangible sense of struggle was often also present, associated with facial expressions of puzzlement, frustration, sighing and frequent pauses. Regarding spiritual distress, participants were asked about definition, identification, interventions they had used to alleviate spiritual distress and how the effectiveness of those interventions had been evaluated. This sequential interview structure was designed to first explore the wider backdrop to spiritual distress, focusing upon spirituality, spiritual needs, and spiritual care.

The issue of prevalence was also important. As described in 4.16, during data analysis prevalence was related to the number of times a theme was identified across all data, rather than within individual interviews alone.

Within this discussion chapter, I have also deliberately included a significant number of transcript excerpts, as it was important to me that participant voices were heard (Brewer, 2000; Lewis et al., 2014). In all transcript excerpts, the letters I and P represent interviewer and participant respectively. Also, transcript excerpts are italicised to aid differentiation from surrounding text and quotation marks have been omitted to aid clarity in layout.

6.4 Research question 1: the wider context

How are the terms spirituality, spiritual care and spiritual needs perceived by community nurses within the different care settings?

The study attempts to situate spiritual distress within a wider context of spirituality, spiritual care and spiritual needs. It was important to attempt to ascertain how these terms were understood by practitioners and what meanings were ascribed to them.

Numerous studies have demonstrated that nursing staff struggle to identify and define spirituality, spiritual care and spiritual needs (Narayanasamy and Owens, 2001; Daaleman et al., 2008; Gijsberts et al., 2011). I was interested to discover if such ambiguity was also reflected in the perceptions/experiences of participants. An awareness of spirituality, spiritual care and spiritual needs provides an important backdrop to spiritual distress and its alleviation. Interviews therefore sought to gain insight into the perceptions of participants regarding these concepts before then focusing specifically upon spiritual distress.

6.4.1 Spirituality: perceptions of participants

As described in the earlier literature review (3.3), practitioners frequently struggle to articulate a coherent description or definition of spirituality (Vachon et al., 2009; Cobb, 2012; Clarke, 2013). During interviews this struggle was similarly evident. The most prevalent themes identified from transcripts were:

- Spirituality is wider than religion alone (7) (5 PH: 2 NHS).
- Participant uncertain or unable to define (7) (4 PH: 3 NHS).
- Spirituality is unique to the individual (6) (4 PH: 2 NHS).
- Spirituality represents what is important to the person (5) (4 PH: 1 NHS).
- Spirituality is difficult to define (3) (2 PH: 1 NHS).

(PH: Pilgrim’s Hospice participant(s); NHS: National Health Service participant(s)).

These themes are examined below.

6.4.2 Spirituality is wider than religion alone

Seven participants expressed this view, which is also widely reported within relevant literature (e.g. Koenig, 2008; Beltzen, 2004). For example, one NHS participant (participant 17) stated:

Participant 17

P. [pauses]. I think; I don't think it is always to do, as I said earlier, with religion. I think spirituality is also, just about the, the wholeness of a person. I think somebody can be [pauses], you know, people, some people with mental health issues with depression; I think that is, that is, that is incorporated in spirituality, because if; physically, everything can be fine on the outside and they can actually, even health wise, be well, but, in terms of mental health, that can take away security of knowing some of the, some of the fundamentals like they're safe, that they’re looked after, that they have a purpose, that they have a hope [pauses], erm, and *a future and not just to [pauses], you know, to actually be in a place where you feel completely hopeless.*

This participant clearly views mental well-being an integral to spirituality, and specifically highlights components such as feeling safe, cared for, having a purpose in life and having a source of hope. In this sense, spirituality is viewed as significantly wider than religious expression alone.

Another NHS participant (Participant 20), when asked to define spirituality, stated:

<u>Participant 20</u>

P. Erm, it would be beliefs. Erm, experiences sometimes, you know, how they spiritually think; their upbringing; erm, and their social groupings and stuff [pauses].

I. So, social grouping would influence spirituality?

P. Erm, yeah. Sort of. With friends, and things. Because they tend to go with the same sort of people, with your beliefs and things. So, yeah.

I. So, you wouldn't have a pat definition, that you keep up your sleeve?

P. No.

I. For spirituality?

P. No. No [laughs]. I take things as they come.

I. O.k.

P. So, everybody's different. Everyone's beliefs are different.

I. Any other components of spirituality that you would see as important?

P. Erm, well, respect; really respecting what they believe, and things. And allowing; if they want to have prayer; if they want to; or if they don't want to have anything like that.

I. Right.

P. Yeah.

I. O.k. Anything else?

P. No. Sorry [laughs].

In this case, spirituality was viewed as a component influenced by the social context of the individual whilst also recognising that individuals differ and therefore their beliefs may differ. Much discourse regarding spirituality similarly emphasises individual rather than corporate spirituality (e.g. Clarke, 2013; Salander, 2012).

A hospice-based participant (Participant 7), whilst describing spirituality as wider than religion and nurturing mental well-being, linked spirituality to resilience; an inner source of strength that helps the individual psychologically cope with challenge. This is clearly important within the context of EOL care.

<u>Participant 7</u>

I. What's your understanding of spirituality?

P. For me, spirituality isn't necessarily about religion.

I. Right.

P. Erm [pauses]; you can have somebody who is spiritual but doesn't follow any religion.

I. Sure.

P. Erm, but on the flip side, they could be very religious and attend church two, three times a week, or whatever. I think it's whatever the patient [pauses]; how anything that they do to help them psychologically, to get through something. So, they could, erm, [pauses]; could be self-help books, it could be, could be religion, it could be a meditation for spirituality, you know; anything that helps them in their mind, I think; to me anyway.

I. So for you, if there was a whiteboard on the wall with spirituality underlined, and you were putting stuff on it, would it be something that the person does to nurture part of themselves?

P. Yes.

I. It would? As against the physical part of themselves?

P. Yes.

I. I'm just trying to tease out….

P. No; yeah. It would; Certainly, nurturing their mental side; the mental side of things.

I. So, for you as a practitioner, it's having an awareness of what, for that person, will nurture them in that component of their being, if you like?

P. Yes.

I. O.k. Great.

For this participant, spirituality facilitated resilience. According to the British Psychological Society, 'most definitions see resilience as reduced vulnerability to environmental risk, the overcoming of stress or adversity, or a relatively good outcome despite risk experiences' (British Psychological Society, 2020). Individuals may clearly respond very differently to adverse events or environments. It is also evident that the concept of resilience lacks a unifying definition:

> Resilience itself is not a unified concept, and a long history of controversy means that there is little consensus on its precise meaning. Exactly how resilience relates to adversity is conceptualised in a variety of ways, including helping people and communities adapt to adversity, interact with it, or transform aspects of it. A further complication is that the understanding of resilience and how it relates to adversity also depend upon the nature of adversity (whether defined explicitly or implicitly), which may or may not be related to social disadvantage (Hart et al., 2016, p.2).

6.4.3 Participant uncertain or unable to define spirituality

Seven participants expressed either uncertainty or an inability to define spirituality. This was frequently associated with a sense of frustration focused upon a failure to define something deemed important, but which remained elusive. For example, an experienced NHS community nurse (Participant 1) stated:

<u>Participant 1</u>

P. I guess what this has exposed for me is my lack of knowledge about it, I suppose. Erm [pauses]. I just go with my intuition and my [pauses], I believe I'm an empathetic person, erm [pauses] and I believe from my experience, I mean I'm fifty-six, and from all of these different experiences I've had, I've learnt a lot about things. But I'm still fumbling around with what a definition of something is. I still don't know, really. I still think it's an individual, eh [pauses]. It's very much an individual thing; what spirituality means to one person could be completely different to somebody else and we're all so unique in that, and we're all different places on *that erm [pauses]. I think it must be very hard to develop a tool that can measure that. Erm [pauses], but I just know, I know [emphasis] that it exists. How I know, however, I come to measure that in my little head, I don't know. I just arrive at something.*

I. Maybe it's an intuitive skill.

P. It is. It is for me, yeah. But I wouldn't know how to explain it or measure it.

Here, spirituality is viewed as something unique to the individual, but which the participant cannot explain or measure. This inability to articulate something perceived as important was an ongoing cause of frustration for both interviewer and interviewees.

Another NHS participant (Participant 16) saw spirituality as loosely associated with personal faith, whilst acknowledging that providing a definition of spirituality was hard. Spirituality here was also associated with the inner soul of the person, though again, this was left undefined. This participant highlights the holistic, embodied nature of spirituality, as a concept involving more than intellectual understanding and/or awareness alone (Robinson et al., 2003, p.23).

<u>Participant 16</u>

P. Yeah. I always find that to define spirituality erm [pauses]; I myself, and probably other people [pauses], don't think of it as just one specific thing.

I. Right.

P. But, we tend to sort of eh, join it up with, a faith.

I. Right.

P. Erm, but actually [pauses] it's, it's, it's hard to actually give a definition of spirituality, in a way [pauses]; erm, but I, I tend to sort of feel that it's about your inner soul.

I. Right.

This hospice-based participant (Participant 8) highlights not only that spirituality is complex, individual and not a 'black and white' concept, but also that spirituality may exist in the absence of perceived spiritual needs or personal faith:

<u>Participant 8</u>

P. [pauses]. I don't think you can define it.

I. Right.

P. As easily as that. Erm [pauses].

I. I think that's a very helpful comment, actually.

P. [laughs]. I'm trying to think of a black and white answer, but it's not black and white, unfortunately. Erm, [pauses], I'm not too sure what I'd say to try and define it. I don't know how I would, erm, put on a board, black and white, this is what it is.

I. Yeah.

P. [pauses]. Erm, [pauses], I don't know.

I. So you wouldn't have on your, eh, mental shelf, a stat little definition, that's very neat and tidy, of spirituality, that you pull off every time that you…

P. No [laughs]. Everybody is so individual.

I. Right.

P. I don't think that you can do that.

I. Right.

P. I think that's why it's so hard.

I. Yeah.

P. And, and some people go, it's all to do with faith; it's nothing to do with anything else. If you don't have faith, you don't have any spirituality needs.

I. Yeah.

P. But it's not; people are far, far more complicated than that.

I. O.k.

6.4.4 Spirituality is unique to the individual

Six participants (2 NHS, 4 PH) expressed the view that spirituality was unique to the individual and five participants (3 NHS, 2 PH) described spirituality as integral to the expressed persona. For example, one NHS participant (Participant 17) stated:

<u>Participant 17</u>

P. I think spirituality is part of; part of the being; it makes up, you know, obviously your mind, body, spirit; it's all incorporated, and it's almost all the bits about somebody that makes them that individual.

I. Yeah

A hospice participant (Participant 3) also viewed spirituality as contributing to the uniqueness of the individual but also situated the concept within the context of holism: viewing the person as a composite whole, rather than as individual components.

Participant 3

P. I think it's really what I was just saying. It's about who that person is, and what makes up that person; what makes them individual [pauses] erm; I think spirituality, maybe, is about how you see yourself; what's important to you [pauses] erm; I think in that comes people's, maybe, I said earlier; I don't know; sort of your individual moral, ethical code as well, that makes up that whole person. Holistic is another word that we use quite frequently; erm, it's about looking at that individual as a whole person and what makes them who they are.

One hospice participant (Participant 6) movingly illustrated how spirituality is unique to the individual whilst describing a patient who had previously been a nurse and for whom beekeeping was an important aspect of his individuality.

Participant 6

P. And then coming for services and feeling supported; getting support for his family; being able to pursue, erm, some of the things he hadn't been able to do. He had a particular interest in beekeeping, and he gave a really fantastic presentation to the rest of the day hospice on his life with beekeeping, and he said, 'I never thought I'd do that'. You know, this was at a time when he was in a wheelchair; he was on steroids, quite a poorly man, and to the end where he felt reconciled that this is where he wanted to die, and he did die upstairs and, erm [pauses], I felt that maybe we had supported what he had inside and had come to some sort of, in a difficult time, we'd helped him maybe sort, sort some of those issues out and maybe support, you know, especially things like doing the presentation, that he found very, very fulfilling, and he said that. Those were his words not mine, erm [pauses]; and I think, that's why we are very, very lucky, that we have a bit more time with people. We can unpick some of those things and try and support them.

I. So spirituality would be something unique to the person?

P. Yeah.

I. That's internal, but not physical?

P. Yeah.

This excerpt highlights the importance of something hard to define yet which is clearly identifiable as significant to the individual. This acknowledgement that spirituality is a unique component of the individual person is commonly expressed within relevant literature (McSherry, 2006).

6.4.5 Spirituality represents what is important to the person

Akin to spirituality being unique to the individual, five participants stated that spirituality was an expression of what was important to that person. The bee-keeping example above would seem a good example. One hospice-based participant (Participant 14) made reference to McCaffery's well-known definition of pain (McCaffery, 1968) (see 1.4), suggesting spirituality represented that which the patient deemed to be important.

<u>Participant 14</u>

P. It's a bit like pain. Whatever it means to the patient [laughs].

I. Right.

P.[laughs].

I. O.k.

P. Yeah. I would say things like; it could be religion; or [pauses] erm; as I've said, mindfulness [pauses]; family.

I. Right.

P. Erm [pauses]; things that are important to a person.

Many participants identified what for them were key components of spirituality; often these were descriptive, rather than definitional, and included 'connection'; 'like an anchor'; 'meaning in life' and 'related to the inner soul'. One NHS participant also stated that she deliberately avoided the section within nursing care plans which dealt with spirituality and spiritual needs because of the ambiguity associated with both terms.

Differences between spirituality and religion were identified by only three participants (2 NHS, 1 PH), highlighting the lack of differentiation between the two concepts. A summary of all participant themes relating to spirituality is shown in 5.2.1.

6.4.6 Spirituality: Summary

As illustrated in the earlier literature review (section 3:3), nurse practitioners consistently struggle with the concept of spirituality, finding ambiguity in both its meaning and how the concept can be incorporated into patient care. Such conceptual confusion was also reflected in participant responses for this study. Of concern is that spirituality is key to the wider context within which spiritual care and specifically spiritual distress are situated.

6.4.7 Spiritual care

Participants expressed diverse views when asked to identify what constituted spiritual care (see 5.2.2) and consistently struggled to provide a succinct definition for this form of care. Although not specifically asked during interviews, no participants identified the alleviation of spiritual distress as integral to spiritual care. The five most prevalent themes expressed by participants when attempting to define spiritual care were:

- Spiritual care is more than meeting religious needs alone (8) (6 PH: 2 NHS).
- Spiritual care is meeting religious needs (7) (3 PH: 4 NHS).
- Spiritual care is about nurturing individuality (6) (5 PH: 1 NHS).
- Spiritual care is helping allay patient fears or concerns (4) (4 PH).
- Spiritual care is difficult to define (4) (2 PH: 2 NHS).

These themes are considered below.

6.4.8 Spiritual care is more than meeting religious needs alone

Eight participants stated that spiritual care encompassed more than religious needs alone (Speck, 1998, p.23). For example, this hospice-based nurse (Participant 14) highlights issues pertaining to body image, as well as music. Spiritual care is therefore care which seeks to meet spiritual needs, such as nurturing individual identity and providing a source of hope and/or strength.

Participant 14

P. I did a course some years ago.

I. Right.

P. And, erm; a dementia course. And I did [pauses] erm; for my presentation, I did spiritual care in dementia.

I. Right.

P. And, I think it's; when I say to my patients, because we have to ask, erm; do you have any spiritual views, you usually get a blank look. So, I tend to say spiritual or religious views.

I. Right.

P. But, I think it's much wider than that.

I. Right.

P. Erm [pauses].

I. Wider than just religious views?

P. Yes, definitely.

I. O.k. Could you say a bit more about that?

P. Yeah [pauses]. Erm; I think if I was a patient, I'd want my legs [pauses] shaved. That would be important to me.

I. Right.

P. And I think that's spiritual. I've got a friend who wouldn't go anywhere without her lipstick, and wherever you; after an hour she'd get her lipstick out, and that would be really important to her. That her lipstick was erm [pauses] and so, I think it's what's important to people about themselves. It's not just somewhere out there or, you know, a religious or spiritual sort of view. It's what's important to that person.

I. So, it would be valuing the individuality..

P. Yeah.

I. Of that person?

P. Yeah.

I. Care that would do that?

P. Yeah. I think so.

I. O.k. [pauses]. Anything else come to your mind?

P. Things like music.

I. Right.

P. Erm [long pause]; and yeah; I suppose it's whatever is important to that person.

I. O.k.

This hospice-based nurse (Participant 2) likens spiritual care to holistic care, seeing the spirit as integral to the persona of the person, much like part of the individual's DNA.

Participant 2

P. And how, you know; some people mix up the spirit with religion.

I. Right.

P. I don't see it as a religious thing. It's a human thing, but not [pauses] religious. You know, religion's human: it's human made. I see spirit as integral, sort of like an inseparable part of our DNA if you like, of our evolution.

I. So spiritual care would very much be holistic care, that would value every part of the person.

P. Yeah.

This hospice-based nurse (Participant 3) again views spiritual care as wider than meeting just religious needs, recognising that patients can easily lose a previous identity from before their terminal diagnosis. In this sense, spiritual care seeks to nurture the identity of the individual, recognising what is important to them.

Participant 3

P. I think spiritual care is what makes that person who they are. It's not about belonging to a particular church group or having a particular religious belief. It's just about who that person is and the experiences that have gone through their life to make them the person they are when they are in front of you.

I. So the care would be trying to meet those…

P. Yeah. I think trying to support people in maintaining that balance, because I think sometimes for patients, when they are given a massive diagnosis; a life limiting diagnosis; when we get *towards end of life, it feels like; I don't know the proper terminology, but there's like a shift; that people maybe sometimes lose who they are, amongst the hospital appointments, and the people that are in and out of the houses, telling them what they should be doing for this symptom and that symptom. They become a patient.*

I. Right.

P. Rather than that person as to who they were: who they were; before all of that started.

I. So without trying to lead the witness, as it were…

P. [laughs].

I. Spiritual care would be about valuing the person for their individuality?

P. Yes [emphasis].

I. And acknowledging their individuality?

P. Yes. That's exactly what I was trying to say [laughs].

6.4.9 Spiritual care is meeting religious needs

In contrast, seven participants described spiritual care as essentially meeting religious needs alone. For example, this NHS participant (Participant 11) describes spiritual needs as being concerned primarily with prayer and arranging for a priest or other member of the patient's religious community to visit, clearly assuming patients with a religious faith are likely to already have connections to a church.

<u>Participant 11</u>

I. The term spiritual care appears in the nursing literature; I'm just wondering what your understanding is of this, and how that is different to say, physical care, or psychological care? Does that term have any meaning for you? Could you put some flesh on the bones?

P. Yeah, well I would probably say that psychological would be, maybe the things that I've just spoken about [pauses]. Probably all of them. I would say [pauses], physical care is our nursing medication; making sure they're not in pain; making sure that they're not; that they're vomiting or whatever is under control; their symptom control. And I would say, spiritual care [pauses] would be more, erm; if they have faith and they want to; have someone in to pray with them, or they want time on their own to pray or what. We've got people; they're not end of life, that we've got to know, and we know they go to church on a Sunday, or we know that they have *the priest visit them once a week or once a month. So, if and when they come on, we would know to contact their church and say this person; but generally, people that have got that, they've already got connections, haven't they? They already have visits, and they already have that involvement. That's what I see as, erm [pauses]*

I. Spiritual care?

P. I do.

This NHS participant (participant 19) also views spiritual care as principally concerning the meeting of religious needs, in this case, facilitated by the visit of a priest.

<u>Participant 19</u>

I. What do you feel spiritual care would be; what it would address, as against, say, physical care? Or psychological care?

P. I think it was psychological care; erm, I've had patients that have seen a priest before I've gone in to see them. That's how; what I understand [pauses] as spiritual care.

I. So, would there be a difference, say, between spiritual care and religious needs? Religious care?

P. Erm, don't think so.

I. O.k.

6.4.10 Nurturing individuality

Six participants described spiritual care as care which sought to nurture patient individuality. For example, this hospice participant (Participant 15) identifies how spiritual care seeks to acknowledge the life the patient has lived and their personal individuality.

<u>Participant 15</u>

P. Related to people. So, it's not just looking at their faith or their [pauses]; it's looking at their identity. Things that they've lost; things that they are not able to do anymore, that are really important to them. You know; loss of a job or they can't drive anymore; those sorts of things. I think it's looking at the whole, the whole picture, really, the whole person.

I. So, spiritual care is really about identity?

P. Erm.

I. Nurturing that individual identity of the person? Would that be right?

P. Yeah. Yes, that's what I think; briefly. I mean, it's probably lots of other things, but that's, that's what I feel.

I. O.k.

This hospice-based participant (Participant 7) also identifies several characteristics that contribute to patient individuality and describes how spiritual care seeks to understand these unique aspects of their lives, so that the patient can be effectively supported.

Participant 7

I. The term spiritual care appears quite a lot in the literature. Erm, what's your understanding of that?

P. My understanding is, erm, for somebody, for an individual [pauses], it's almost the meaning of life; the meaning of their life [pauses]; what does it feel like [pauses] to love and to be loved; and peace; how much peace they feel, erm, the support; whether they have faith or if they don't have faith, where their faith is tested by a diagnosis and a prognosis, or whether they've never had faith before, but then suddenly get faith after a diagnosis and prognosis.

I. So spiritual care would be an acknowledgement of those aspects of their lives?

P. Yeah.

I. And seeking to meet those needs, or?

P. Yeah. To discuss them and to understand them, and then see what we can do to help those needs. Is there anybody that we can be talking to? To refer them to. To look at support for that. We know that [pauses] total pain can be [pauses]; can include spiritual pain.

6.4.11 Helping allay patient fears or concerns

Four participants described helping to allay patient fears or concerns as a key to spiritual care. For example, this hospice-based participant (Participant 16) suggests that spiritual care within the hospice should be holistic and seek to address both physical and mental health needs, in this case, the patient's fears regarding the nature of their death. They also highlight the importance of the MDT, represented here as the spiritual care lead/chaplain.

Participant 16

I. Would you say the hospice delivers spiritual care?

P. [pauses]. I think we do, yeah, yeah.

I. Could you give me an example of that?

P. Well, I think, erm [pauses]; because we, we sort of [pauses] ask them about [pauses]; we're looking after, I know it seems a bit of a phrase, but it's total patient care.

I. Yeah.

P. So, we're looking at their physical as well as mental sort of health.

I. Yeah.

P. And for some of them, it is quite a traumatic time.

I. Sure.

P. And I think we do offer, you know, the counsellors and, and our spiritual lead, as well. But if, if they're struggling with [pauses] things like "I'm really frightened about how I'm going to die", erm, and then we, we will get our spiritual lead to come and talk them through things, so, but then, I think; I don't know whether in the hospitals and things there is erm, a chaplain around that would be able, that regularly supports people in hospital. I'm assuming there is, but erm [pauses]; but yeah.

Another hospice-based participant (Participant 4) described a conversation with a younger patient who was fearful of leaving his children, outlining how this was addressed within the wider remit of spiritual care provision.

<u>Participant 4</u>

I. So those attitudes or aspects of fulfilment. Can you just give me say, an example of that?

P. Erm [pauses] [sighs]. I tend to go back a lot to the time I worked in day Hospice, which was before I qualified, actually. We used to have really, really good conversations with people. It used to be quite a busy day Hospice and erm, I can just remember sitting outside with a gentleman that came here, and he sort of talked about, he just said 'I just need to talk to someone about not wanting to leave my children' and erm, [pauses] what did I think he should do and [pauses]; so, one side of that was just giving him an opportunity to talk in a quiet place, and then the other, erm, side of that conversation because, erm, I was wondering what I could *do to try and help, was to put into place thoughts along the lines of well, we could help you write a letter, we could help you do a memory box or some sort of, cos, I couldn't say that what you're talking about is not going to happen, because sometime in the near future you are [emphasis] going to leave your children, erm, so [pauses], [sighs].*

6.4.12 Spiritual care is difficult to define

Four participants stated that spiritual care was difficult to define. For example, one NHS participant (Participant 10) described their struggle with articulating a view of spiritual care.

<u>Participant 10</u>

I. The first of these is the term spiritual care. What's your understanding of spiritual care?

P. See, this is always a difficult one.

I. Difficult because?

P. O.k. So, to me I would say spiritual care [pauses] because you've got the beliefs, which is like their religion and making sure that we uphold their wishes. But to me, spiritually, it would be their belief [pauses]; like care after death; like where, it's sort of like some people say that the eyes of the soul; that sort of spiritually like [laughs]. It's really hard for me to get it out. But erm…

I. Take your time. There's no rush.

This hospice-based participant (Participant 16) expressed a similar difficulty:

<u>Participant 16</u>

I. What about the term spiritual care? Again, this increasingly appears in the nursing literature. What would you say if you had a whiteboard on the wall, and spiritual care was underlined? What would be on there?

P. I would say that would probably be from, erm, priests, because, and people like that. Because, I think generally, I think nurses find it a bit difficult [pauses] to, to talk about spiritual care, because they don't quite realise what it is [pauses]; and what it; do you know what I mean?

As stated in the earlier literature review, adequate spiritual care correlates with higher satisfaction of hospital care and treatment (Yardley et al., 2009; Williams et al., 2011).

However, health care professionals consistently struggle to define what constitutes spiritual care (Govier, 2000; Draper and McSherry, 2002; Strang et al., 2002; Barnett, 2013; Rushton, 2014). Spiritual care could be defined as:

> care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship and moves in whatever direction need requires (NHS Education for Scotland, 2009, p.446; RCN, 2011, p.3).

Essential components of spiritual care include:

- Recognising, respecting, and meeting patients' spiritual needs.
- Facilitating participation in religious rituals.
- Communicating through listening and talking with patients.
- Being with the patient by caring, supporting, and showing empathy.
- Promoting a sense of well-being by helping patients find meaning and purpose in their illness and overall life.
- Referral to other professionals, including the chaplain/pastor.

(Baldacchino, 2015, p.594).

Participants were unable to provide succinct definitions for spiritual care nor identify key components of this important aspect of holistic care described within relevant literature.

6.4.13 Spiritual care and therapeutic relationships

Over two thirds of participants mentioned the importance of therapeutic relationships to effective spiritual care. Therapeutic relationships are important within EOL contexts and when caring for those with a life limiting illness (Seymour et al., 2003; Mok and Chiu, 2004). Such relationships could be viewed as unique, combining intimacy whilst also maintaining appropriate professional boundaries.

Therapeutic relationships are characterised by personal qualities and caregiving skills which reflect attributes identified by palliative care patients as important. These include skilled communication, respect for patient autonomy and diversity, mutually derived goals of care, and shared decision-making, with the most important qualities relating to 'the nature of the connection' nurses make with patients and their families. Therapeutic relationships also provide an enriching experience for nurses, trusting and connected relationships and a source of revitalising energy for patients (Mok and Chiu, 2004).

Participants identified such relationships as facilitating communication with patients, facilitating identification of patients' needs and requiring time to establish and maintain. For example, this NHS nurse (Participant 11) highlights how such relationships require time and allow practitioners to identify what is important to individual patients, in this case painting.

Participant 11

P. But I make that a point of looking at his book. Or, if I've got someone with me, I will say aww; this man does some wonderful [pauses]; and at the point of his end of life, all of us that have been in there, know that that's what's important to him. So, that's what you talk about. That's [pauses]; and he's so proud of this; and they are [pauses; they're amazing.

I. So that, that kind of process goes on inside what you might term the therapeutic relationship, between you and the patient, as you get to know them more, so you're aware of them more as a person?

P. Yeah. And I think that comes with continuity of care.

I. Right.

Another hospice participant (Participant 14) used the metaphor of 'walking alongside' patients for such relationships, which seems to capture the essential nature of such relationships.

Participant 14

I. But what you're saying: it's the quality of the relationship that seems very important in this process; being able to assess her spiritual needs?

P. It's part of erm [pauses]; walking alongside people, I think.

I. Right.

P. Getting alongside them [pauses].
I. Yeah. That's a nice metaphor for your role, isn't it?
P. Erm.

This hospice participant (Participant 16) describes how giving time to patients facilitates the development of rapport and openness.

<u>Participant 16</u>

P. Erm [pauses]; I mean, I think, I think that's why I personally enjoy [pauses] a lot of the elements of this job [sighs]. But I think it's, it's the fact that [pauses] I can give them time.
I. Sure.
P. To actually open up and talk about things and then [pauses], and help them and [pauses] and it's, it's a bonus really, when you see people sort of, coming through their journey and accepting parts of that as well.
I. Sure.
P. And I think [pauses] that is the nicest part of the job, that you can build that rapport with people and see them on a regular basis. Erm, [pauses] but, you know, I feel quite privileged really, that I'm able to do that, because I know that other people can't. But, yeah [pauses]. Yeah.

6.4.14 Spiritual care: summary

Saunders (1965) suggests that within hospice contexts, spiritual care is 'not an optional extra'. Small (1998) further describes hospice care as incorporating a 'well-established tradition of spiritual care'. All participants identified aspects of spiritual care (themes) which they deemed significant. As shown in 5.2.2, participant understanding of spiritual care displayed wide variation, making this form of care difficult to implement or evaluate with any degree of consistency. There was also marked differences between hospice and NHS participants, principally due to the contrast in available resources between hospice and NHS contexts. Participant views regarding spirituality also did not appear to translate into aspects of spiritual care practice. Conceptual ambiguity therefore contributed to diverse and fragmented spiritual care interventions which appeared to lack both uniformity and consensus. Problematic is that these concepts are integral to the wider context in which spiritual distress is situated, and such conceptual confusion is likely to make the identification and alleviation of spiritual distress more challenging.

6.4.15 Spiritual needs

The National Institute for Clinical Excellence (NICE) suggest that 'spiritual needs relate to a person's search for meaning' (NICE, 2016). Nineteen themes were evident in participant responses when asked to identify what constituted spiritual needs for EOL patients (5.2.3).

No participants were able to provide a succinct definition for spiritual needs. However, the following components were deemed integral to such needs. Each was identified by a single participant:

- Communication and support.
- Similar to religious needs.
- Wider than religion.
- Coping with loss.
- Therapeutic relationship facilitates identification.
- Can be neglected.
- Connection to nature.
- Connection to another person.
- Continue beyond death.
- Creativity.
- Dealing with threats to personal faith.
- Setting small, realistic goals.
- Nurturing creativity.
- Nurturing individuality.
- Prayer.
- Helping prepare for death.
- Relationship with God.
- Respecting individuality.

- Similar to psychological or emotional needs.

As described in the earlier literature review, nursing staff consistently have difficulty in defining the term spiritual needs and differentiating such needs from physical, psychological, or social needs (Best et al., 2020). During interviews it was evident that participants similarly struggled, frequently finding it difficult to differentiate between spiritual needs and religious needs and/or assuming the terms were synonymous. Patients also indicate that their spiritual needs remain unmet within 'standard clinical environments' (Balboni et al., 2007; Delgado-Guay et al., 2011)

For example, this NHS participant (Participant 11), although unable to provide a succinct definition for spiritual needs, nevertheless identifies that spiritual needs are integral to nurturing an individual patient's personality and creativity. In this case, expressing creativity through embroidery was a key spiritual need, as was the related concept of 'location'; the place where the patient felt at home and at peace. Both were important to this patient.

<u>Participant 11</u>

I. Another term is spiritual needs. Which also appears in a nursing context, sometimes in care planning. What would you say spiritual needs are for a patient?

I. [pauses]. We spoke a bit earlier about spiritual care. And giving care.

P. I had a lady who couldn't use their hands anymore, and I commented on her embroidery on the wall. And I said, "Oh, I love that "and she said, "I used to do it all, but I can't now". And I said, "it's wonderful" and, you know, "that's really special" and she said, "would you like to do it"? I said, "I'd be useless". And she gave me all her embroidery stuff [laughs] to try. But each time I saw her she said "so, how are you getting on"? And I'd take in this little scrap of mess and she'd say to me "right, well unpick that"; but she then thought we didn't go in talking about her end-of-life [pauses]; she was teaching me what she'd known and what she could do. So, I've now got a cupboard full of embroidery that I don't do, but actually that lady, I feel that I helped her. And when I open it, aww, I remember her [pauses]. I feel that I helped her; not forget about her illness and dying [pauses]; she knew she was. I think the daughter said you *made, you made life easier, and you brought joy; cos I'd always take it back and she'd say "unpick that" [laughs]. Erm…*

I. For that lady in question, part of her spirituality was about expressing creativity.

P. Yes.

I. Which is something you enabled her to do.

This NHS participant (Participant 3) describes how they view religious needs as being contained within spiritual needs, but that the term 'spiritual' encompasses a wider group of needs than religion alone. This is a theme repeatedly identified in relevant literature (see 3.10). They also share their sense of sadness when patients express the view that this aspect of their care has been ignored.

<u>Participant 3</u>

I. In a nursing context as well, the term spiritual needs appears. Would you say they're the same as religious needs or would you say they are wider than that?

P. They're wider than that. I think they're wider than that. I think religious needs are part of it and people identify with a religious need, in that it's easier to put a pin on, if you like. But erm, no, I think it's more than that. I think erm [pauses], it's sort of, from my own sort of journey really, if you like, I think it's much broader than labelling someone as having a religion, erm, and it has a much deeper significance erm, [pauses]. It's a feeling of being human, you know, and that's what I hope I am, when I'm with somebody. They are the most important thing that's in the room at that time, and my relationship with them is the most important thing at that time, and it's all to do with being human and respecting other people's individuality, erm[pauses], and connection and empathy. That's how it feels when I'm with somebody. That's how I want to be, and I want them to know that I'm receptive to that erm, relationship; it's a relationship.

I. So it's much more than just a physical care aspect?

P. Oh absolutely, absolutely. For me, yes. I'm very sad when I go to a patient who has received input from other people and they say no one has asked me that before, or no one's said that to me before, and I don't understand why they haven't. Erm, [pauses], it makes me sad.

This hospice participant (Participant 4) again struggles to succinctly identify spiritual needs but situates her description within the realm of loss, something frequently experienced by EOL patients. This participant also highlights that the term ‘spiritual’ may also be hard to access for patients, who may initially believe that they do not have any spiritual concerns or issues, but in subsequent conversation then identify issues that situate within a spiritual dimension, such as body image change or loss of a work role. It is therefore important that language used by practitioners is accessible for patients.

<u>Participant 4</u>

I. If you had a whiteboard on the wall, and you wrote up spiritual needs; what would you put on the board?

P. Erm [long pause]; I don't know, actually; now I’m thinking about it. Erm; [longer pause]; I suppose it’s just helping somebody, erm [pauses]; identify, I guess; because sometimes, patients think I haven’t got any spiritual concerns; I haven’t got any spiritual issues. And then they start talking to you about something, and you think well, actually, that is quite spiritual, because it’s looking at, you know, the loss of; their loss of self; the fact that they can't do the job that they used to be able to do or, they can't drive a car anymore, or, or, erm; body image sometimes is quite important, I think, especially if you’ve got, erm, patients, particularly ladies that have had breast cancer; who have had to have their breasts taken off, erm; so, it’s looking at how we support those sort of things, I guess, erm, but I'm not, I can't be any more specific than that, I don't think.

This NHS participant (Participant 17) identifies several themes relating to spiritual needs, including:

- Spiritual needs are separate from medical needs.
- Spiritual needs can be neglected in an environment where medical needs dominate.
- Prayer may constitute a spiritual need for patients.
- Being able to talk about their situation (patients) constitutes a spiritual need.
- Families/loved ones also have spiritual needs.

- Spiritual awareness is universal.
- Therapeutic relationships are crucial, integral to which is trust.

The participant was a practicing Christian, and it is evident how this informs their practice and degree of insight.

Another NHS participant (Participant 18) poignantly identifies 'connection' as being a key spiritual need. This theme resonates significantly with relevant nursing literature, where connection is viewed as a key component of spirituality (Robinson et al., 2003; McSherry, 2006). In this excerpt, connection with another is facilitated using touch, and illustrated by the nurse sitting at the patient's bedside. This participant also identifies connection to nature and facilitating a sense of transcendence through wheeling the patient to an open window or door so that they could view the sky or trees.

Participant 18

I. Spiritual needs. How would you see that in a nursing context?

P. I suppose that's similar to spiritual care. I suppose spiritual needs is what that person has, you know, is, may be requesting or needing, and I think that could be down to whether they need you to just sit beside them and hold their hand.

I. Sure.

P. Erm, gloved hand [laughs], so then that, you know, so if they're feeling a need to just be quiet, and they want you to sit and hold their hand, you are giving them spiritual care in a way, but it's their spiritual need.

I. Yeah. So, if their need in that moment was for connection with another….

P. Yeah.

I. Then the power of touch could be …

P. Yes.

I. A powerful way of…

P. Yeah.

I. Meeting that need…

P. Yeah. Which a lot; sadly, which a lot of dying people don't have, because people get very scared and then, you know, [sighs] you know, I think they worry that they are a china doll and they're going to break; especially elderly people, they miss out on that. So, our spiritual care might be sort of, you know, giving that care, but it's their need, I suppose, that then [pauses] and I suppose that's when you have to sometimes, [pauses] read between the lines, slightly, as a nurse.

I. Yeah. And I suppose if that particular person, say, was particularly creative, as an artist…

P. Yeah.

I. Or a knitter.

P. Yeah.

I. Or a crochet person….

P. Yeah. Yeah. Then you might wanna, you know, and I feel like this at the moment. Erm, I think there's a big thing as well, about being [pauses] in nature and outside and erm [pauses], just even if they can be wheeled just to an open window or a door, you know, just to be able to see outside in this beautiful blue sky and some trees and stuff. Erm, I think if they've got that need, then we have to try and give that care.

I. Yeah [pauses]. That's really helpful. Thank you.

Another NHS participant (Participant 10) viewed spiritual needs as an aspect of care that continued beyond death, using the example of a patient who had wanted to donate her body to medical science. For this participant, an important spiritual need for this patient remained unmet until their body was 'at rest' in London.

<u>Participant 10</u>

But we have to put their spirituality and beliefs and psychological and social support; everything, all in a care plan. But we have handover, and we discuss it with all the members of staff on; if I'm not available then, I would obviously have a full conversation and say right, o.k. We have eh, a lady who, erm, wanted to donate her body to medical science, for example. Erm, and we know that we've only got sort of roughly about an hour window, because their body has to be transferred up to London. So, we have to verify very quickly, for the, erm, funeral *directors to put the body in a fridge for a certain amount of time, and then transfer the body. So, again, [pauses], in a sense that's like spiritual needs; it's like making sure that after they've gone, as well, that erm, that we're still there, if that makes sense; we're still continuing; the journey doesn't just end, just at that time of death. It carries on and on until the body is at rest, really.*

6.4.16 Spiritual needs: summary

Interview transcripts illustrate that participants struggled to succinctly define spiritual needs within the context of EOL care. Participants also found it difficult to differentiate between spiritual needs and religious needs, often using the terms interchangeably. Spiritual needs may also be mis-identified as other needs. This reflects current literature (White, 2006, p.82; Koenig, 2008; Clarke, 2013). As a result, participants, though able to respond to spiritual needs, did not appear to assess for such needs on admission, or as part of ongoing patient care.

This ambiguity influences the delivery and quality of nursing care delivered by practitioners, as highlighted previously by authors such as McSherry (2006) and raises important questions for nurse training and continuing professional development.

6.4.17 Summary: ambiguity/uncertainty

Uncertainty/ambiguity was evident within many participant responses, particularly relating to spirituality, spiritual care and spiritual needs, all of which are important in the care of EOL patients. Surprisingly, uncertainty was equally evident in the responses of both NHS and hospice participants. My assumption had been that hospice participants would have been more able to define these 'core' concepts as they dealt daily with patients who were either approaching EOL or at the point of death. However, this was not the case amongst those who were interviewed. Such uncertainty impacts directly on the ability of practitioners to acknowledge and address the unique spirituality of individual patients, effectively assess spiritual needs, and in the delivery of quality spiritual care for EOL patients.

6.5 Research question 2: Participant perceptions of spiritual distress

How is spiritual distress perceived by community nurses within the different care settings?

Identifying participant perceptions regarding spiritual distress constituted a second key focus for data analysis. As shown in the earlier literature review, definitions of spiritual distress vary. The term ‘spiritual distress’ is also used interchangeably with both ‘spiritual suffering’ and ‘spiritual pain’ in some studies (Best et al., 2015, p.1336). In a previous systematic literature review, the authors suggest that ‘spiritual suffering’ is defined as:

> An all-encompassing, dynamic, individual phenomenon characterised by the experience of alienation, helplessness, hopelessness and meaninglessness in the sufferer that is difficult for them to articulate. It is multidimensional and usually incorporates an undesirable, negative quality (Best et al., 2014, p.6).

Observing this form of suffering when caring for community-based EOL patients and considering how such distress could be alleviated was the primary motivation for this study, though not all patients manifested such distress.

Participants struggled to define spiritual distress and all participants perceived spiritual distress negatively. Ten participants specifically stated they could not provide any kind of definition for spiritual distress or suggested it was impossible to define. Twenty-seven themes were identified in participant responses, as shown in Fig 12 and Table 11 (5.3).

Approximately half of participants (7 PH, 3 NHS) were unable to offer a definition of spiritual distress; this was often associated with a sense of frustration/struggle regarding a phenomenon they recognised in practice but struggled to describe in words. Two participants (PH) stated that spiritual distress related to unresolved issues, such as the family unit not being together or the individual having something still to do or to sort out. Three participants (1 PH, 2 NHS) stated that spiritual distress related to existential issues; questions and reflections patients may have about their lives, the meaning of life and what lies beyond death. Such reflections could be positive or negative. One of the NHS participants poignantly described her experience with a patient who showed no emotion and simply sat alone in a darkened room all day long in-between nursing visits. This nurse was also a Christian and described how her sadness regarding this patient led her to pray for him. Two participants (1 PH, 1 NHS) likened spiritual distress to Terminal agitation (see 6.5.2). Three participants (1 PH, 2 NHS) stated that spiritual distress was caused by regret(s), three participants (2 NHS, 1 PH) linked spiritual distress to a ‘lack of peace’ or patients being ‘ill at ease’ and two participants (1 PH, 1 NHS) linked spiritual distress to anxiety and worry. The remaining descriptors were all identified by a single participant, as shown in Table 11 (5.3). One participant likened spiritual distress to ‘total pain’, a term first coined by Dame Cicely Saunders to characterise the multidimensional nature of the palliative patient's pain experience, which included the physical, psychological, social, and spiritual domains (Saunders, 1972; Howard, 2001; Mehta and Chan, 2008; see also 6.6.2.).

Causes of spiritual distress were also linked by several participants to both mental and relational issues. Loss of relationship, unresolved relational stress and patients having different beliefs to their families were all identified as integral to spiritual distress, as were mental anguish, lack of hope and the spiritual beliefs of an individual being ignored. There were also no significant differences in perception between hospice and NHS participants. This was again surprising, particularly as seven of the nurses who stated that spiritual distress could not be defined were hospice-based. My assumption at the start of this study had been that hospice-based participants would be more able to articulate a definition of spiritual distress as they cared predominantly for patients who were approaching death. This contrasts with the more generalised approach of NHS community nurses where EOL care, though integral to their role, represents only one aspect of their work. It was interesting that more practitioners who could have been deemed ‘specialist’ stated that it was not possible to provide a definition for this phenomenon. Participant responses are discussed in sections 6.5.1 – 6.5.4 below.

6.5.1 Participants unable to define spiritual distress

Approximately half of participants stated they were unable to offer any kind of definition of spiritual distress in EOL patients. For example, an NHS participant (Participant 15) gave this response:

Participant 15

I. The last term I want to ask you about is spiritual distress, which is the primary focus for this study.

P. Ahem.

I. Is that a term you have heard about? Or read about?

P. Erm [pauses]. No, I haven't. If I'm honest.

I. No. That's fine. So, you wouldn't have any kind of working definition of what you thought that might be about?

P. [pauses]. Not without sort of, having a, having a little ponder, and thinking about it.

I. O.k. Fine.

This NHS participant (Participant 16) was also unable to provide a definition, but likened spiritual distress to terminal agitation, a type of agitation they had previously observed in EOL patients.

<u>Participant 16</u>

I. What do you understand by the term spiritual distress? Is that a term you've heard? Or read about?

P. I've heard about it [pauses]. I couldn't really sort of give you a definition of such, really, erm [pauses].

I. Again, if I had a white board on the wall, and wrote spiritual distress and underlined it, what would you put on the board?

P. [pauses]. I think that I would; I think that sometimes people, at the very end of life, when we, when we sort of put them under [pauses]; when we say they're terminally agitated.

This NHS participant (participant 21) was also unable to define spiritual distress, and again likened spiritual distress to terminal agitation, also using the term terminal distress.

<u>Participant 21</u>

I. What about the term spiritual distress? Is that a term you've ever heard about, or read about?

P. No.

I. So, you've not; again. If I had a little whiteboard.

P. You'll make me go and read this. I'm going to go and read this now, aren't I? Yeah. Yeah. It's thought provoking.

I. So, if I had a little whiteboard and put-up spiritual distress.

P. Because to me, it all comes under one umbrella. You know; when they've got, like, erm, terminal agitation, and terminal distress.

Evident from related literature is that terminal agitation differs significantly from spiritual distress, encompassing a wider range of manifestations and often results from a range of complex aetiologies, as described below.

6.5.2 Terminal agitation

Terminal agitation is a term used to describe anxious, restless and occasionally aggressive behavior occurring in the last few days of life. Marie Curie UK (2020) suggest this form of agitation may also be described as terminal restlessness, terminal anguish, confusion at the EOL, or terminal delirium. Symptoms and signs of terminal agitation can include:

- Distressed behaviour, sometimes including anger and possible aggression.
- Confusion.
- Calling out, shouting, or screaming.
- Hallucinations.
- Trying to get out of bed or wandering.
- Being sleepy during the day but active at night.
- Being unable to concentrate or relax.
- Jerking or twitching.
- Fidgeting, including repeatedly picking at clothes or bed sheets.

This form of agitation can be very distressing for the patient and their carers, family, or friends. Terminal agitation is seen in individuals who are already compromised by advanced illness and causes may include:

- Medication, such as opioids or corticosteroids.
- Alcohol intoxication or alcohol withdrawal.
- Nicotine withdrawal.
- Uncontrolled pain.
- Urinary retention.
- Constipation.
- Nausea.
- Brain tumours, including metastases or swelling in the brain (cerebral oedema).
- Sepsis.
- Organ failure.
- Altered blood levels including urea and creatinine, calcium, sodium, glucose.
- Oxygen deficiency (hypoxia).
- Emotional or spiritual distress.

(Marie Curie UK, 2020).

Though agitation can be a sign that an individual is approaching death, agitation may also occur in earlier stages of their illness (Marie Curie, 2020). Terminal agitation is very different to spiritual distress, and manifests from a wide range of underlying physical or physiological causes, for example, terminal organ failure. In contrast, spiritual distress is primarily related to aetiologies that are spiritual or existential in nature (e.g. regret or fear of death), even though spiritual distress may also encompass a range of physical manifestations, such as withdrawal, and pain localised to the abdomen.

This hospice-based participant (Participant 3) was also unable to offer a definition for spiritual distress, stating they were aware of the phenomenon, but found it difficult to ‘quantify’.

Participant 3

I. One of the terms that’s key to this study is the term spiritual distress. Is that a term you’ve heard or read about?

P. Erm [pauses]. Yeah. It’s not a term that I use particularly; but it’s obviously something that we're aware of. It's, it’s another one of those things it's quite difficult to quantify isn’t it? As to what that is for somebody.

Another hospice-based participant (Participant 5) simply stated they didn’t know how to describe this form of distress.

Participant 5

I. If you were to, again, to put on a whiteboard, spiritual distress is…

P. Erm [pauses]. I would put [long pause] erm, I don’t know.

A further hospice-based participant (Participant 6) stated that spiritual distress was often discussed amongst the nursing team but remained unable to offer any kind of description or definition. This suggests the team were also unable to objectify this form of distress.

Participant 6

P. God, I don’t know really. I think it’s just, erm, [pauses]; it’s something that we often talk about as a team.

A further hospice-based participant (Participant 9) was completely unfamiliar with spiritual distress and had not heard the term used by any other nursing staff. They reported that the term ‘emotional pain’ was frequently used within the hospice but were unsure if this was the same as spiritual distress.

Participant 9

I. Erm. Can I ask you about the term spiritual distress? Is that a term you've heard about or read about? And if it is, how would you define it?

P. I don’t think that’s a term I’ve ever used.

I. Right.

P. Erm [pauses].

I. Is it a term that you’re familiar with at all?

P. No. It's not a term that I've ever heard anybody use, really. Apart from the fact that I've heard of erm, you know, having a problem with, I can't think of the word I'm looking for; something with your faith, but I don't think I've really heard of spiritual; I mean emotional pain, we use that a lot.

I. Right.

P. In palliative care. So, I suppose that, whether spiritual distress is the same as emotional pain, I've no idea, really.

6.5.3 Other descriptive themes associated with spiritual distress

A range of other themes were evident within interview data relating to participant perceptions of spiritual distress. For example, three participants stated that the term referred to a generalised lack of peace, or simply not being at ease. One NHS participant (Participant 12) stated:

<u>Participant 12</u>

I. How would you define spiritual distress, if you did?

P. Erm [pauses].

I. Do you have a working definition? Is that a term that you're familiar with?

P. I mean; I'll be honest. I did kind of Google it a little bit.

I. Right.

P. So, so; there's this thing of not being connected, erm; loss of hope, erm; there was quite a few things mentioned; erm, I'm afraid my memory's not that good. So, but it's really just kind of [pauses]; it's just somebody that's really, erm; eh, not at peace with themselves, erm [pauses]; you know, in a very deep way.

Patient regret was identified by three participants (2 NHS, 1 PH) and is a component frequently mentioned in related literature (e.g. Caldeira et al., 2013). For example, this NHS nurse (Participant 17) movingly describes how patients can look back over their lives and view only negative aspects, leading to profound regret. They then describe a patient they had personally encountered who was manifesting not only regret but also withdrawal from social interaction.

<u>Participant 17</u>

P. Not a definition, really, but I would, I would definitely say someone who is, sort of, still asking a lot of questions, maybe, about spiritual things, about faith, about God, about, erm, praying, starting to look at their life, people who are reflecting and asking, perhaps looking back and, sometimes in conversation they'll say "Oh, I'm just wondering what I've done with my life, I've", you know, "I didn't spend as much time with my family as I should have done", people who are asking those kind of questions, that actually who are really re-evaluating, erm, their life, and what they've done with their time on Earth; I would say are, I would put in that category; they're, they're spiritually distressed, because they're starting to; it's different if they're looking back and actually feeling really satisfied with their life, and they're reflecting and seeing lots of positives. But people who are looking back and seeing only the negatives, who are in a really low mood in themselves. Erm, we had a chap on twilights, when I used to do evening work. And he, erm, he was just completely; felt cut off. No emotion whatsoever. Erm, he had not long been diagnosed; and had a poor prognosis, and he, erm; I remember; I do remember praying for him, because he just seemed completely, I can't think of the word, but, just, there was no emotion whatsoever. He just went and sat, between our visits, in a dark room, all day long, and completely withdrew from everything.

I. Right.

P. And people who have withdrawn from not only interaction with you, but also with family and, and also interaction from life. Like I say, literally that hopelessness; I just don't want to do anything, I just want to sit here and be left alone. Erm, those are people that I would put into that category.

Another NHS participant (Participant 18) described an associated panic that may ensue as EOL patients reflect upon their lives, again associated with regret. This combination can be a profound cause of spiritual distress to the individual.

<u>Participant 18</u>

P. So, so, you know, they're facing this, and then, I think you can then start getting this almost panic, where, you know, people start reflecting on their life. They start reflecting on themselves, *you know, what they've done, what they haven't done, and I think it can [pauses]; so, to me, that's not having peace [pauses].*

I. Right, as they've reflected on the life, they may have regrets? Or other issues?

P. Yeah. Yeah. And, and so they are not feeling at peace with themselves, and it becomes like, to me, you know, a physical panic, where you start feeling panicked, you know; I can't cope with this, because I don't know what I'm doing; it's like that in a way, this is what it is to me; I might be completely wrong here, erm, with an official definition, but for them, it's like that, but it's like about themselves and about, you know, maybe it might be that their needs aren't being met, and it's making them upset and [pauses].

Three participants stated that unresolved existential questions were also integral to spiritual distress. For example, this hospice nurse (Participant 13) likens spiritual distress to terminal agitation, but also comments on the openness of male patients to counselling services. They also describe how potentially debilitating symptoms may undermine the ability of patients to address such questions.

<u>Participant 13</u>

I. What do you understand by the term spiritual distress? Is that a term you've heard before?

P. Yes, lots. Yeah, yeah, yeah.

I. How would you define it? What would you say it is?

P. Well, again, I struggle. Because, as we know, people can get terminal agitation [pauses]. And, and, in the end, I don't think anyone really has been able to establish; is it purely physical? Is it [pauses] emotional? Is it spiritual? Erm; is it a combination of the, of the lot? So, [pauses]; we don't, we don't really know. I think that; obviously; if people have the cognitive ability to express themselves, give them every opportunity to express themselves; erm; and explore with them. Now, again; some people don't necessarily; they can't; I mean, it's a classic, isn't it? Men don't tend to accept counselling, by and large: older men, I should say, eh, my age, don't tend to do counselling, when I offer it to people. A lot of them don't seem to take it up, as, eh, as a thing that could be helpful to them. In the same way, if you've got someone who is really at the end of their life; especially if they're in discomfort with whatever symptoms they are coping *with; trying to then verbalise what they are thinking, about their life; the meaning of their life; is there a life beyond; all those sort of big questions; erm [pauses]; and I think some people haven't got the mental energy to deal with it [pauses].*

The remaining themes were expressed principally by a single participant and could be grouped into five thematic groups. These were:

- Fear, anxiety, and distress/stress.
- Grief and loss.
- Unresolved issues/questions.
- Loss of hope.
- Other.

Each represent components of spiritual distress (Caldeira et al., 2013). Examples from interview transcripts are shown below.

Fear, anxiety and distress

This hospice nurse (Participant 3) describes a patient who was distressed because, though having expressed a desire to die, physically he was not yet at the end of his life.

Participant 3

P. Erm [sighs], [pauses]. I had a patient a couple of months ago who; I described him to the team as anguished, because he was just so, [pauses]; he wanted to die. It was a chap with, erm, oesophageal cancer; not able to eat, erm; and he was ready to die weeks before his body was ready to die, really.

Another hospice-based participant (Participant 13) highlighted patient fears related to the possibility of God's impending judgement as integral to spiritual distress. This type of fear appears associated with views the person has concerning both the nature of God and the nature of their individual faith. For example, an individual may perceive God to be distant and punitive, with a 'big stick mentality', as described below.

Participant 13

P. We, we all have them; to some degree or another. Erm [pauses]; so, that can be a big issue. I think, erm, being frightened about [pauses] what is beyond death, and again, sometimes; and again, this could be a bit of a cliché, and I apologise; but you know; I think, with a lot of people feel, some folks with a strong Roman Catholic faith, seem to have a struggle at end of life. Because it appears you've got this big stick mentality; He's gonna judge you; erm; so, I think if you have in that situation a religion, or a faith even, even a love of Jesus, but you, you're worried about what sort of judgement you are going to receive [pauses]; but, again, we're guessing. Many people aren't necessarily expressing that. I think some people will say [pauses]; you do get a few people who are frightened to go to sleep at night or close their eyes, because they're, yeah; they're just frightened; to go to sleep.

Grief and loss

This hospice-based nurse (Participant 14) describes how spiritual distress, though not the result of a specific physical cause, such as cancer, can still manifest as physical pain. She also poignantly speaks of the distress which may result from loss, in this case loss associated with no longer being able to participate in the lives of children or grandchildren. This participant also shares an interesting view on professional clergy who, in her view, do not respond well to their own impending death, even though they may have been a source of comfort to dying patients during their ministerial careers.

Participant 14

P. Yeah. Again [pauses]; I think it's; what I understand; I might not be right; but I think of [long pause, sighs]; distress that is not; that you can't relate to pain. It's not physical. It's [pauses].

I. No.

P. [pauses]. And yet, I think spiritual distress can probably cause physical pain.

I. Yeah.

P. Erm [pauses]; so, it's distress because of [pauses]; you know, what's happening to somebody? Or [pauses]; because they're; perhaps with our patients, because they're going to leave their family; they're not going to see their children, or grandchildren grow up. That's what

I would [pauses]; that's how I would [pauses]; erm; and with vicars, [pauses]; erm; I think sometimes it's a fear that well, we've been saying this all of our lives, supposing it's not really true [laughs].

I. Have you experienced this?

P. Yeah [laughs]. Yeah. Vicars don't die well. I'm not saying all of them don't. But, yeah.

I. It's a really interesting observation.

P. Scary, isn't it? [pauses].

This NHS nurse (Participant 1) provides a moving autobiographical example when trying to define spiritual distress, relating both to a relative and themselves. In this case, the relative had expressed a desire to receive communion before they died, something they had previously struggled to express. Unfortunately, this request was ignored, causing significant spiritual distress to the relative. The participant also highlights the importance of proximity between nurse and patient, which helps facilitate nurse-patient relationships that are therapeutic. This nurse was the only participant who stated they had personally experienced spiritual distress.

<u>Participant 1</u>

P. I think, sometimes, it's almost like the stages of grief. And, and loss. So, some people will be unnecessarily angry, and some people will be emotional but won't know why they're emotional. And other people [pauses]; it's just this wish to speak to somebody, they want to speak to somebody; it's not that they want somebody there, they need that relationship, the proximity of that relationship. I think [pauses] that's probably multiple reasons, and spiritual distress is one of them. Which, even for me, I can't put my finger on, eh [pauses], what spiritual distress exactly means to me. It's just that I know that when she was dying, I knew she had needs. This is completely diverting off of it. You see I wanted the minister to take her communion. And he was too busy. And erm, I definitely had spiritual distress then. Cos, I knew that she would have been over the moon to have him do that for her. And then he was too busy. And then she died. And I was angry. Really angry about that. Cos I just thought that was something he could easily have done. And erm, I knew that she had that need. Erm, cos she had had historically lots of anger towards things and she also had a religious belief which she *had trouble expressing. And so, I know, erm, that I was in spiritual distress, and I think she was in spiritual distress, and that made me really sad. Erm, [pauses]; but as far as actually identifying, when you're with a patient, you're exploring if they can communicate effectively, erm; what would they need, and it would be on your list of questions to ask. I suppose is there anything you would like to do? Is there anyone you would like to speak to? Is there anyone you would like to express any personal thoughts with? Erm [pauses], but I guess really, I'm fumbling around, aren't I?*

I. I think you're maybe expressing that it's difficult to define.

P. Yeah.

<u>Unresolved issues/questions</u>

Several participants identified either unresolved issues or unresolved existential questions, when asked to define spiritual distress. Unresolved issues were commonly linked either to regret or fear. For example, this hospice nurse (Participant 4) identifies unresolved issues as a key component of spiritual distress.

<u>Participant 4</u>

P. I think [pauses]. It is hard to put into words because I can understand what you mean by spiritual distress, and those sorts of issues that I would apply to it. But I think it's when inside you feel that things aren't [pauses], aren't right, aren't reconciled, I suppose, yeah. But you have still got things that you need to do, eh, to do, to sort out.

This hospice nurse (Participant 5) also identifies unresolved issues as a component of spiritual distress; specifically, those related to the patient's family situation.

<u>Participant 5</u>

I. O.k. I'd like to ask you about your understanding of the term spiritual distress.

P. [pauses]. O.k.

I. Is that a term you've heard of? Or read about? Or? If it isn't, it doesn't matter.

P. Erm [pauses]. No, I haven't really read about it [pauses]. I don't know. I think, I would feel it was some, you know, [pauses]; maybe someone's just, you know, dying, possibly, eh, and just things aren't settled, you know. Maybe they've got things at home that are not settled; all sorts of things; family, the family units not together, maybe, I don't know, but I would maybe put that under that heading.

This NHS participant (Participant 11) identifies mental anguish as a component of spiritual distress, from issues which may remain unresolved. Here, the participant describes a patient experiencing distress because of previous relational breakdown within the family, describing how such distress is commonly treated using drug therapy which may subsequently render it impossible for the individual to undertake any kind of resolution to the underlying cause(s). As described earlier, sedation is a common intervention utilised within community contexts.

<u>Participant 11</u>

P. We just get a phone call saying can you go and set up a syringe driver. Can you go and give a stat injection? You're then getting information from the patient, about the patient from the family. And it may be that the family say to you, erm, you say, you know, "are they the only child"? "No, there's four of us, but we don't see the others, and that one stole off of us, and that one did this, and that one did that". So, you've got a bit of a picture, [pauses]; and it may be that that patient's distressed because they want to see their children, or they want to make amends or they want to; but we would never know, because we've not had that build-up of [pauses]communication [pauses]; to find that out, which is quite sad really, isn't it? Because then we respond to it with medication. They're distressed, but actually, we have no idea why they're distressed. And by the time we go in there, we're not [pauses]; the patient's not at that point that they could tell you why they're distressed.

This NHS participant (Participant 17) highlights patients having unresolved questions regarding faith and/or life as being a key feature of spiritual distress. In this example, such questioning is particularly linked to regret.

Participant 17

P. Not a definition, really, but I would, I would definitely say someone who is, sort of, still asking a lot of questions, maybe, about spiritual things, about faith, about God, about, erm, praying, starting to look at their life, people who are reflecting and asking, perhaps looking back and, sometimes in conversation they'll say "Oh, I'm just wondering what I've done with my life, I've", you know, "I didn't spend as much time with my family as I should have done"; people who are asking those kind of questions, that actually who are really re-evaluating, erm, their life, and what they've done with their time on Earth; I would say are, I would put in that category; they're, they're spiritually distressed, because they're starting to; it's different if they're looking back and actually feeling really satisfied with their life, and they're reflecting and seeing lots of positives. But people who are looking back and seeing only the negatives, who are in a really low mood in themselves.

This NHS participant (Participant 18) also highlights the distress which may be caused by an individual having to face their impending death, integral to which is a re-evaluation of what is important.

Participant 18

P. Erm, [pauses]. Well, to me [pauses], that possibly means when somebody is feeling [pauses]; it might be that their whole [pauses] views on life are changing, and they've been given this diagnosis; they're dying, you know, or maybe they've had the diagnosis a long time, but they're actually facing dying.

Loss of hope

Loss of hope was another defining feature of spiritual distress, as described by this NHS participant (Participant 17).

Participant 17

I. What about the term spiritual distress? Is that a term you've heard? Or read about?

P. Erm, a little bit. I have read a couple of articles about spiritual distress.

I. So, if I had the imaginary white board back?

P. Yeah. I would put, erm, hopelessness?

I. Right.

This participant also highlights patient withdrawal, not only from social interaction and family but also from life, as characteristic of hopelessness associated with spiritual distress.

Participant 17: excerpt 2

P. And people who have withdrawn from not only interaction with you, but also with family and, and also interaction from life. Like I say, literally that hopelessness; I just don't want to do anything, I just want to sit here and be left alone. Erm, those are people that I would put into that category.

6.5.4 Summary: Participant perceptions of spiritual distress

Participants struggled to provide a succinct definition for spiritual distress. However, most participants were able to identify individual or multiple features of this phenomenon, which they had personally observed or encountered in clinical practice. No participants referred to relevant literature. As in the case of spirituality, perceptions of participants regarding spiritual distress varied and were difficult to conceptualise. Such ambiguity is likely to directly influence the delivery of patient care, as shown in section 6.7. How exactly participants assign meaning(s) to spiritual distress also appears complex. This is discussed further in 6.8.

6.6 Research question 3: Identification of spiritual distress

How is spiritual distress identified by community staff within the different care settings?

Identification of spiritual distress was a third focus for data analysis. Despite difficulties in defining spiritual distress, participants described multiple manifestations that would lead them to assume an individual patient was suffering such distress. Key themes are considered below. Twenty-seven separate themes were mentioned, as shown in Fig 13 and Table 12 (5.4). The most prominent manifestations identified by participants related to communication. Most common was patient withdrawal, as identified by eight participants (2 NHS, 6 PH). Four participants identified patients seeking forgiveness or confession (2 NHS, 2 PH) and four (2 NHS, 2 PH) terminal agitation or restlessness. Four NHS participants expressed the view that spiritual distress could easily be confused with distress resulting from physical causes, such as urinary retention or pain. Three participants identified loss of relationship or connection (1 NHS, 2 PH), patients who stopped communicating (3 NHS) and patient regret (3 PH). A range of emotional manifestations were also identified by participants, for example anger (2 PH), depression (1 NHS, 1 PH), fear (2 PH), unhappiness (2 PH), anxiety (1 NHS) and generalised distress (1 NHS). One NHS participant likened spiritual distress to grief, suggesting this could similarly manifest in a variety of ways and one hospice-participant identified withdrawal from religious community. Indicators of spiritual distress are considered below.

6.6.1 Identification of spiritual distress: participant themes

Patient withdrawal

The most common sub-theme identified by participants was patient withdrawal, either from staff, family, loved ones or the patient's religious community. Such withdrawal is commonly associated with fear, despair, loss of hope and feelings of abandonment (Caldeira et al., 2013). For example, this NHS participant (Participant 17) highlights patient withdrawal associated with loss of communication.

Participant 17

I. So, those things you've mentioned, the sort of withdrawal, the loss of connection, the inability to communicate any more, obviously someone who's reflecting and has a lot of regret about their life. They're the kind of manifestations that you'd be looking for: when you see a patient?

P. Yeah. Yeah.

This hospice-based participant (Participant 3) also highlights patient withdrawal as an important identifying feature of spiritual distress and describes how this may be associated with observed changes in the personality of the individual, such as a reluctance to engage in conversation.

Participant 3

I. And would there be anything else that would lead you to think that this person was showing signs of being distressed? Spiritually distressed?

P. Erm.

I. Rather than just by physical symptoms. Although clearly, physical symptoms can cause an impact.

P. I suppose people becoming more withdrawn; not wanting to particularly engage with things; erm [pauses], you sort of hear carers [pauses] saying that they're (the patient) changing; their personalities are changing; they don't, erm [pauses], participate in conversations anymore; those sorts of things.

Another hospice-based participant (Participant 6) also identifies patient withdrawal, this time highlighting withdrawal ('shutting off') from family, which can clearly be challenging for both staff and family/loved ones.

Participant 6

P. It's very difficult to explain it, isn't it? Erm, when you are in the situation, erm, but to actually explain to someone how I would, would, [pauses], erm, I think it's definitely distress. I mean, emotional. Some people may become emotional, some people may become quite shut off, and not want to engage. I think [pauses] in a way, that's a form of distress.

I. Yeah.

P. So I think it's, yes it can go, it can manifest in lots of different ways, really. Erm, when people shut off their families, erm, want to be left alone, erm; I think that's sometimes a way to show that they are distressed, spiritually [pauses].

Restlessness/terminal agitation

Another indicator of spiritual distress was restlessness and/or terminal agitation, as identified by four participants. For example, this hospice-based participant (Participant 15) describes how spiritual distress can easily be missed, because of a predominant focus amongst staff upon physical symptoms alone.

Participant 15

P. Erm [pauses]. I mean it's hard, because if you are seeing somebody who's actively dying at end of life, within, within the home [pauses], they're distressed or agitated for lots of reasons, potentially; physical symptoms and things, so you might not necessarily pick up spiritual *distress, I guess, as such, [pauses] cos we're sort of, you know, someone's; if you're visiting someone at home and they're actively dying; they're agitated, it's because they're probably in pain, or they're feeling nauseated or they're just generally distressed, because, it's a term we use; we put terminal agitation; I don't know if that's a term you've heard of before? That's a term that we tend to; that's how we would probably see that. But it could be, because they've got some spiritual issues that we haven't been able to deal with. It could be that but, you know, it's at that stage they're probably where it's [pauses]; too late; well, I wouldn't say too late, but you would be looking at the physical symptoms, rather than that, I would have said; it's difficult for me to actually pinpoint a time.*

As discussed in 6.6.4, this tendency to miss indicators of spiritual distress is often combined with a lack of assessment tools or indeed any specific assessment process at all. The use of the term 'terminal agitation' (see 6.5.2) can also be misleading in this context and prevent practitioners from addressing distress originating from a spiritual rather than a physical aetiology.

This hospice nurse (Participant 2) also identifies physical agitation as a defining feature of spiritual distress but highlights unresolved emotional issues (anger and fear) as a possible cause. Such unresolved emotions are therefore expressed physically, which may include 'pacing' in patients who are not yet approaching death.

<u>Participant 2</u>

I. How would you identify spiritual distress in an end-of-life patient in the community? What would lead to think that this person is manifesting spiritual distress?

P. Somebody who was extremely unhappy.

I. Right.

P. Somebody who at the very end, is unaccepting, eh, maybe, eh, angry [pauses]; eh, could be even fearful, but fearful, maybe, behind the anger; somebody who still has a lot of emotional content which is unresolved; unresolved, eh [pauses]; somebody who was not physically settled within themselves.

I. Right.

P. They could be pacing, or restless [pauses].

I. O.k.

Seeking forgiveness or opportunity for confession

A further indicator of spiritual distress identified by study participants was patients who may be seeking either forgiveness or an opportunity for confession, relating to past events in their lives. For example, this NHS participant (Participant 16) describes a patient who had sadly experienced relational breakdown with a child, with whom they had not communicated for some years. Evident within this excerpt is the importance of the developing therapeutic relationship, which may provide a context for patients to address their desire for forgiveness and reconciliation. This participant also highlights that not all patients may wish to seek reconciliation.

Participant 16

P. But then [pauses], you, you do come across some people that have had erm, like, they haven't spoken with either one of their children and things and sometimes, that can cause them distress, because either one or the other isn't ready to sort of; they can't make up.

I. Yeah.

P. And I think sometimes, erm, people sort of put boundaries, you know, and sort of say "well, I'm, I'm not going to talk to her" [sighs] erm, so, I mean sometimes, we can sort of [pauses] ask them "would you, would you want to sort of make amends, and would you want to do this", and erm [pauses]; some, initially, some of them go "no, no, no", but then, after a while, when you've been seeing them, sometimes they say "I've been thinking about what you said, erm, and actually, I think I would like to try erm, and make amends" with a long lost daughter, son or whoever, erm, which then, we obviously, we can help them with that. But, yeah; I mean sometimes people are just [pauses]; just because they're dying, they don't want to…

I. Yeah.

P. To bring all that back up again, as well.

I. Sure.

This NHS participant (Participant 21) poignantly describes a patient who expressed a desire to confess to her husband that their son had a different biological father, something she had never told him throughout the duration of their marriage. This participant also views spiritual distress as essentially a holistic phenomenon, whereby spiritual issues may manifest physically (this reflects my own view).

Participant 21

P. Yeah. Or sometimes, they just want to confess something. I mean, I've haven't had personally, but I've heard of people sort of saying, you know, things like erm [pauses]; actually, I did have a lady, a long, long time ago, who'd had a child, and she'd never told her husband it wasn't his. And she just felt she needed to.

I. Before she died?

P. Yeah. Tell someone. She'd never told him. But, actually, it's not his son.

I. That's profound.

P. Yeah. Yeah [laughs].

I. Erm, so, what would lead you to think it was spiritual, and not just physical?

P. Yeah. No, that's what I; that's what I mean, where I take it as one umbrella. I kind of intertwine them all together. I don't distinguish between all the different, bits of it; it kind of comes as one. That's your holistic thing. Yeah. I kind of see it, yeah, all as one.

I. O.k.

P. Whatever their needs are. Yeah. I wouldn't pinpoint it, to a spiritual or a [pauses].

Regret

Regret (a feeling of sorrow or remorse for an action) was a further identifying feature of spiritual distress highlighted by three participants. Regret may also be the primary motivation for a patient seeking forgiveness or opportunity for confession. For example, this hospice-based participant (Participant 8) describes a patient experiencing profound regret concerning actions they had taken in their past, in this case involving criminality, which they wished to confess before their death. Soon after the patient had taken opportunity for confession, they died. The participant also describes how, in her view, this form of spiritual distress requires more than drug therapy alone.

Participant 8

I. Can you give me an example of that?

P. Erm, [pauses], I'm just trying to think of one, erm, when you erm, said [long pause]. We had; so sometimes, they want to talk about something that's happened in their past, and then when you kind of go into it, erm, they say they've done some wrong things, erm, [pauses], criminal things.

I. Right.

P. But they have not spoken to anybody about before, and then, right in the end, they're really distressed, no matter how much medications they're given, they're still restless, the family are all restless and it's not until sometimes you go in, and you have a one to one conversation, and they just say 'I've done something when I was twelve years old that I can't forgive myself for. And I can't forgive myself before I then go; I know I'm dying' and then, all of a sudden, they'll get it off of their chest and they'll go [pauses]. And I think that, I don't know, it's where something's; you're still so worried about something that you haven't spoken about, or not wanted to speak about, I think, a lot of the time.

I. So, in that case it's clear that the patient has something that they haven't been able to offload yet, or deal with yet…

P. Address, yeah.

This participant also described a younger patient who had profound regrets about leaving his wife and young family without adequate financial provision. Again, she highlights that this form of spiritual distress may present with an inherent physicality which may be resistant to drug therapy.

Participant 8 (transcript b)

I. Anything else, do you think, that would sort of flag up that this person is spiritually distressed? As against to, physically?

P. Erm, [pauses]. I think, if we have a lot of things really uncontrolled, erm, you know, we use the pneumonic of total pain; it's not always about physical pain.

I. Sure.

P. It can be about something inside, it can be again, psychological. I think that erm, we're quite good at; we're reviewing analgesia and things like that, but if are still not being controlled, despite a good amount of erm, analgesia, we will then come together as an MDT and be like, there is something else. Whether it's financially; erm, we've had, like, young couples who have been in; newly married, young children and [pauses], lots and lots of analgesia, like big, big, big amounts and, which can be for some people. However, it wasn't until we really divulged it was a fact that his finances wasn't erm, suitable to obviously leave his wife and his two young children behind; and it wasn't until we sorted out all of his finances; the social workers and attendance allowance and things like that, that, erm, that it really helped him and just really calmed him, so, even though it's coming out as pain, it's not, it's not maybe always physical pain.

I. Sure. I think that's really helpful.

<u>Patient withdraws from communication</u>

Another identifying feature of spiritual distress described by three participants is withdrawal from communication. For example, this NHS participant (participant 12) highlights the importance of establishing whether a patient's lack of communication is a normal feature of their personality or a change that had become evident as their illness had progressed.

<u>Participant 12</u>

P. Yeah. [pauses]. Erm; yes. I think if somebody wasn't [pauses] erm; communicating; they were very quiet; I would try to understand that; I would try to talk to them and find out are they like that all the time.

I. Right.

P. And is that part of their personality or, is there something wrong? Erm; and is there something I can do to help? And most of the time, but of course not always, you have people around that patient; their family, carers, whatever, who can help you understand the patient, if you don't know them. Erm; I mean, what's better, is if you do know them; you've visited them a few times. I think, erm [pauses]; seeing that patient; this hypothetical sort of patient scenario; perhaps, erm, where they're not communicating with you. There's obviously something not *right, and you would start to get that feeling in you that somethings not right; you need to kind of, try and explore this; help a little bit; but whether you can achieve it is [pauses]…*

I. Sure.

Loss of mental well-being

Other identifying features of spiritual distress were highlighted either by two participants or a single participant. The majority of these related to a loss of mental well-being for individual patients, particularly as their proximity to death increased. Features identified by two participants included:

- Anger.
- Calling out or reaching out to someone.
- Total pain.
- Unhappiness.
- Changes to mood or persona.
- Depression.
- Fear.

Each are illustrated in the short transcript excerpts below.

Anger

This hospice-based participant (Participant 2) identifies anger as an identifying feature of spiritual distress.

Participant 2

I. How would you identify spiritual distress in an EOL patient in the community? What would lead to think that this person is manifesting spiritual distress?

P. Somebody who was extremely unhappy.

I. Right.

P. Somebody who at the very end, is unaccepting, eh, maybe, eh, angry [pauses]; eh, could be even fearful, but fearful, maybe, behind the anger; somebody who still has a lot of emotional *content which is unresolved; unresolved, eh [pauses]; somebody who was not physically settled within themselves.*

I. Right.

Calling out or reaching out to someone

This hospice-based participant (Participant 16) identifies calling out or reaching out on the part of the individual patient.

Participant 16

I. Are there any other manifestations of spiritual distress that you would look for? Anything that would highlight for you that this is distress of a spiritual nature, rather than something that is to do with physical pain, or nausea?

P. I think sometimes when they are calling for somebody.

I. Right.

P. If it's their wife, or husband, erm [pauses]; sometimes people can get quite distressed then.

I. O.k.

P. Calling out for their mum or their wife, but that's; I suppose that's, that's the only one I can think of at the moment.

6.6.2 Total pain

Dame Cicely Saunders, one of the founders of the modern hospice movement, coined the term 'total pain' nearly fifty years ago. She described this pain experience as 'multi-faceted, containing physical, psychological, social, emotional, and spiritual components'; it is the combination of each of these elements which then leads to the experience of 'total pain'; this is individualised and specific to the patient (Saunders, 1970). Evident from interview data is a lack of clarity regarding the use of this term and its possible management.

Randall and Downie (2006) suggest that 'total pain' can simply mean the physical pain which a patient perceives, influenced by emotional and mental factors via a highly complex neurological network. Alternatively, the term may encompass a patient's 'entire experience of distress resulting from terminal illness' (Randall and Downie, 2006, p.150). The first interpretation appears non contentious, as perception of pain is known to have a complex aetiology which can include physical, emotional, spiritual and psychological influences, all of which may be highly individualised (Payne et al., 2004). The second interpretation, however, is more problematic as this suggests that practitioners deliberately 'try to alter the patient's psychosocial and spiritual state' to modify or negate individual pain experiences (Payne et al., 2004). As Vachon (2004) states:

> The assessment and treatment of the psychosocial ('spiritual') distress associated with terminal illness involves distinguishing between the normal symptoms of adjustment to a terminal illness and the symptoms of a major psychiatric disorder. The skilled practitioner must be able to identify, assess and, when possible, treat the physical symptoms of the disease together with the increasing debility and changes in social roles and social isolation associated with the disease and the dying process (Vachon, 2004, p.961).

However, is it realistic for health care professionals to 'treat' a change in social role or the adverse effects of 'social isolation'? Also, as Payne et al. (2004) highlight, it is contentious to assume that the normal adjustment process to terminal illness produces 'symptoms' which then require 'treatment'. In effect, this 'medicalises an inescapable part of every human life' (Payne et al., 2004, p.150). Certainly, this may be the case with the use of medication for spiritual distress. More recently, authors such as Mehta and Chan (2008) have suggested that the lack of a comprehensive and accepted definition of pain within palliative contexts presents a challenge to both nurses and physicians in their efforts to optimise pain management (Mehta and Chan, 2008, p. 27).

Unhappiness

This hospice-based participant (Participant 2) identifies unhappiness as an identifying feature of spiritual distress.

Participant 2

I. How would you identify spiritual distress in an EOL patient in the community? What would lead to think that this person is manifesting spiritual distress?

P. Somebody who was extremely unhappy.

I. Right.

P. Somebody who at the very end, is unaccepting, eh, maybe, eh, angry [pauses]; eh, could be even fearful, but fearful, maybe, behind the anger; somebody who still has a lot of emotional content which is unresolved; unresolved, eh [pauses]; somebody who was not physically settled within themselves.

I. Right.

Changes to mood or persona

This hospice-based participant (Participant 4) describes changes to mood or persona in patients who were attending the hospice as day patients. She also highlights how, in her view, a therapeutic nurse-patient relationship facilitates the identification of such mood changes.

Participant 4

I. So how might you identify that? Would it be the things the person was saying? Would it be expressions on their face? Maybe they're withdrawn? Or?

P. When you get to know somebody, so again, I was lucky enough to do the, erm, years in the day services, where we got to know people really well, and I could tell, when somebody walked in the room, if something had changed, and sometimes that would be physical, but a lot of times it would be, you know, the way they were feeling that day. Because maybe a physical aspect of their disease progression had changed, and whilst they might be managing that pain, or that nausea, I think maybe the realisation that things had moved on was causing them that; I suppose you could call it spiritual distress, and a lot of time again that would be sitting down and having a chat. Talking about it.

I. So identifying it would really be within the quality of the relationship that you had with them?

P. Yeah, yeah. I think so.

Depression

This NHS participant (Participant 12) highlights depression as a possible identifying manifestation of spiritual distress.

Participant 12

I. Are there specific manifestations that lead you to think this is a patient who was distressed spiritually, rather than, say, physically?

P. Yes; I see what you mean. Yes. Yes. Almost like a, erm; a depression, sort of thing?

I. Maybe.

P. Yeah. [pauses].

Fear

Fear was also identified as a specific manifestation of spiritual distress. For example, this hospice-based participant (Participant 14) describes patients who may be experiencing fear of impending judgement because of previous actions during war service.

Participant 14

P. I think there's fear.

I. Right.

P. I mean, we don't get it; I suppose we do get it as well. But, erm [pauses]; you used to see it a lot, erm, in older men that had been in the war, because they said that, you know; "we've done bad things; I've done bad things". And that was, like, the fear [pauses]; they were they going to be judged? Yeah [pauses].

In contrast, this hospice-based participant (Participant 9) likens spiritual distress to 'emotional pain; here both phenomena are described as stemming from a fear of loss of control, as the patient's disease progresses:

Participant 9

I. What would you put in the category of emotional pain?

P. Emotional pain is; a lot of that would be [pauses]again; fear. Fear of loss of control; huge, that's a huge issue. Loss of control, erm, erm; loss of role in life; so, all of those are emotional pain. So, whether spiritual distress is the same; I would have thought it probably was. Because it; emotional pain stems back to the individual. So, yeah, I think it's the same idea, but I've never heard that one used.

I. O.k.

Mental morbidities identified by a single participant included:

- Lack of concentration.
- Talking to or arguing with dead relatives.
- Patient upset.
- Crisis of faith
- Believing they had let God down.
- Disappointment.
- Anxiety.

These are illustrated in the short transcript excerpts below.

<u>Lack of concentration</u>

This hospice-based participant (Participant 5) identifies an inability to concentrate as an identifying feature of spiritual distress.

<u>Participant 5</u>

I. And how would you recognise that sort of distress? Intuitively, what would…

P. I think, you know, a lack of concentration [pauses] erm, yeah; very thoughtful [pauses], yeah; not able to concentrate on too many things, [pauses], mind wandering, yeah.

I. O.k.

Clearly, such loss of concentration is evident in many EOL patients and may also result from fatigue, adverse symptoms, drug therapy or a combination of these.

<u>Talking to or arguing with dead relatives</u>

Certainly, talking to or arguing with dead relatives is not identified within current literature. However, this feature was highlighted by an NHS participant (Participant 10) as indicative of spiritual distress.

<u>Participant 10</u>

I. So, would there be any; would you be able to identify spiritual distress in an EOL patient before death?

P. [Pauses]. It depends if they're unconscious or not. If they are unconscious, erm, or unresponsive, erm…

I. Probably not.

P. Probably not.

I. But if they were conscious?

P. Then hopefully they would be able to communicate, and [pauses], like I said. Some people, when I was at the hospice, they'd sit there and talk to their dead relatives and, and then sometimes argue with them. So, I would say, that sort of aspect… [pauses].

<u>Patient emotionally upset</u>

This NHS participant (Participant 18) identified patients who were upset, combined with other factors such as anxiety. Again, it was difficult for the participant to articulate this, as evidenced by a long pause prior to response.

<u>Participant 18</u>

P. So, I'd most probably write, erm, [long pause]; upset, anxious, not wanting to think, blocking out, erm [pauses], needs not being met [pauses]; I don't know, maybe that's not what it is officially, but [pauses].

<u>Crisis of faith or losing faith</u>

One hospice-based participant identified patients experiencing either a crisis of faith or indeed losing their faith as indicative of spiritual distress. This participant (Participant 13) suggests those who previously had a 'strong faith' may struggle more to cope with the existential threat posed by terminal illness. This may be combined either with believing they had let God down in the way they had lived their lives or in believing that their lives had been a 'mistake'.

<u>Participant 13</u>

P. To some degree, yeah. To some degree, but again, I think, again; those things are common to humanity, aren't they, I think? Erm, again; with people with no faith, or strong faith. Erm;

some people, who have a strong faith, can sometimes struggle more. Erm; because they; I have had people express, obviously, eh, letting God down; erm; not measuring up; letting God down; making mistakes; [pauses] erm; or, even losing their faith, of course, at the last minute. Erm; and feel, feel maybe their life had been a bit of a mistake. Erm; yeah, so that, that's; yeah; thinking about it; that's a big one, and again, I haven't heard it expressed a lot; I've certainly heard it a few times over the years.

This form of thinking is clearly destructive and may be rooted in either wrong belief, poor theology, or both.

Disappointment

This hospice-based participant (Participant 16) identified disappointment as an identifying characteristic of spiritual distress. This disappointment is rooted in grief, caused by an inability to fulfil activities or plans.

Participant 16

I. Some of the literature suggests things like spiritual distress is around regret and unresolved issues; issues that people wish they'd sorted out which aren't sorted out at this moment. Would you see that kind of thing as relevant?

P. I mean, quite a few people will say [pauses]erm, they're very disappointed that they've, and angry that they've got cancer and they're terminal and, they had so many things they wanted to do [pauses].

Anxiety

Anxiety was identified by an NHS participant (Participant 18) as indicative of spiritual distress. Patients may experience anxiety for many reasons, but this participant poignantly describes encountering profound anxiety in a patient who was dying at home, and in her view, displaying spiritual distress. This form of anxiety appears to be existential in nature and related to the patient's proximity to death.

Participant 18

P. [long pause]. We did have a patient that, erm; it was when I first started back on the community and I went there, eh, with my team lead, and erm, we went to give a stat dose and then when we got there erm [pauses], there was something like four paramedics, erm, loads [emphasis] of family; he was like divorced, and there was like, not only the new wife, there was the ex-wife there as well, and all the family; eh, the GP came; just [emphasis]so many people around, and we were trying to move him and get him comfortable, [pauses] erm, and he was just so anxious; you could see it in his eyes; he was just so anxious, and it was like, right, we need to calm this whole situation down; it was like it was too much, there was too much going on [pauses] and, actually, we, we cleared the room for a little while and we managed to get him a little bit and he did, he did start to settle down, and then we gradually let the family back in, erm, which was really important, because he did die, not long after that, erm, while we were there, erm, but it was just that anxiety in his eyes [pauses].

I. O.k. That's helpful.

Two final characteristics of spiritual distress identified by participants were relational strain and physical pain localised to the abdomen which lacked a recognised underlying cause.

Relational strain

Relational strain with family/loved ones was identified by two participants. For example, this hospice-based participant (Participant 16) described how patients may previously have erected unhelpful barriers ('boundaries') between themselves and family members, which they are now regretting. Unfortunately, such boundaries may have been in place for a substantial period, and some patients may therefore not wish to seek reconciliation.

Participant 16

P. But then [pauses], you, you do come across some people that have had erm, like, they haven't spoken with either one of their children and things and sometimes, that can cause them distress, because either one or the other isn't ready to sort of; they can't make up.

And I think sometimes, erm, people sort of put boundaries, you know, and sort of say "well, I'm, I'm not going to talk to her" [sighs] erm, so, I mean sometimes, we can sort of [pauses] ask *them "would you, would you want to sort of make amends, and would you want to do this", and erm [pauses]; some, initially, some of them go "no, no, no", but then, after a while, when you've been seeing them, sometimes they say "I've been thinking about what you said, erm, and actually, I think I would like to try erm, and make amends" with a long lost daughter, son or whoever, erm, which then, we obviously, we can help them with that. But, yeah; I mean sometimes people are just [pauses]; just because they're dying, they don't want to…*

I. Yeah.

P. To bring all that back up again, as well.

I. Sure.

Physical pain localised to the abdomen

This NHS participant (Participant 18) identifies that spiritual distress can manifest as physical pain, often localised to the abdomen. Such pain can easily be confused with physical causes of discomfort, again highlighting that spiritual distress may be expressed physically, even where there is no specific pathological cause.

Participant 18

I. I think, erm, just an observation is that that kind of anxiety and regret and a range of other emotions that go with that, tend to localise somewhere in here (pointing to lower abdomen).

P. Yeah.

I. Or, that it has a physicality.

P. Physical, a physical pain. Sometimes, if you can just bring everything back down to a peace; it's back to this word peace again, I think.

Hard to identify

One NHS participant (Participant 12) highlighted their own difficulty in trying to identify spiritual distress, stating they personally do not look for such distress enough.

Participant 12

P. And, I think that probably; eh, if I just speak for myself, erm; it's not something I'd find easy to; I probably don't look for it enough, erm [pauses]; and don't really know how to look, look for it.

6.6.3 Labun’s components of distress

Evident from interview transcripts is that participants, although unable to provide a succinct definition for spiritual distress, nevertheless identified a range of possible indicators that would lead them to suspect individual patients might be experiencing such distress. As described in the earlier literature review, Labun (1988) helpfully identified seven components of spiritual distress (Labun, 1988, p.317). These were:

Spiritual Pain

Experiences of discomfort related to one’s human and/or transcendent relationships as well as one’s transcendent beliefs and values.

Spiritual alienation

Experiences of loneliness not filled by other human relationships.

Spiritual anxiety

Fear of the unknown and/or of impending doom for one's self or one's loved ones. This may be based on specific events, on the unknown, or on possible events.

Spiritual guilt

Concern about one's lifestyle and the values and beliefs which it has expressed.

Spiritual anger

Feeling about the injustice of a situation, blaming an undefinable transcendent source, God, or experiencing diffuse anger.

Spiritual loss

Feeling of having lost hold of those aspects of life which give ultimate and transcendent meaning and purpose.

Spiritual despair

Feeling that the person's hope in ultimate values, beliefs and transcendent experiences which were previously meaningful are no longer possible or that they will never be possible. A feeling that life makes no sense and that it is not possible to make sense of it.

Reviewing those indictors identified by participants, it is evident that all seven of Labun's categories are present. However, one category I would suggest not sufficiently represented/emphasised is that of physicality, a component of spiritual distress which manifests as pain experienced in the abdomen and/or chest. Labun (1988, p.317) does identify 'discomfort' related to spiritual pain, relating this to human and/or transcendent relationships, as well as the transcendent beliefs and values of the person. Such discomfort may manifest as:

- Behaviours conveying discomfort or suffering relative to one's relationship with God, fellow human beings and/or transcendent values and beliefs.
- Expression of feelings related to lacking spiritual fulfilment or of feeling empty in relation to fulfilment and meaning.
- Inability to come to terms with one's reason for being or one's relationship with the source of creation.

Table 10 below provides a comparison of Labun's seven components with patient indicators described by participants.

Table 10: Participant indicators used to identify spiritual distress in EOL patients compared to Labun's seven spiritual distress components

Component (from Labun, 1988)	Participant indicators (examples)
Spiritual pain • Loss of connection to God/others • Lack of fulfilment/meaning	• Calling out/reaching out to others • Loss of relationship(s) or connection • Physical expressions of spiritual pain/distress
Spiritual alienation • Lack of personal meaning • Loss of connection to others	• Lack of communication • Withdrawal • Total pain
Spiritual anxiety • Fear of the unknown • Fear of the future • Fear of God	• Crisis of faith • Fear of separation • Generalised fear
Spiritual guilt • Concern about one's lifestyle and the values/beliefs this has expressed	• Seeking forgiveness • Fear of judgement

Spiritual anger • Blaming a transcendent being/source • Questions such as why me?	• Anger • Strain in relationships with significant others • Disappointment
Spiritual loss • Loss of contact with God • Uncertainty about sources of ultimate or transcendent meaning	• Crisis of faith • Expression of having let God down • Withdrawal from religious community
Spiritual despair • Feeling abandoned by God • Loss of faith	• Total pain • Regret • Depression

6.6.4 Assessment tools for spiritual distress

The assessment of spiritual distress is key to its alleviation. As discussed in 6.5, participant responses concerning the identification of spiritual distress displayed both significant ambiguity, and lack of consensus. As outlined in the earlier literature review, there are numerous tools which may be of use to practitioners when attempting to assess such distress, though none of these were designed specifically for use with spiritual distress alone. Participant responses regarding assessment tools and their use are summarised in Figure 13 and Table 14 (5.4.2).

Eighteen participants were unfamiliar with any specific assessment tools for spiritual distress; over half were unsure whether spiritual distress could be measured, and four believed the assessment of spiritual distress using such tools was not possible.

Several participants mentioned the use of the IPOS assessment tool (see Appendix 1). The IPOS in one of a group of tools developed to measure the palliative care needs of patients and their families (pos-pal.org, 2020). The IPOS can be completed by both staff and/or family members and focuses upon a three-day window of assessment. The assessment incorporates physical symptoms, anxiety, worry, depression and patient/carer views on care, as well as an assessment of activities of daily living (ADL's).

Noteworthy is that the only IPOS question that focuses specifically on spiritual needs is 'Over the past three days, have you felt at peace?'. This is ambiguous, as 'peace' is undefined and may clearly mean different things to different individuals, as identified by several hospice-based participants. Patient and family members may also have different interpretations in relation to the assessment criteria. For example, the difference between the terms ‘most of the time’, ‘sometimes’ and ‘occasionally’ is left unspecified. The IPOS also assumes a certain degree of understanding and cognitive ability. If patients are unable to complete the assessment themselves, this is then completed on their behalf by a nurse, which may undermine the efficacy of the assessment. The IPOS also makes no reference to sources of strength or hope that patients may choose to draw upon during their illness, nor does it identify specific manifestations of spiritual distress such as loss of hope, regret, or patient withdrawal. In contrast, assessment tools such as FICA include questions that specifically focus on both spirituality and spiritual needs, including ‘What gives your life meaning?’ and ‘What helps you cope in times of stress or illness?’. Similarly, the FAITH tool includes the questions ‘What are your sources of hope, strength, comfort and peace?’ and ‘Has being sick (or your current situation) affected your ability to do the things that usually help you spiritually? Or affected your relationship with God?’. These tools are summarised in Appendix 1, along with the SPIRITual and HOPE tools. None were specifically designed for the assessment of spiritual distress in EOL contexts. However, each appears significantly more comprehensive and focused than the IPOS tool. Two hospice participants also stated that they doubted the efficacy of the IPOS tool, even though they were familiar with its use.

Anecdotally, whilst visiting one of the Pilgrim’s hospices to meet with a study participant, I observed first-hand how the IPOS was used within the main reception area. Two patients and their spouses duly arrived and were asked to wait in reception. The reception area was noisy, and both patients were then given an IPOS to complete. I observed both patients struggling to complete the IPOS, and repeatedly asking their spouses for help regarding the ambiguity of key questions, which their respective spouses also struggled to interpret. Both patients were also clearly feeling unwell which, combined with the context chosen to administer the IPOS left me doubting the efficacy of the assessments I had just witnessed.

Unfortuanately, a comparison of the efficacy of individual assessment tools was beyond the remit of this study.

6.6.5 Summary: How is spiritual distress identified by participants?

Spiritual distress is a complex, multi-faceted phenomenon with a wide range of possible aetiologies. This may help explain why participants struggled to offer a succinct definition of such distress. Components of this form of distress may be extremely debilitating for the individual and challenging for nursing and medical staff to address and alleviate. Participants identified a range of indicators which may help the identification of spiritual distress in patients within EOL contexts. However, these were often single manifestations alone. Most participants were also unaware of any specific assessment tools that might aid the recognition of spiritual distress in EOL patients. The only tool mentioned by participants was that of the IPOS; this was exclusively identified by hospice based participants but lacks both specificity and objectivity for the assessment of spiritual distress and appears ineffective as an assessment tool overall.

Alongside the focus on single manifestations alone, the lack of appropriate and robust assessment protocols further contributed to spiritual distress remaining unrecognised and/or unassessed by nursing staff, as described in associated literature (Kahn and Steeves, 1995; Arman et al., 2004; Best et al., 2015).

6.7 Research questions 4 and 5: Interventions to alleviate spiritual distress.

4. What specific interventions (forms of practice) are utilised by community nurses in the different care settings to help alleviate spiritual distress?

And the subsidiary question:

5. Is there any commonality of practice between the different care settings?

Adequate symptom control is integral to effective palliative care. Only when debilitating physical symptoms such as pain and nausea are well controlled can EOL patients focus upon issues which are deemed spiritual, emotional or social (Hermann and Looney, 2001). Twenty-three specific themes relating to therapeutic interventions to help alleviate spiritual distress were described by participants, as shown in Fig 15 and Table 14 (5.5). Most prevalent were the use of medication, practitioners investing time in talking with patients and referral to professional counselling or talking therapies. Each are considered below.

6.7.1 Use of medication

The use of medication was mentioned by over two thirds of participants. It is a common intervention for EOL patients, particularly as death becomes imminent (Engström et al., 2007; Claessens et al., 2008; Bruce and Boston, 2011). However, medication use was not viewed positively by all participants. Several participants expressed the view that medication simply 'numbed' a difficult situation with the resulting sedation then preventing patients from having opportunity to address underlying causes of spiritual distress. Kearney (2000) similarly suggested that unresolved physical pain (i.e. pain which is refractory to analgesic and/or sedative use) may in fact be an expression of deeper, unresolved spiritual concerns which, if left unaddressed, will simply continue. The use of sedation may actually 'silence an anguished cry', leaving the presence of spiritual distress unacknowledged (Johns, 2004).

Often, challenging symptoms at EOL (e.g. pain, breathlessness) cannot be adequately treated without compromising the consciousness of the patient (Hermann and Looney, 2001). Such symptoms may also profoundly influence both physical and mental well-being and increase as patients approach death. They may also disrupt the dying process itself, resulting in deaths impossible to categorise as 'good'. These symptoms are commonly treated using palliative sedation, a practice also described as 'terminal sedation', 'continuous deep sedation until death', 'proportionate sedation' and 'palliative sedation to unconsciousness' (Seymour et al., 2011, p.1). Such ambiguity is unfortunate and hinders ethical analyses of the reasoning and motives of clinicians. There is also significant unexplained variation in the incidence of such sedation across countries and care settings and associated ethical concerns regarding the use, intentions, risks and significance of the practice (Seymour et al., 2011, p.1).

Palliative sedation describes intentionally sedating a patient suffering uncontrollable refractory symptoms in the last days of life to the point of almost, or complete unconsciousness, and maintaining sedation until death – but not intentionally causing death (Claessens et al., 2008; Murray et al., 2008). This form of sedation 'brings intolerable suffering to an end and allows people to die peacefully' (Bruce and Boston, 2011, pp.2734-5).

Definitions of 'existential suffering' also vary (Albinsson and Strang, 2002; Breitbart et al., 2004), challenging assumptions that such suffering can be easily identified and therefore appropriately treated using medication. Components of this form of suffering include loss of personal meaning, loss of purpose, fear of death, despair, anguish, hopelessness, being a burden to others, loss of dignity, helplessness and betrayal (Bruce and Boston, 2011). Lavoie et al. (2008, p.5) describe existential anguish as the 'fear felt when facing the prospect of going to the beyond and anguish which comes from the apprehension of nothingness'. Blondeau et al. (2005, p.245) argue that existential suffering evokes expressions such as 'existential distress', 'psychical distress', 'existential anguish', 'mental anguish', 'mental distress', and 'emotional, psychological, and spiritual distress'.

In a study which asked chaplains, palliative care physicians and pain specialists to define existential pain, Strang et al. (2014) reported that chaplains stressed 'guilt issues as well as religious concerns', palliative care physicians described existential pain as being related to 'annihilation and impending separation' and pain specialists stressed that 'living is painful'. The authors concluded that existential pain is 'mostly used as a metaphor for overall suffering' and may be important in enhancing the experience of physical pain or indeed be the primary cause of physical pain. This resonates with my own observations of the physicality often associated with spiritual distress, which commonly localises to the thorax or abdomen.

The use of palliative sedation to treat intractable existential suffering in terminal illness also remains controversial; spiritual distress is one form of such suffering. Further, palliative sedation 'remains an uneasy practice', in which 'debates have centred on ethical issues surrounding decisions to use sedation and on separating the intent of palliative sedation (relief of intolerable symptoms) from the intent of euthanasia (hastening death)' (Bruce and Boston, 2011, p.2732).

Other authors have highlighted similar tensions (Engström et al., 2007; Simon et al., 2007; Seymour et al., 2011; Claessens et al., 2012). Such ethical ambiguity is further heightened by the lack of a universally agreed definition of existential suffering, so limiting consensus regarding the use of palliative sedation. Claessens et al. (2012, p.311), in an extensive literature review state that 'despite a very extended theoretical discussion in the medical literature, many questions remain unanswered due to a lack of conceptual clarity, clear definitions and guidelines, and the huge number of contradictions in the international empirical literature on the subject'. The authors also found the reported incidence of palliative sedation varied significantly, particularly in terms of setting, definition, and methodology. Possible explanations for this included a lack of clarity regarding 'refractory symptoms', variation in accepted indications for sedation, studies being situated within both community and hospice settings, methodological issues, patient characteristics, the country of origin (e.g. is euthanasia acceptable in law) and cultural issues (Claessens et al., 2012). Valid and reliable instruments specifically geared to assessing existential suffering in palliative care settings are also lacking. Again, this is similar for spiritual distress. Most instruments were based on self-developed questionnaires, incorporating little or no validation process and undermining the efficacy and generalisability of results. Also, most studies provided only vague information about procedures for obtaining informed consent from extremely ill and vulnerable patients. Also evident is that:

> Spiritual distress may be difficult to distinguish from psychological and physical distress, indicating the need for differential diagnostic markers to distinguish between genuine spiritual experience and psychosis related to the physical death process. Further, for hospice patients who are in genuine need of amelioration through pharmacologic suppression, the question of when and how to medicate becomes paramount as the distinction between spiritual process and psychosis becomes less evident (Kennedy and Cheston, 2003, p.131).

Curlin (2018, p.197) suggests that frequently such sedation is experienced as a loss by patients and loved ones, even though it appears to bring both peace and comfort: 'to be sedated is to be cut off existentially from human experience, to be made incapable of engaging self-consciously in any human action. To that extent, to lose consciousness is to lose something of real value'.

In summary, although palliative sedation guidelines for treating uncontrolled physical pain display broad international agreement, profound questions remain about the use of this form of sedation for 'unmanageable or intractable existential suffering' in terminally ill patients. Further, 'the challenges of treating existential suffering are compounded by multiple variations of definition, the subjective nature of its expression in both patients and clinicians as well as personal experiences of distress and vulnerability in nurses and physicians who witness existential suffering in their patients' (Bruce and Boston, 2011, p.2736). Stang et al. (2004) also highlight that staff frequently described a sense of 'feeling lost' when addressing these kinds of concerns and that existential issues present unique challenges in their management. Such suffering can create considerable conceptual and personal challenge for practitioners. Individual feelings of vulnerability, pain and fear amongst practitioners may also influence their ability and motivation to understand and assess existential suffering (see 3.17). Within EOL contexts, palliative sedation is commonly administered sub-cutaneously, using a McKinley T34 battery-operated syringe driver (see Appendix 4). The use of such sedation in community settings for existential suffering provided the origin for this study. However, my experience of community-based EOL care left many questions unaddressed, particularly within NHS contexts, including decision making regarding the use of sedative medication, dosages and treatment protocols, initial and ongoing assessment strategies, issues regarding patient consent, assumptions regarding the role of medication in facilitating a 'good death' and how such judgements were made. These questions could provide the focus of a separate thesis.

The most frequently utilised intervention mentioned by participants was that of palliative sedation. For example, this NHS participant (Participant 11) describes how sedation is used for patients who are distressed but unable to communicate verbally, either because they are close to death or because they lack mental capacity.

<u>Participant 11</u>

I. So, talking with patients can be helpful. Drug therapy: does that have a role, do you think?

P. I think it does. As I say, if you can't speak to; if you can't get; you're right on the last legs, and you can't [pauses] speak to them; you can't [pauses]; they may have dementia; they may have not got that mental capacity to discuss; they don't know what's troubling them [pauses] or not able to express what's troubling them [pauses]; yeah, I think we do, use the medication.

In contrast, another NHS participant (Participant 12) highlights their discomfort in using sedation routinely, describing this as ‘numbing the situation’ and preventing the patient from being able to address the cause(s) of their distress, should they wish to do this.

Participant 12

P. Well; I think the, the EOL medication can help patients that are agitated. Or [pauses]; eh, yeah, that can't settle, eh [pauses]. But I think in this spiritual distress, I'm not sure that medication would be the right thing. I think it would kind of just numb the situation. Or sort of make the patient sedated, that they wouldn’t be able to address it.

Clearly, enabling those patients who wish to address the causes of their spiritual distress is key within holistic approaches to EOL care.

This hospice-based participant (Participant 15) also expresses the view that medication may not always be appropriate, even though commonly used. The participant identifies that spiritual distress may predate any cancer diagnosis and suggests that analgesic or sedative medications are inappropriate. More effective would be to offer the patient opportunity and support to address the cause(s) of their distress.

Participant 15

I. So, things like drug therapy, would you say that had a role in that?

P. Sometimes; it just depends [pauses], in relation to what it is specifically that they're, they’re talking about. I mean; I don't think pain; I don’t think drugs necessarily would have helped her in that respect, apart from obviously, the ones that you would give for pain control. Erm, I don’t think drugs would have particularly helped with that, because a lot of it was, was stuff that had happened or stuff that had been started before she had even been diagnosed with the cancer. Erm; so, it may do, but without again, having a; without doing, you know, like you say, an audit of all of it, it’s difficult to determine I guess, really.

Another hospice-based participant (Participant 16) identifies how mild sedation is useful when combined with the physical presence of nursing staff. This participant describes how the use of both sedation and touch can be very helpful in patients who may be experiencing disturbing flashbacks, perhaps related to previous experiences in war time. However, such memories may have a range of possible causes, and be combined with regret, grief, or other difficult emotions.

<u>Participant 16</u>

P. And maybe, that is why, because they're, they're getting flashbacks and things. But, I mean, we tend to verbally say to them, "you're safe", you know, "we're with you, we'll stay with you", and everything [pauses], just to support them through that. Erm, but I mean sometimes, we, we, do offer them sedation, and sort of say, you know, erm, "we could give you some light sedation", sort of thing, "if you feel that would help".

I. Yeah.

P. And especially if it's during the night-time and things, then we would give them like, sleeping tablets and things, so that would just help [pauses] calm them, so they could have sleep and things, but; so, we use sort of a mixture of both; medications and, eh, talking to people. Being there with them, I think, is, is the main thing; for one of us just to stay [pauses] with that person, and just reassure them; hold their hand and say "it's, it's, you know, you're safe"; it's, that's not happening now", and things, so; but yeah, it's one of the ways.

This NHS participant (Participant 17) highlights the importance of ruling out possible physical causes of agitation, before administering medication. They also describe how they believe the use of such medication is only appropriate in patients who are either semi-conscious or unconscious, and therefore unable to communicate verbally. This differentiation between physical and possible spiritual causes of distress highlights the danger that sedation is used routinely, without adequate reflection.

<u>Participant 17</u>

I. And what about drug therapy?

P. I think, when patients are [pauses] semi-conscious or unconscious and become agitated and distressed, we do tend to give medication. So, we would tend to; if the family have called us in, and the patient seems agitated and distressed, and is, you know, clearly, erm, unable to explain what's going on, and they can't talk anymore, but they seem agitated and, and moving around in the bed a lot, and I; we, we would give Midazolam, usually as a stat dose, erm [pauses]; so, *we do. I haven't ever given that, I don't think, when someone's been able to communicate verbally what's going on. I, I think, certainly in recent years anyway, I've; really, I've only ever given that if somebody has been unable to communicate and they're, they're no longer alert.*

I. Sure.

P. Erm, so yeah, that's obviously an option as well, erm, having ruled out things like have they got a full bladder.

I. Sure.

P. All the physiological causes. Are they in pain? Are they, you know, trying to address all those, you know, rule out all the other problems it could be first and then, if they are still that way, then obviously, we'd give them Midazolam.

I. Sure.

This NHS participant (Participant 18) highlights the importance of non-verbal means of communication such as touch. Here, they identify sitting next to a patient and holding their hand. However, work related time pressures may prevent practitioners from doing this. This participant also highlights how drug therapy can be employed too quickly, resulting in patients being unable to focus on possible spiritual causes of distress. They also identify how patients who are dying at home may become anxious if left alone, which in turn may increase their physical sensation of pain. This then becomes a composite experience, whereby their degree of distress may influence their perception of pain.

Participant 18

P. Erm, [pauses]. So, I think talking, or giving that person the opportunity to talk, because not everybody wants to talk. I think it can be just coming down to sitting with somebody, like we were talking about before, just sitting and holding their hand, and giving them that time, which, unfortunately, we don't always have. Erm, [long pause]; the trouble with giving too many medications like; if a patient's agitated, and like, you know, it's, it's very easy, isn't it, to up and up their medication [pauses]; but I think sometimes, we have to give that [pauses]; I think we have to give something else a try first, sometimes. You know, obviously, you don't want that patient in pain so, you give them the painkillers, but, sometimes, it's like I must, they *must be, you know, they’re in pain; they're, they're anxious, they need Midazolam, you know, and actually, we can shoot that medication into them through a syringe driver, quickly, and then it numbs them, and then they're not able to [pauses] then, maybe, [pauses] focus on anything else, maybe like their spiritual side?*

I. I think that’s a really helpful differentiation between medication that just suppresses...

P. Yeah.

I. Erm, and medication that actually helps the person, to engage with something that, to them, is very important.

P. Yeah. We’ll start off really low, you know, and then sit with the person, or get the family to sit with them, hold their hand and, you know, see if that calms them down. I think the trouble is when, you know, patients have decided to die at home and the relatives want them at home, it's really hard for them when we leave and they’re there they're on their own, and I think there can become this panic [pauses] and, if you as a patient feel panicked; if, if your relatives or somebody around you is feeling panicked, then you pick up on that, and I think it can cause panic and agitation, and then they can become distressed, and then it can lead to their pain, but is it their spirit’s? Is it spiritual distress that is making them, you know, upset, anxious and then, in turn, their pain then is increasing, because it's, it's the whole thing, isn’t it?

This NHS participant (Participant 19) identifies how the syringe driver itself can cause distress to patients and families, because of its symbolic association with death. The participant graphically describes how a family member assumed that community nurses used syringe drivers to routinely perform euthanasia on patients, and therefore did not want the syringe driver box (essentially, a plastic toolbox containing the syringe driver and associated supplies, such as giving sets and syringes) within the home. This can be very difficult for practitioners to address, particularly within community contexts.

<u>Participant 19 (excerpt a)</u>

I. Where would you think that the, say, the syringe driver and the drug therapy fits into all this? Do you think that has a role in this?

P. In spiritual distress?

I. Yes. In alleviating spiritual distress. Do you think drug therapy is the…?

P. I have seen the actual syringe driver box, bag, cause distress. Taking that into a house. So, that's actually not alleviated the stress, it's caused stress, and its upset families before. Because they don't quite understand what it is we do. So, I have been asked before, don't bring that black box in here.

I. Right. How did you deal with that?

P. The daughter worked for an Undertakers.

I. Oh, o.k.

P. She was of the opinion that district nurses just came in, drugged the person up, and then they died.

I. Right.

P. And then her job took over. And though I explained to her, we're not here to actually perform euthanasia, it's just to make the patient comfortable [pauses]; erm, so that was, that was very difficult to actually do my job then, for that patient, erm, without upsetting the family, but I just explained that we're not doing that, we're just making the patient comfortable. So, erm [pauses] it's; you sometimes, you trigger something in somebody else, which causes an issue. That's why I was saying communication is sometimes a problem.

This participant also describes how, in their view, medications delivered via a syringe driver may not address the underlying causes of spiritual distress, but rather just suppress the manifestations. They also highlight the importance of ensuring that symptoms of distress may not have a simple physical cause, such as a full bladder.

<u>Participant 19 (transcript excerpt b)</u>

I. Do you think the syringe driver and the drugs are alleviating distress? Or just suppressing the level of distress?

P. I think they suppress it, because when the syringe driver runs out, people then; you can see they become more distressed. And then, quite often, we are increasing the dosage, aren't we? So, erm…

I. So, it's not necessarily addressing the issue? Or the underlying cause?

P. I don't think it's addressing it, yeah. So, that's why I'm saying we should address the issues first. Erm, sometimes people are so distressed, they could be, they're, they're not passing urine, and things like that. People don't think that could be a simple solution, not stick someone straight on a syringe driver, because they're distressed. It could be they're not passing urine, which is painful. You know, and just give them a pain patch or something to stop them being sick. Or, you know, on their tongue. So, yeah.

This hospice-based participant (Participant 8) describes her own experience of carers requesting sedation for a patient via a syringe driver because, in their view, it was unfair for the patient to continue living. This is disturbing and appears to be a request for euthanasia in a patient who was at the time conscious and communicative.

<u>Participant 8 (transcript excerpt a)</u>

I. Do you think that the; I'm trying not to lead the witness here. Do you think that the syringe driver cocktail of drugs is useful? Midazolam, maybe? I'm just interested. Not suggesting…

P. No, no, no. I think in some cases, yes. Erm; I think the Education behind the syringe driver with families is, erm. I had one today; the minute I got there they said, 'we need a syringe driver'. The twenty-four-hour carers were saying 'yeah, he's for a syringe driver, you know, 'he needs to be sedated, it's unfair for him, erm, to continue this life'. And I went in there; he's in a hospital bed, but he was talking, he was coherent, he was eating and drinking, he was swallowing, he was on his tablets erm, and I think their understanding was this is gonna put you to sleep and hasten death.

I. Right.

P. Erm, they weren't that impressed that I said at the time, that I don't think it's appropriate for him to have a syringe driver. I'm not saying he won't need one in the future, but [pauses], the medications that go in a syringe driver; he didn't have them symptoms. So, yes, he was worried about and anxious about that he wasn't ready to go; he wasn't ready to leave his beloved wife; there wasn't anything in the syringe driver that I could give to help him. He has Oxazepam that's there, that hasn't been given. So, I advised on that and on breathlessness, and advice on Oramorph and stuff, erm, but I think sometimes people's understanding is totally different on what it actually is. Erm [pauses], I think Midazolam helps a lot of people, especially

when they are imminently dying, and they are very restless, erm [pauses], but a lot of it, I think, is reassurance and family being there.
I. Yeah.

Transcript excerpts 19(a) and 8(a) raise important questions regarding expectations of family members and the knowledge base which underpins those expectations. Participant 8 also expressed the view that the use of medication should be combined with talking-therapies, and not used alone, describing how medication can prevent practitioners from listening to patients and identifying possible underlying causes of their distress. In their view, listening is important.

<u>Participant 8</u>

I. So talking therapies are quite important. Would you say drug therapy has any role in that kind of distress?
P. [pauses]; [sighs]. I don't know if it always does. I think it; it depends. If it's huge anxiety, then it might be that you do need to use some sort of drug therapy. As long as you use something else with it. As long as you use the talking therapies with it; because otherwise, you are just giving them a pill. That's all that everybody does. You just give them a pill. And then nobody actually listens to what it is they're talking about. So, it depends. I think you need to do the listening first, and then if you can figure out if there's a particular anxiety around, you know, they're very, very breathless and that then increases their anxiety, and then maybe drugs come into it, but I think you have to do the listening first to then figure out. Anti-depressants and things like that are always difficult because they take so long to get into the system, [pauses], and erm, our patients don't always have to have that long.
I. O.k.

Whilst it is evident that medication is the most utilised intervention for spiritual distress, it remains unclear why this is so. This may simply reflect existing clinical protocols, but other factors may also contribute to the dominance of palliative sedation as the primary intervention for spiritual distress. Also evident is that such sedation may prevent patients from attempting to address causes of spiritual distress, should they wish to do so. In this sense, medication may potentially undermine the delivery of holistic care. Further work is required to explore which (if any) of these hypotheses appear feasible.

6.7.2 Palliative sedation and work stress in palliative care nurses

An important question is does the prominent use of sedation serve to help reduce practitioner stress? Work related stress is well documented. For example, the UK Health and Safety Executive identify six domains of stressors within the workplace. These are:

- Inability to cope with demand (workload, work patterns).
- Inability to control the way work is done (lack of influence).
- Lack of information and/or support (managerial commitment).
- Relational issues (e.g. intimidation or bullying).
- Role specific issues (lacking understanding regarding role and/or responsibilities).
- Issues pertaining to support and change (managerial commitment/integrity).

(Source: Health and Safety Executive, 2020).

In an Irish study involving children's palliative care nurses, McCloskey and Taggart (2010, p.234) highlight six specific demands identified by participants:

- Emotional load (e.g. bereavement support, anxiety).
- Ethical conflicts.
- Constraints to the delivery of 'good care' (e.g. time constraints).
- Limited resources.
- Administrative burden.
- Living and working in the same community.

Regarding such 'emotional load', numerous questions appear pertinent regarding the use of medication within EOL contexts. These include:

1. Could the use of sedative medication also constitute a strategy to reduce work related stress for staff, by reducing the degree of engagement required with patients manifesting spiritual distress?

2. Are ‘stress’, ‘burnout’ or ‘compassion fatigue’ significant issues within palliative care settings, requiring staff to employ self-care strategies such as deliberately distancing themselves from distressed patients? Does the use of medication provide a source of such distancing?
3. Where service demands upon practitioners are significant and ongoing, does palliative sedation also provide a means of helping manage emotional demands upon staff?
4. Does the use of the syringe driver actually constitute ‘pharmacological last rites’?

Although stress and burnout within acute care, oncology and accident and emergency settings are well documented (Chang et al., 2007; Lim et al., 2010), studies specific to palliative care contexts are less common (Peters et al., 2012). The experience of burnout describes a loss of physical and mental energy, often combined with signs of distress, that make it impossible for those affected to perform normally, principally because of exhaustion. Burnout also differs from other healthcare related issues such as stress, vicarious trauma, moral distress and compassion fatigue (Pereira et al., 2011) and affects both the physical and mental health of the caregiver. Plante and Bouchard (1996) demonstrated that the level of occupational stress and burnout was significantly lower for palliative care nurses, compared to colleagues working in medical oncology units, due to the level of professional support. Payne (2001) also found that in hospice contexts the level of burnout, identified by the presence of significant levels of emotional exhaustion, depersonalisation of patients, and a reduced sense of personal accomplishment was low. Palliative care is also a unique context for nursing staff, due to its focus upon the needs of dying patients and their families, as opposed to contexts such as critical care, surgery or rehabilitation (Martens, 2009). Although work demands were a common cause of reported stress, ‘there was no strong evidence that palliative care or hospice nurses experienced higher levels of stress than nurses in other disciplines’ (Peters et al., 2012, p.561). This may be the result of palliative care nurses utilising effective strategies for coping with stress and avoiding burnout, the availability of effective support structures within palliative care settings or both. Common causes of stress related to ‘work environment, role conflict, and issues with patients and their families’. Further, the experience of stress is clearly individualised, and may be influenced by numerous factors, such as background and previous experience (Chang et al., 2007). Authors such as Wakefield (2000) have also highlighted the need for palliative care nurses to practice ‘relentless self-care’, particularly as this patient group may induce a sense of sadness amongst community palliative care staff (Newton and Waters, 2001). More recently, Brown (2021) has also highlighted the importance of practitioner self-care within EOL contexts, to allow practitioners to remain ‘present’ to those who are facing death.

Time was also a significant factor in participant responses. Nine participants (7 NHS, 2PH) described repeatedly feeling they had insufficient time to fulfil their caseload. Such time pressures may well impact both practitioner well-being and the use of palliative sedation, rather than the use of other interventions which are more time intensive (e.g. talking with patients. In contrast, eight hospice-based participants described having enough time to fulfil their role, a view shared by none of the NHS participants. Six participants (4 NHS, 2 PH) also described their workload/caseload as unrealistic, which appeared to negatively impact both their interaction with patients, job satisfaction, and overall well-being as practitioners.

To ascertain more effectively if medication usage also represents a self-care strategy, rather than simply constituting a key palliative care intervention, further research is required.

6.7.3 Palliative sedation and practitioner death anxiety

A further important question regarding the primacy of medication use for the alleviation of spiritual distress is whether this reflects a strategy to help minimise the emotional cost of caring for the dying? As described in the earlier literature review (see 3.17) the concept of practitioner death anxiety would appear relevant, as ‘high levels of death anxiety among those working in the health care setting may negatively influence their attitudes and behaviour towards the dying patient and their family’ (Boyle and Carter, 1998, p.38). Practitioner death anxiety has also been reported to negatively influence the quality of care provided to EOL patients (Brockopp et al., 1991; Santisteban et al., 2006; Braun et al., 2010). To date, the impact of death anxiety upon the ability of practitioners to prescribe and deliver nursing care within community-based EOL contexts remains largely unexamined. This study did not examine whether the use of medication was also a strategy to reduce either anxiety or the emotional cost to practitioners of caring for patients manifesting signs of spiritual distress or other challenging symptoms. Also evident was that practitioner death anxiety was not mentioned by most participants. This could reflect a lack of such anxiety, lack of awareness, denial or a reluctance to admit to emotions which could be perceived as weak or unprofessional. Or it could simply reflect that interviews did not attempt to explore this topic. This area would benefit from further study.

6.7.4 Talking with Patients (nurse-patient interaction)

Over half of participants identified talking with patients as a key intervention for the alleviation of spiritual distress. This was separate from the specific use of counselling or other talking therapies administered by members of the MDT such as counsellors or chaplains.

For example, this hospice-based practitioner (Practitioner 15) describes how, in her experience, patients frequently want to talk about what may be distressing them. In this example, the conversation took place during an initial visit to the patient’s home, during which the patient identified several important issues causing them distress. This then led to an MDT referral for counselling support.

Practitioner 15

I. With patients that are manifesting that kind of pain, what kind of interventions do you think help alleviate that? For example, talking with patients? Or drug therapy? What would you use for that?

P. Probably talking, because a lot of the time, they just want to talk to somebody about what they’re, what they're feeling. Erm, going back to the lady I mentioned before, I think she [pauses]; it came through as an urgent referral; with an urgent referral we have to see them within a couple of days; erm, because of her pain. And, I’d spoken to her on the telephone and made some adjustments to her medication before I saw her, erm, and then, when I went to see her at home, we talked about the pain and then it's; all this other stuff just came out, erm [pauses], and I think; I felt privileged in some respects, you know, it’s the first time I’d met this lady and she's telling me about all these things that happened; she talked to me about a friend that she’d, erm [pauses], loaned lent lots of money to, erm; and then when she found out that she had cancer, she hadn’t spoken to this friend since; all this stuff that came out; that I’m *thinking, God, I never would have expected this, when I came into this house today. I was expecting to come in and sort of, you know, tell her; ask her about her pain, and give her some recommendations about how we could manage the pain, but all that stuff came out; so, I think at that point, I think I said that I would come and see you again, the following week, erm; I asked the counsellors to make contact with regards to, because her husband's poorly as well, erm, and they were concerned about the fact that he wasn't working, erm [pauses]; I talked about complementary therapies, because I felt that might, may of helped and sometimes, when the complimentary therapy people go out; not necessarily the, erm, volunteer ones; they will just do the massage and stuff; but, obviously, the main one will sometimes have conversations with them erm, or, I think, well, I'll refer [emphasis], because I think they need some complimentary therapy but, they've got lots of issues with regards to their general well-being and their self, that, that could be brought up in the conversation, erm; I think that's how I did it, so, it's more talking; I don't think you can do physical things for total pain; if you see what I; for part of that total pain, it's just I think, a lot of the time they just want their, they just want their concerns[pauses]; they just want to talk about what, what's concerning them and how we can help support them, I think.*

Another hospice-based participant (Participant 2) highlighted the importance of listening in seeking to understand both the individual and their needs. Listening is clearly integral to effective communication, particularly where patients may be coping with a range of debilitating symptoms related to their disease, such as pain and fatigue.

Participant 2

I. O.k. Anything else apart from acupuncture?

P. Erm, I think listening is a big, big, big part.

I. Right. A sense of [pauses] arriving at understanding people who need to be understood. I think when a person feels understood by another human being, it goes a long way.

I. Sure. Yes, it does.

This NHS participant (Participant 21) again highlights the importance of listening to patients alongside the need for rapport, to facilitate communication. Sadly, they also describe how during day shifts, they do not have enough time to spend with patients. This was a common theme identified in interviews with NHS participants.

Participant 21

I. Putting aside the physical things, if we could, like the, maybe they've got a full bladder, if that's an issue, or maybe they've got physical pain, have you used any specific interventions, to help alleviate spiritual distress? So, for example, the lady you mentioned who wanted to confess something.

P. Yeah.

I. What would you do about that?

P. I've just sort of sat and listened, really. Just tried to; and that's what I say with relationships. When it's good to get to know them, and you know yourself, as a nurse; certain people get on better with other people.

I. Sure.

P. So, if I want to; if I had a patient and I got the; I got the vibes that they weren't keen on me, and I knew that they really got on well with another nurse, I'd kind of let them go in more, because they will get more, get more out of them. Erm, but no, as I say, it's timing really, because we don't get to stay with them. During the; when I've done nights, or whatever, you've got more time; you can sit with someone and [pauses] comfort them, and they will say "don't, don't leave me yet", or "can I just, can I just talk to you"; you just sort of gauge it from them, really.

This hospice-based participant (Participant 6) highlights the importance of talking to patients prior to the use of medication and trying to establish what individual patients may be feeling.

Participant 6

I. With that form of distress, are there specific interventions that you think help that, for example drug therapy or talking therapies that you would use personally if you saw patients with that? What would your approach be?

P. Ahem [pauses]. I think, erm, trying to establish, [pauses]; I mean, [pauses], really what that person's feeling I think is quite important. Erm, I mean, so talking I think is good, but obviously if talking cannot help, then I think the drug therapy would be something we would use, yeah. But I think if we can [pauses, sighs], attempt someone's distress, and help, before drugs, I think is a good thing, but I think there is a place for both, to be honest.

Another hospice-based participant (Participant 5) highlights the importance of talking with patients because counselling services within the hospice may have a waiting list and therefore initially be unavailable. Evident is that hospice-based nursing staff have far more daily interaction with patients and are therefore particularly situated to talk with those who may be manifesting signs of spiritual distress.

<u>Participant 5</u>

I. Are there particularly interventions that you would use for them? Maybe talking to people, or drug therapy, if it's anxiety?

P. Erm [pauses]. We do use medicinal erm, medications.

I. Right.

P. Erm, but I always think it's best talking and communicating, as best we can. We do refer to councillors: erm, our counselling team is very good [pauses], because they can't always talk to family, always. The unfortunate thing is there is sometimes a waiting list for the counsellors, so that could be difficult, you know; it's not as readily available, maybe, erm [pauses].

Unfortunately, there is no data to describe how long participants spoke with patients, nor the content of such conversations, or how such conversations were evaluated as to their effectiveness. However, talking with patients was identified by over half of participants.

6.7.5 Counselling or talking therapies (wider MDT- patient interaction)

Approximately half of participants identified referral to counselling or other talking therapies as a specific intervention for spiritual distress, as shown in Fig 15 and Table 14 (5.5). Four of these (1 NHS, 3 PH) had also identified talking with patients. Evident was that most participants who identified counselling or talking therapies were hospice-based; NHS participants who mentioned this intervention also described referring patients to the hospice counselling service. Again, this reflects the wide range of resources readily available to hospice-based participants, in contrast to NHS participants.

For example, this hospice-based participant (Participant 14) describes their own willingness to engage in conversation with patients concerning ‘spiritual concerns’, giving the example of a patient who fears judgement after death. However, despite this willingness, they also describe how they did not see this as ‘their place’ and previously had referred patients to the hospice chaplaincy service.

<u>Participant 14</u>

I. Just thinking about that form of distress that….

P. Erm.

I. That you’ve mentioned; erm; have you used any specific interventions to help alleviate that? For example, talking with patients, or drug therapy?

P. I have; I would talk to people [pauses]; I mean, obviously, if they are afraid of what happens when they die, and if they’re going to be judged that’s [pauses]; not really. I mean, I'm quite happy to talk to people, sort of on a spiritual basis, so that’s good. But, I wouldn’t [pauses] think that that was really my place. I would [pauses]; years ago, we used to have a [pauses] a, a member of the clergy here; we had a, oh, what’s it called?

I. Chaplain?

P. Chaplain. Thank you. Just know, you can fill in the blanks for me [laughs]. We could go and [pauses] we did. I used to go, if the chaplain was around; I would say “can you come and see this patient. I think they would benefit from”, say, “counselling”. I mean, we’ve got the counsellors. Still, obviously, I would refer them on, I think.

I. So, counselling would be one thing that would be useful?

P. Yeah.

Another hospice-based participant (Participant 16) explains how they would usually refer patients to other MDT members such as a spiritual lead or counsellor, highlighting that some individuals, particularly older patients, may find it difficult to articulate the reason for their distress as such sharing of personal issues was foreign to them.

Participant 16

I. That sort of distress; when people have angst about various things. Erm [pauses]; what kind of interventions do you think help that? What have you used for that, if you have got someone, for example, very fearful, or in; I know you have this term here called total pain?

P. Ahem.

I. The kind of pain that is in the gut.

P. Ahem.

I. Because of various issues that may be around family, or whatever. What kind of things do you use for that? Do you use talking therapy? Or drug therapy? Or?

P. Well, I mean, we do encourage them to, to talk about it.

I. Yeah.

P. Erm [pauses]; that's where we would get our spiritual lead or counsellors or, you know, the nursing staff [pauses], erm, will [pauses] let them talk through what they want to talk about, whatever is, you know, distressing them. I mean, sometimes, some people just can't talk about it, if it's something like post-traumatic stress and things. Those people haven't, you know, the older generation just haven't been encouraged to actually talk about it [sighs]; and I find sometimes, that they're the ones that get very distressed [sighs].

I. Sure.

This hospice-based participant (Participant 3) suggests that medication may not be appropriate for the alleviation of spiritual distress, instead highlighting the importance of supporting patients as they engage with possible causes of their distress. They also highlight the use of talking therapies and proximity to available resources, such as the MDT.

Participant 3

I. Would you see, for example, taking with patients, or drug therapy; would they have roles for you in trying to alleviate this form of distress?

P. Erm. I don't know that medication is the way to go with sort of, spiritual distress. We've got a whole raft of different anti-depressants and things like that; that we can use, but it doesn't always feel appropriate to medicate. A lot of the time it's about supporting people to work through it than it is trying to medicate the symptoms of it.

I. So taking therapies would be something that you would utilise as well?

P. Absolutely.

I. Anything else that you have seen or used, or that you think would be appropriate in helping the patient with that sort of distress? That you have found helpful?

P. I don't think so. As I've said, here, we are very lucky. We have a real multidisciplinary approach to supporting patients and so, I would often refer to other members of the team.

I. O.k.

Access to counselling or other talking therapies was clearly an important intervention for the alleviation of spiritual distress

6.7.6 Referral to other MDT members

All participants that identified referral to other MDT members were hospice-based. This is likely to reflect both the availability and proximity of other MDT members within the hospice context, an arrangement not mirrored within NHS community contexts. For example, NHS participants generally only attend MDT meetings monthly, and would normally have to travel to such meetings. All hospice-based participants that mentioned referral to other MDT members as a specific intervention for spiritual distress did so favourably. The transcript excerpts below (Participants 13 and 3) were typical responses, highlighting the value of the MDT as a key resource for hospice staff.

<u>Participant 13</u>

I. Have you used any specific interventions to help alleviate spiritual distress.

P. I think we do quite well, in the sense that we have got the multi-professional team; so, obviously, we have got spiritual leaders, of whatever sort, and denomination, we can go to. We have the counsellors; we have other people; the O.T's have got, I think, some knowledge in behavioural, cognitive support, and things like that. So, there are things; there are people we *can go to, if we feel we are getting out of our depth. So, I think, from that aspect, we probably take a step towards more spiritual care.*

I. Right.

Participant 3

I. In terms of that kind of distress, would you use any specific interventions to help alleviate that, in your experience? Are there particular things that you think yeah, they are the kinds of things that would be helpful? What would they be?

P. Yeah. There's sort of our MDT here, the councillors, the chaplains, the social workers, some of the therapeutic groups, that go on in our day therapy centres. Erm.

I. Sorry. Would they also go out into the community?

P. They can go out, yeah. Anyone will go out to visit people at home, and if patient's are able to get here, we run an art group here, and the girls who run the art group, they will go out to see patients at home, erm, if they are unable to get in, and do some work with them erm, [pauses]; making memory boxes, and things like that. We find, with some patients, it's sometimes that distress can be about o.k., they're going to die, so what's their legacy going to be? What are they leaving behind? What are people going to remember them for so, erm [pauses]; they do a lot of work with people about making memory boxes [pauses], so that they know they had an impact on the world when they no longer in it; that they made a mark, and they made a difference to people.

This hospice-based participant (Participant 8) contrasts their previous experience as an NHS community nurse, highlighting not only the use of medication administered by syringe driver and time pressures in their previous role but also how the availability of MDT resources within the hospice was a new experience, facilitating increased options for intervention.

Participant 8

I. So, drugs may be, but particularly listening; communication you've said. Anything else that helps? That would help someone who is manifesting spiritual distress. To help alleviate that.

P. [long pause]. Erm, [pauses], I think, this will sound daft, but a bit of honesty of what's going on? Erm, cos sometimes you're very surprised about how far people have come, and they just *have no idea what's going on. The family have no idea; it comes down to communication, unfortunately [laughs].*

I. That’s a very valid point.

P. And erm, erm, reassurance but, I think [pauses], us [pauses], I think a district nurse background, we've always been like symptom control, syringe drivers and everything, because we're not with them all the time.

I. Yeah.

P. And we see them when their syringe driver really comes up, or when they've needed their injection, injectable medications first. Erm, whereas here, we have such a big; we have a large rapport with them, and we can see them for a year or so and have regular contact, erm, so I think [pauses].

I. And I suppose you have got access to a whole range of other, erm, professionals here?

P. Which I’ve not been used to. Which I’ve not been used to at all. Erm [pauses]. Yeah, I think that the drugs are the last thing that sometimes people think about, because [pauses]; with healthcare professionals, they know that we do the drug stuff; it's all the other stuff that’s important to them that we need to do.

I. O.k.

Typically, for NHS community staff, access to the MDT was sporadic and face to face MDT meetings usually occurred only monthly. This contrast was repeatedly evident within interview data. In my own experience, this lack of access to other MDT members frequently hindered communication, impacted patient care and constituted a significant source of stress.

6.7.7 Referral to Hospice

Five participants identified referral to the hospice as interventions. Two of these were NHS participants (Participants 11 and 17). The first describes how, in their view, the hospice MDT have more time to engage with patients, compared to NHS staff. The second highlights that the patients they referred were all able and willing to communicate their feelings regarding their illness.

Participant 11

I. Would you see anything else? A referral to other agencies? Or use of, if the patient's able, say craft?

P. Generally, the hospice are really good with that, aren't they? They will go and talk to them, because they have more time. We fit in what we can fit in. As I say, I could talk for England. I try and make them laugh a bit, so that the next time I go, they're then at ease, and they will tell you things. They do tell you; like the lady whose daughter had gone out, and then she said, "I do have two other children". She just wanted to say it, I think.

Participant 17

I have had patients, as I said before, who I've referred to the hospice. They've been very much able to communicate how they're feeling about things, and I've referred to the hospice for counselling and they've accepted that.

The remaining three participants were all hospice-based and described how they would refer patients to the hospice day hospital or other members of the MDT. The following response (Participant 3) was typical. Here, the participant poignantly describes the use of memory boxes for patients, to help them address the issue of leaving a personal legacy for their loved ones. They also identify a wide range of other MDT resources, including art therapy.

Participant 3

I. O.k.

I. In terms of that kind of distress, would you use any specific interventions to help alleviate that, in your experience? Are there particular things that you think yeah, they are the kinds of things that would be helpful? What would they be?

P. Yeah. There's sort of our MDT here, the councillors, the chaplains, the social workers, some of the therapeutic groups, that go on in our day therapy centres. Erm.

I. Sorry. Would they also go out into the community?

P. They can go out, yeah. Anyone will go out to visit people at home, and if patients are able to get here, we run an art group here, and the girls who run the art group, they will go out to see patients at home, erm, if they are unable to get in, and do some work with them erm, [pauses];

making memory boxes, and things like that. We find, with some patients, it's sometimes that distress can be about o.k., they're going to die, so what's their legacy going to be? What are they leaving behind? What are people going to remember them for so, erm [pauses]; they do a lot of work with people about making memory boxes [pauses], so that they know they had an impact on the world when they are no longer in it; that they made a mark, and they made a difference to people.

Once again, the mismatch between hospice and NHS resources is evident.

6.7.8 Referral to a spiritual advisor

Four participants (3 NHS, 1 PH) identified referral to a spiritual advisor as key interventions. Surprisingly, fewer hospice-based participants chose this option. For example, this NHS participant (Participant 1) describes how they have contacted a local priest and arranged a prayer partner for a patient when asked.

Participant 1

I. What would they be? Can you give me some examples?

P. Erm, I've contacted the local vicar, or the local priest. And even, erm [pauses] I've hosted people to the church as a whole, the pastoral side of church. So, if anyone wants a prayer partner, erm, I know how to signpost for that and to seek their permission, if they want the contact made, if they are uncomfortable about making the contact themselves. I've been asked to do that for people.

Another NHS participant (Participant 17) describes how they routinely ask if patients would like to see a religious leader, though none to date had responded to this invitation. She also comments that patients may already have access to a spiritual advisor if they are part of a religious community.

Participant 17

I. Anything else?

P. Erm [pauses]. I have always asked if somebody, if anybody would like to see a religious leader. Nobody has actually said yes to that, yet, and I think some people, some people who are usually people who actively have a faith, that is, they're, erm, practising their faith;

normally, they've already arranged that, and family have already asked for either a vicar or a religious leader to come in and, erm, see them [pauses].

This hospice-based participant (Participant 14) describes how previously, patients would be referred to a hospice chaplain. This term is now being replaced by that of 'spiritual-lead'.

Participant 14

I. Just thinking about that form of distress that…

P. Erm.

I. That you've mentioned; erm; have you used any specific interventions to help alleviate that? For example, talking with patients, or drug therapy?

P. I have; I would talk to people [pauses]; I mean, obviously, if they are afraid of what happens when they die, and if they're going to be judged that's [pauses]; not really. I mean, I'm quite happy to talk to people, sort of on a spiritual basis, so that's good. But I wouldn't, [pauses] think that that was really my place. I would [pauses]; years ago, we used to have a [pauses] a, a member of the clergy here…I used to go, if the chaplain was around; I would say "can you come and see this patient".

6.7.9 Complimentary therapies

Five participants (1 NHS, 4 PH) identified complimentary therapies as key to the alleviation of spiritual distress. This differentiation may again reflect the availability of MDT resources within the hospices used for data collection. For example, this NHS participant (Participant 20) describes the use of multi-sensory stimuli, such as music, joss sticks and scented candles.

Participant 20

I. Anything else, that you think would be useful, in helping alleviate spiritual distress? [pauses]. In end of life patients.

P. Ahem. End of life. Erm [pauses]. What else would be useful? [pauses]. I've had people that have sort of used Incense, and things like that.

I. Right.

P. And they've found that's, that's what they've wanted; when you go in, and you've got the Josticks, or centred candles, and erm, that's what they found has calmed them down. I had *another one that had very, erm, soothing music. They had, like, classical music on in the background, which is what they wanted.*

I. So, that would be sensory?

P. Sensory, yeah.

This hospice-based participant (Participant 14) highlights yoga and massage, but also describes how such therapies may only be useful as a 'starting point', when the level of distress was more moderate. This seems an important differentiation. Of interest is their description of medication as a more 'professional' intervention.

<u>Participant 14</u>

I. Anything else, that would help alleviate that form of distress?

P. Erm [pauses].

I. That you've used here, or you've used in your own practice?

P. Well, we've got, erm, complimentary therapy.

I. Right.

P. Erm [pauses]; So, I would refer them to complimentary therapy, if I felt that would be helpful. Yoga [long pause].

I. And, do you think they reduce or alleviate the distress? Or distract from the distress?

P. [pauses]. I think they can alleviate the distress, but again, that would depend on; perhaps, the level.

I. Right.

P. [pauses]. Erm; whether they needed more professional [pauses]; drug therapy or something; I think it would be a good starting point; [pauses].

I. Right.

I. And any other interventions that you personally use? Or would?

P. Well, I know that they; massage has been used, but I know that comes under complimentary therapies, doesn't it. Erm [pauses]; and, and some of the girls on the ward do hand massage.

I. Right.

Another hospice-based participant (Participant 15) suggests that while alternative therapies may not address the underlying cause(s) of spiritual distress, they do provide relief and promote relaxation, allowing the patient 'space' to address their distress, should they wish to. Again, this seems an important differentiation.

Participant 15

I. And, do you think those complimentary therapies; are they [pauses] ways of actually addressing the spiritual pain? Or are they distractions from the spiritual pain?

P. Possibly distractions?

I. O.k.

P. But, I think having the complimentary therapy allows people to relax and [pauses] yeah; I mean it might; it might, it might do, but it, it probably would, like you say, it would distract them enough so they're not probably, possibly thinking about those issues at that point. But then will relax; I think when you're relaxed, things are a bit easier to deal with than if you're really tense and het up about stuff, because then you can never get, never get anywhere, I don't think.

I. Or, maybe give them a space to process?

P. Ahem. Yeah, yeah.

I. Those issues that they are trying to deal with. O.k.

6.7.10 Other communication-based interventions

In addition to talking to patients, a small number of participants also identified other communication related interventions. These were:

- Clarifying misconceptions.
- Allowing patients time to share concerns.
- Attending to professional image.

Each are illustrated below.

Clarifying misconceptions

This hospice-based participant (Participant 8) highlights how patients and their families may be unaware of what is happening, even though they may have had contact with the hospice for some time. This may be due to poor communication but clearly could also result from a process of denial.

Participant 8

I. So, drugs may be, but particularly listening; communication you've said. Anything else that helps? That would help someone who is manifesting spiritual distress. To help alleviate that.

P. [long pause]. Erm, [pauses], I think, this will sound daft, but a bit of honesty of what's going on? Erm, cos sometimes you're very surprised about how far people have come, and they just have no idea what's going on. The family have no idea; it comes down to communication, unfortunately [laughs].

I. That's a very valid point.

This NHS participant (Participant 1) also highlights the need to clarify misconceptions, which here centre upon the syringe driver and referral to a priest or spiritual leader. In the experience of this participant, both have come to symbolise that death is imminent, which clearly may not be the case.

Participant 1

P. Erm, and just encourage people to have the conversation. So, relatives who are afraid to speak, because they think, quite often if they hear mention of the syringe driver, or if you mention the words syringe driver, people think 'I'm about to die'. If you mention the word, would you like to see a priest, or would you like to have the vicar to come round for communion, erm, or the sacrament for the sick, they think I'm about to die, and they don't want to hear that, thanks, because quite a lot of them, you see, 'no, no, not happening' [raises voice].

Both participants would appear to be encouraging honesty in communication between patients, families and nursing staff.

Allowing patients time to share concerns

Two hospice-based participants (Participants 13 and 4) identified allowing patients enough time to share concerns, should they wish to do so, within the daily demands of the hospice. For example:

Participant 13

I. Are there specific interventions that you have used? As a practitioner?

P. Well, I think; well just, yeah; I mean, again [pauses]; I think erm [pauses]; I think certain skills are used intuitively, in a way. So, I wouldn't be able; as I say; it's a question of not, not being worried about what people are going to say to you, or feeling you've got to cut them short, or again; there is a balance of course. Because you can't give a person half a day, to; you know; you've got to have some boundaries. Erm; but, as far as you can, as a practitioner, you know; it might be giving an extra ten minutes, fifteen minutes, whatever it is; if, if people are to share about their fears and their previous, you know, concerns about life, and things like that; it's giving them that space to do it. Erm; now again, that is such an individual thing, about [pauses]; when we do that and when we don't do that. Erm, again; I'm not sure you can easily [pauses] factor in, eh, a procedure, for doing that.

Attending to professional image

One NHS participant (Participant 20) identified professional image as important to the alleviation of spiritual distress. They were the only participant to mention this form of non-verbal communication as a specific intervention. In this excerpt, they also highlight the importance of using perfume and lipstick to boost their own 'professional persona' and so aid their delivery of effective patient care and personal coping as a practitioner (e.g. Hayward and Tuckey, 2011).

Participant 20

I. And any particular interventions that you have personally used?

P. [long pause]. Don't know. I always make sure that when I go in, I've, I've, erm, maybe put a bit of lippy on and, sometimes, a bit of perfume [laughs]. Depending on what the situation is. Yeah, so, eh...

I. Because?

P. I don't know whether that's for my own; you know, if I feel, if I feel o.k., I think right, I can deal with whatever they throw at me, really. If they say, "oh, this hasn't gone right", or "what do you think about this", then I can say.

I. So, it helps your professional…

P. I think it helps my own professional persona, yeah. Yeah, makes me feel a bit better [laughs].

I. And that helps you cope with it?

P. Yeah. That's probably part of my coping mechanism [pauses] yeah; because I might refer to; another part my own coping mechanism is that erm, I might use their first name when I'm talking to them, but in my notes and that, I will always put their surname. And I think that's; erm, that's how I, sort of, erm, cope.

6.7.11 Other interventions

Other interventions identified by a single participant included:

- Eliminating physical causes of distress.
- Limiting the number of family members present.
- Use of memory boxes.
- Readings from the Bible.
- Support of family/loved ones.

These are illustrated below.

<u>Eliminating physical causes of distress</u>

As mentioned earlier, patient distress can be caused by a variety of physical causes. This NHS participant (Participant 11) describes how seeking to identify such causes of distress is integral to nursing assessment. However, the participant does not identify spiritual causes of distress.

<u>Participant 11</u>

P. Only. Yeah. Like the patient that actually had a full bladder. Erm, so, I think you do your nursing assessments first, don't you? But, apart from that, if there's nothing obvious. They may be in pain, or they may have a sore brewing, or red areas that are causing them discomfort. Are we talking about them not being able to tell you? Or earlier?

I. I'm talking about patients that you may have identified having a spiritual need. Spiritual pain. Not physical pain. Like the gentleman who…

P. Yeah. I don't think I identify it. I think; we are what we are, aren't we? [pauses]. We do what we do.

Limiting the number of family members present

Spiritual distress can result from unresolved relational issues or relational breakdown. This NHS participant (Participant 17) describes how patients may be distressed either by the presence or absence of family members/significant others, and how distress can be reduced by limiting the number of family members present. Clearly, this may not address the specific cause of distress.

Participant 17

P. The other thing we've had, erm, as well, is if we've arrived and there's a room full of relatives, and the patient is clearly, even if they're able to verbalize it, would never dare tell their family how it's making them feel, and then actually have asked them just to leave for a moment, and had a chat with the patient, erm, and sometimes, if they're unconscious, obviously just made that decision, and, and taken the family to one side and said "look, it's lovely that you want to be here. I think it might be causing a bit more distress, cos there are so many of you". You know, "maybe you could come in in pairs, rather than everyone all at once". For other people, I've actually asked, erm, "has everybody been?"; "has everybody visited"? Because, for some patients, you really get a sense that they're waiting for someone; that they've, you know, they're, they're anxious and distressed, cos they haven't seen; maybe it's a daughter that's; or you necessarily, sometimes you know that their daughter is on their way; they live a long way away; family have already called them, and you know that this patient; you're surprised almost, that they're still, erm [pauses], you know, they're still alive, really. Because it feels like they're hanging on for something, and then a relative that is erm expected, arrived and literally, the next day, the patient dies, erm, and the family will say well, they were very calm, very peaceful, you know, and actually you think well, I think they were waiting for that member of the family. So, I think having; I think all those things are things you look at; has everybody seen them that they wanted to see? Are too many visiting at once? Do we need to ask them to come in just in pairs? And I have seen that make a difference as well, where actually, you know, we've had several visits where they seem quite agitated; there's lots of people around the bed, and then actually, to have had that conversation with the family and then, you know, the next visits you've made, the patient's much more calm, because they are spacing out the visits [pauses].

Use of memory boxes or digital filming

A possible cause of distress to patients was that they would not be remembered. An intervention to help alleviate this anxiety is the use of memory boxes or digital filming, as described by this hospice-based participant (Participant 4). This activity highlights the importance of leaving a personal legacy.

Participant 4

I. So the memory boxes and the digital filming are helping to alleviate distress related to being remembered? To their families remembering them.

P. I think it's a very individual. For some people with young children, it's about being remembered and maybe giving them some of their wisdom from life, putting that in the box, you know, this is what I've learnt. Erm [pauses]. And I think; I think sometimes for older people, and maybe for men, and I might be generalising here, some of the gentlemen, I think it's maybe, it's putting down or writing down what they couldn't say, face to face. I don't know. Some people are more guarded aren't they, than others, erm, but maybe they still want to want to leave that as a memory.

I. So for them, the alleviation of the distress, is about being able to share what's precious to them?

P. Yeah, yeah.

Readings from the Bible

An NHS participant (Participant 17) who was also a Christian described reading from the Bible to a patient who was no longer able to communicate, an intervention which had a dramatic impact on the patient's degree of distress and was witnessed by nursing colleagues. This seemed wholly appropriate for this patient.

Participant 17

P. We did have, eh, a lady; this was in my training so, going back sometime, and I knew that she was a, erm, she was a Christian and she followed; I can't think of [pauses]; Salvation Army.

I. This was a patient?

P. Yes, she was a patient. Yeah. And she had; she was dying, and right up until the end, she was talking to people about her faith and sharing verses and so, when she was dying, she did seem very agitated and I sat down and read to her from her Bible from the Psalms and picked a couple of Psalms out that I knew would be reassuring, I suppose, because I had the same faith. It helped that I had an idea of where to go in the Bible, and that very much made a massive impact; she completely calmed down, she was much more sedate, she was calmer, erm, and as she died, I was reading to her as she died, and for her, that was very [pauses], erm, obvious, that it made a difference, cos from the moment [pauses]; you could see from before we started reading to her; there were several nurses around, you know, in the room, and from then to actually starting to read to her, during; the further I got through them, the more calm she became, erm, and she couldn't communicate; she was beyond communication to us, so I've done that.

<u>Support of family/loved ones</u>

One NHS participant (Participant 1) also identified supporting family members/loved ones who may themselves be displaying signs of distress, often from witnessing a patient exhibiting distress. Support of family/loved ones then becomes an integral aspect of holistic care.

<u>Participant 1</u>

P. When you think people are agitated, and irritated, and they are. You, you don't know why they're agitated and irritated, so I guess quite often our response is sort that out [laughs]. The other thing we might possibly do unknowingly, is treat the family.

I. Right.

P. Because they're distressed at seeing the distress.

I. So, what do you feel you can offer them?

P. Erm, I offer them my time.

I. Which is a precious commodity.

P. And I will stay with them and talk with them about what do you need? Do you need, and if they just need a breather, erm, to be able to come back and cope, if they need to speak to somebody, I can make a phone call for them, again, but I just spend time speaking to them, *just hopefully letting them know that their health is as important to me as the health of the patient. Yeah.*

6.7.12 Themes relating to delivery of interventions

Time related issues and training needs were the most prominent themes, followed by the lateness of patient referral. For NHS participants, referral which was too late and very close to death frequently resulted in patients who were either semi-conscious or indeed unconscious, making assessment of possible distress virtually impossible and negating the possibility for interventions should these have been appropriate.

Time related issues divided into two defined sub-themes; practitioners who felt they had sufficient time to address symptoms and possible causes of distress and those who felt they lacked sufficient time to address either. For example, nine participants (7 NHS, 2 PH) stated they had insufficient time to manage their caseload, whereas eight participants (all hospice - based) stated there was sufficient time for caseload management. Six participants (6 NHS, 2 PH) stated their caseload was consistently unrealistic. Once again, the difference between hospice and NHS participants was evident, underlining both variability in case load demand and availability of additional resources, such as the MDT.

The need for organisational staff support was highlighted by seven participants (1 NHS, 6 PH), and six participants (1 NHS, 6 PH) identified the importance of individual self-care. Both themes would appear to reflect the unique demands of EOL contexts.

Five participants (4 NHS, 1 PH) identified the emotional cost to staff of providing specific interventions and five NHS participants identified communication issues with other colleagues, such as GP's. These issues were perceived negatively (e.g. difficulty in contacting MDT members if medication dosages needed to be changed). Five participants (4 NHS, 1 PH) identified other medication related issues, such as difficulty in medication procurement. Once again, this reflected the lack of immediate MDT resource and/or medication availability.

Four participants (1 NHS, 3 PH) identified the theme of nursing staff symbolising the approach of death to patients and their families, particularly in relation to either bringing a syringe driver and/or syringe driver box (a box containing syringe driver equipment such as giving sets, batteries etc.) into the home or by being connected to the hospice. For some patients and/or their families, such symbolic meaning(s) led to a profoundly negative emotional reaction requiring considerable skill and insight to overcome.

6.7.13 Is there any commonality of practice?

Some commonality of practice was evident. For example, the two most identified interventions (medication use and talking with patients) were utilised both by NHS and hospice-based participants. However, more hospice-based participants identified talking with patients and two thirds of participants who identified referral to counselling were also hospice-based. All participants who identified referral to other MDT members were hospice-based, as were those who mentioned referral to therapeutic groups such as art or aromatherapy, reflecting the immediate proximity of such resources. Further, daily contact between hospice participants and other MDT members facilitated both referral and access to advice. All three hospice sites also offered day hospital facilities for patients well enough to travel. Other interventions identified by participants seem to reflect practitioner preference and experience. None would appear to form part of a specific protocol for the alleviation of spiritual distress within either context.

6.7.14 Categorisation of Interventions.

Interventions can be categorised using the following framework.

Distractive

These interventions do not attempt to address possible cause(s) of spiritual distress but rather seek to distract the patient, so reducing the experience of distress. The use of music or other sensory interventions (e.g. massage) are examples of this type of intervention.

Suppressive

These interventions also do not address possible causes(s) of spiritual distress but rather seek to suppress possible manifestations. The use of sedative medication(s), often administered via syringe driver, is an example of this type of intervention.

Focused

These interventions directly attempt to address possible cause(s) of distress, such as loss of hope or relational breakdown. Practitioners talking with patients and specific talking therapies such as counselling are both examples of this type of intervention.

Blended

These interventions are used in combination to both suppress possible manifestations of spiritual distress and allow the patient to then address possible underlying causes, should they wish to do so. The use of medication and/or sensory interventions, combined with subsequent talking therapies such as counselling is an example of a blended approach. Medication dosage is clearly important, to ensure that sedation does not undermine patient engagement with the interventions employed.

6.7.15 Perceived effectiveness of interventions: themes

The most common theme from interview data was that the effectiveness of specific interventions was an intuitive judgement made by individual practitioners. The use of intuition alone was identified by nine participants. Additionally, seven hospice-based participants stated that alongside their own intuitive judgement, effectiveness of interventions would also be assessed in consultation with the wider multi-disciplinary team. No NHS participants mentioned consulting the MDT in this way. For example, the response of this hospice participant (Participant 3) was typical and illustrates the use of intuitive judgement in assessing the effectiveness of interventions.

Participant 3

I. O.k. Those kinds of interventions. Do you think there's, erm, a way of measuring how effective they are? Would that again be something you'd do intuitively? Or in discussion with others? Or do you have any measures that you use?

P. Erm. So, the IPOS that I mentioned. We do that every time we see patients, or if they are doing a group or something like that; they would do it at the beginning; they would do it at the end; and that puts a numerical score on something, so we can see if there's a difference, erm, from that perspective. But, as I've said, numbers don't always help. It's often about intuition, and what the patient actually tells you, and whether they feel it's made a difference, rather than tick boxes that come out with a score at the end.

I. And would you involve the patient's family or carers in those discussions?

P. Yeah. Yeah.

This NHS participant (Participant 17) also mentions intuitive judgement and relates this to discussions with other nursing colleagues (rather than the wider MDT).

Participant 17

I. Do you think there's a way of measuring; erm, those kinds of interventions; the talking therapies, the drug therapies, whatever it might be. Do you think there's any way of measuring how effective they are?

P. I think there is, because we have; as I say, in my experience, I've seen; again, it's just intuition and you're picking up on cues all the time, of, of how that patient is. So, I can see; if I can see how somebody is calmer after an intervention has taken place, or after family members come, or after they've been having talking therapy; I think if I can see a physical difference, in how they are, and how they seem in themselves, there must be a way of measuring [pauses], to a point.

I. Yeah.

P. So, I would say, yeah.

I. And is that intuitive judgement something that you make, but also with reflection with colleagues? Is that something you do as a team?

P. Yes. Yeah. Yeah. Definitely. We'll sort of look at has; erm, for example, if we've referred someone on to, you know, the hospice, for talking therapy, you know, or the family and, actually, afterwards, kind of been able to talk to them. Erm, I remember a lady we saw on twilights, and talking to her; she'd been to the hospice, and she was, erm, going to; I think they are we doing like art sessions with her?

I. Sure.

P. Erm; she was finding that really helpful, and really effective, and you could see it, just by talking to her; she was sort of saying 'it's, it's been wonderful; I've really enjoyed going; and it's really given me something to look forward to'. Erm, so I think yeah, you can definitely measure that.

I. But, you don't have say, standardised methods?

P. No.

Three hospice-based participants stated that, in their view, it was difficult to measure effectiveness of specific interventions and three participants reported that they were unaware of any standardised tools that could be used to measure effectiveness. Three hospice-based participants stated that they had used the IPOS when patients had attended the hospice as a day patient. Two participants (1 NHS, 1 PH) stated it was not possible to measure effectiveness because of the number of variables that would need to be considered; two NHS participants stated they had not considered if effectiveness could be measured. It was also evident that responses relating to attempts to measure the effectiveness of interventions differed between NHS and hospice-based participants, and that the assessment of effectiveness was not standardised throughout both NHS and hospice care settings. This is unfortunate and suggests that the effectiveness of interventions may be perceived differently by individual practitioners, particularly as few specific assessment tools were utilised in either setting to help objectify the process of assessment.

It could also be argued that intuitive judgement changes with experience; however, this was not a specific aim of the study and further research is required to establish the impact of practitioner experience and the use of intuitive judgement in assessing the effectiveness of specific interventions utilised for the alleviation of spiritual distress.

6.7.16 Summary

Interview data highlight a range of interventions utilised by participants to help alleviate spiritual distress. Also apparent is significant resource inequalities between hospice and NHS participants, particularly in terms of talking therapies and availability to other MDT members. Such inequalities make it significantly more difficult for NHS practitioners to address spiritual distress in EOL patients dying at home. This is unfortunate. For many participants, the perceived effectiveness of interventions generally relied on intuitive judgement alone, rather than the use of assessment tools or specific local protocols. Again, this is unfortunate and may result in variation in the perceived effectiveness of interventions amongst practitioners within the same clinical context. Some commonality in terms of interventions was also evident between the two community contexts. However, there was once again a significant difference in available resources between hospice and NHS settings.

6.8 Meaning making for practitioners

Though not a specific research question, the way in which practitioners formed conceptual meanings regarding key concepts appears important. For example, this study arose from my experience of using a McKinley T34 syringe driver (Appendix 4) to deliver drug therapy to community-based patients designated 'EOL'. As well as being a simple battery powered pump, the syringe driver also appeared to represent a symbol replete with meaning; personally, organisationally and to wider society. For example, several participants identified how the syringe driver was perceived negatively by families, viewing both the syringe driver itself and the box containing it as symbolising that death was imminent.

Symbols are important. As Jones (1980) states 'Symbols bind up reality for us. When the symbols die, we die too'. Symbols therefore 'bind up' or become a repository for 'realities' which are frequently very powerful. A wedding ring, though a simple gold band, may represent a repository of profoundly important meaning for the couple who chose the ring to symbolise life-long commitment to one another. A flag, though a simple piece of fabric, once again symbolises a reality powerfully linked to personal and national identity, as demonstrated when flags are burned by protesters. Important questions include what reality or meaning does the syringe driver symbolise, and how is this reality created?

As shown in the earlier literature review, there is currently a paucity of literature considering meaning making per se and specifically how practitioners may attempt to make meaning(s) within EOL care (e.g. regarding the syringe driver and its use). Other associated literature also highlights the existence of conceptual ambiguities regarding spirituality, spiritual care, and spiritual needs (see 3.1-3.10) making it difficult for practitioners to effectively utilise these concepts within nursing practice. For patients and their families, the experience of spiritual distress may also present profound and unique challenges and presents additional ambiguities for practitioners, both regarding definition and specific interventions for the alleviation of such distress. This apparent disconnection between the wider theoretical landscape and everyday nursing practice would appear to significantly impact meaning making amongst practitioners and the practice of EOL care within community contexts.

A further important question is whether specific interventions to help alleviate spiritual distress may also constitute attempts to eliminate such ambiguities? For example, is drug therapy simply a pragmatic, central intervention in the control of challenging symptoms commonly seen as death approaches, or does the administration of medication also help alleviate potential dissonance and anxiety for individual practitioners?

Due to its inherent complexity, an extensive theoretical consideration of meaning making is beyond both the remit of this thesis and the competence of the writer. In fact, this subject could easily form the subject of a separate thesis. This process may also be influenced by the increasing medicalisation of palliative settings, and the changing context of NHS community nursing, as described below.

6.8.1 Medicalisation

Medicalisation refers to 'a process by which non-medical problems become defined and treated as medical problems, usually in terms of illnesses and disorders' (Gabe, 2013, p.49). In effect, social life is viewed through a medical framework, such as the experience of death. Medicalisation therefore refers to the process by which social life is viewed through a medical framework (Howarth (2007). Foundational work by Illich (1976, 1995) attributed medicalisation to the increasing professionalisation and bureaucratisation of medical institutions associated with industrialisation. For Illich, the growth of modern medicine created a dependence upon doctors and effectively removed the ability of individuals to practice self-care. Zola (1972) also argued that medicalisation was rooted in an increase in available technologies and a reliance upon those perceived as 'experts'. Clark (2002, p.905) suggests 'the term has become synonymous with the sense of a profession reaching too far; into the body, the mind and even the soul itself. Its use is now almost always pejorative, negative and antagonistic'.

Illich's original critique of medicalisation highlighted its impact upon the dying process. Key criticisms included:

- A loss of the capacity to accept death and suffering as meaningful aspects of life.
- A sense of being in a state of 'total war' against death at all stages of the life cycle.

- A crippling of personal and family care, and a devaluing of traditional rituals surrounding dying and death.
- A form of social control in which a rejection of 'patient hood' by dying or bereaved people is labelled as a form of deviance.

Prior to Illich's work, there was already a growing consensus in both the USA and UK that EOL care needed to be improved. In the UK this focused upon the 'medical neglect' of dying people, whereas in the USA the focus was upon futile treatments which attempted to prolong life (Howarth, 2007). Such concerns feature significantly in the development of community-based palliative care.

Clark (2002, p.906) further suggests that as palliative care has developed, its primary focus has increasingly become pain and symptom management, opening the specialty to the charge of 'creeping medicalisation', as described below.

6.8.2 Medicalisation of hospice care

Key to changing values has been increasing medicalisation within hospice care. Conrad and Schneider (1980) suggested that medicalisation occurs at three distinct levels: conceptually, institutionally and within doctor-patient interaction. In present day contexts, this third level could be extended to include health care practitioners within a variety of specialisms, including nursing. Conceptual medicalisation occurs when medical vocabulary is used to define a problem, such as 'palliative care'; institutional medicalisation occurs when organisations adopt a medical approach to treating problems relating to their specialty, and practitioner-patient medicalisation occurs when a problem is defined purely medically, and the focus of treatment remains medically focused. Gabe (2013, p.49) suggests that Conrad and Schneider's typology can be viewed at the macro, meso and micro level for analysis purposes: 'Macro-level actors include medical researchers and journals, governments and national organisations; the meso level would include local organisations, while the practitioner-patient interaction concerns mainly micro-level actors'. Authors such as Halfmann (2011) argue that medicalisation occurs at all three levels, noting that micro-level medicalisation can involve a variety of clinical personnel, including non-medical staff such as counsellors or educators. Gabe (2013, p.51) also states that many writers conceive medicalisation negatively, suggesting the phenomenon has created a form of 'medical social control that serves particular interests in society'. In contrast, others emphasise clinical and symbolic benefits of medicalisation, whereby identifying a condition as appropriate for medical attention brings new opportunities for symptom alleviation or cure, adds legitimacy and potentially reduces associated stigma and disapproval. Evident is the need for 'a more integrated theory of the process of medicalisation, its causes and consequences, and to relate these to recent changes in society and health related knowledge' (Gabe, 2013, p.52).

Howarth (2007, p.121) suggests that 'in modern societies the doctor has replaced the role of the priest at the deathbed'. Thus, rather than preparing a patient for death, medical concerns now centre upon the provision of pain relief and prolonging the 'life trajectory' wherever possible. Where death was previously viewed as natural and unavoidable, and framed within religious discourses, in present day contexts death is now viewed as a challenge for medical science that can be 'solved by appropriate intervention and medical based technologies' (Howarth, 2007). For example, in a UK study, Van Brummen and Griffiths (2013, p.85) suggest that 'despite birth and death being described as natural life events, Western societies have continued to medicalise experiences of birth and death, moving them from the home setting into the closed and increasingly technological environment of the hospital' [or indeed, hospice?], so creating associated ethical conflict(s) for staff. Clark (2002) also highlights the challenges associated with attempting to balance technical intervention against a humanistic approach to those who are dying.

Within such narratives of modern day, death now frequently represents the failure of medicine, resulting in dying patients being subjected to increasingly invasive and unnecessary treatments as attempts to prolong their lives. In effect, the work of medical and allied professionals within such settings is framed within a discourse of treatment and cure, where the role of medicine is to cure illness and save lives and the role of nursing focuses upon caring and restoration to health. Such discourses frequently portray death as failure whereby dying patients may be both marginalised and feared (Glaser and Strauss, 1965; Kubler-Ross, 1970; Krueger, 2006; Howarth, 2007).

In a comprehensive review of written narratives provided by those with terminal disease, Bingley et al. (2006) highlight aspects of the experience which have remained constant over the last five decades. The authors describe how such narratives identify the importance of personal autonomy when facing death, even though personal autonomy is not always compatible with the medicalised contexts within which the process of dying frequently occurs. This again may constitute a significant stressor for patients. Problematic is when medicine is the sole or dominant discourse in dying, as illustrated by the pioneering work of Glaser and Strauss (1965) regarding awareness contexts. Glaser and Strauss (1967) also highlighted how 'open awareness' contexts pose a threat to the routine and order of hospitals and therefore are frequently averted.

6.8.3 De-medicalisation

A key consideration is whether the use of medication delivered via syringe driver symbolises medicalisation in action or is simply an effective use of modern technology to deliver drug therapy to those experiencing deliberating symptoms at EOL. The use of the syringe driver may represent both; there is clearly a demarcation between use for the alleviation of symptoms such as pain or nausea and the administration of drugs at dosages which deliberately hasten death: in effect, euthanasia disguised as caring palliation of symptoms.

Hospitals also remain the context in which most terminally ill patients die, accounting for approximately 60% of such patients in the UK and US, with 12% dying in nursing and residential homes, 5% dying in hospice settings and the remainder (approximately 20%) dying at home (Howarth, 2007, p.129). Though studies have repeatedly shown that most people would prefer to die at home (e.g. Gomes et al., 2012, 2013, 2015) the majority sadly do not achieve this aim, a situation further complicated by the present Covid-19 pandemic. Howarth (2007) also highlights the rise of professional and lay attempts to de-medicalise death, suggesting that the hospice movement represents part of a 'resistance movement' to medicalisation. A key question would appear to be is such resistance now waning? This question is beyond the remit of this thesis but clearly worthy of further study.

6.8.4 The changing context of NHS community nursing

Over recent decades there have also been major philosophical, organisational, and resource-based changes affecting the delivery of NHS community nursing. Due to increasing medicalisation, the availability of new treatments and the goal of minimising the time that patients remain in hospital settings, community nursing has faced growing and significant pressures. These originate from three principal sources:

- Attempts to facilitate early discharge from hospital, whenever possible.
- Attempts to prevent unnecessary admission to hospital.
- Attempts to increasingly manage complex care (i.e. patients with multiple needs) within the community, whenever possible.

Rising demand and costs therefore means that community resources are increasingly focused upon people with the most complex health and care needs (Wordsworth et al., 2016). Also problematic is the growing numbers of EOL patients discharged from hospital to home, commonly days from death and requiring both social service support (i.e. carers who typically visit several times per day) alongside community nursing input for symptom control, typically managed via the use of medication administered via syringe driver.

In my experience such patients are frequently experiencing multiple, deliberating symptoms, making it difficult for any meaningful assessment of spiritual distress to be undertaken. Such patients would also find it virtually impossible to engage with talking therapies, such as counselling. The nature of community nursing also tends to be increasingly task orientated due to increasing numbers of patient visits, making it difficult to develop therapeutic relationships both with patients and their loved ones within which meaningful conversations can occur. The home is also a unique context for the delivery of care, which may significantly influence communication between patient and nursing staff, both positively and negatively. Once again, this area would benefit from further research.

6.8.5 Meaning making amongst practitioners: possible variables

As identified in the earlier literature review, meaning making within EOL contexts would appear to have received minimal attention in current literature. Once again, the concept of ‘noise’ or ‘ambiguity’ is evident, with practitioners commonly having to deal with a range of personally demanding situations or contexts where assumptions, philosophy or values may be ill-defined, ambiguous, or both. Such ambiguity would appear to hinder the process of meaning making regarding key concepts such as spirituality, spiritual care, spiritual needs and specifically spiritual distress. Further, for meaning making to be effective, it would appear important that such conceptual ambiguity is at least minimised, allowing practitioners space and opportunity to reflect upon experience and develop new meaning(s) where relevant.

From my own experience, I would suggest that multiple variables may influence meaning making for individual practitioners. Such variables appear to divide into three categories: practitioner, societal, and contextual.

Practitioner variables include EOL care experience, emotional intelligence, personal experience of death/bereavement, perceptions/assumptions regarding a good death, personal faith, resilience and available support networks (e.g. via chaplaincy service, spiritual advisor or church community). Societal variables include the increasing medicalisation of hospice care, increased secularisation, the development of multiple death narratives, decreasing religious observance, and policy and funding issues (e.g. number of available hospices). Contextual variables include patient distress, distress amongst family members or loved ones, other workload stressors (e.g. shifts, staffing, resources), organisational values, philosophy and policies, research base (or lack of), ambiguity regarding terminology (e.g. ‘EOL’; ‘spirituality’; ‘spiritual distress’; ‘existential distress’; ‘good death’), and availability of supervision (individual or group). Both the identification and mode of interaction of such variables within palliative contexts appears lacking from current literature and could again easily constitute a separate thesis.

6.8.6 Summary

Practitioner perceptions and meaning(s) regarding spiritual distress would appear to be influenced by multiple factors, many of which are complex, as is their pattern of interaction. Meaning making constitutes an ongoing, complex and dynamic process, whereby meaning is constantly informed by experience and reflection and open to change and revision. For practitioners, conceptual ambiguity, previous experience(s) of grief and bereavement, personal spirituality, religious belief(s) and practice, worldview and ontology may all influence meaning making within EOL contexts. The role of group supervision for practitioners, personal counselling and other support networks also appears important.

For practitioners meaning making also occurs whilst functioning within multiple roles, for example employee, nurse, individual, person of faith (or none), citizen and family member. Practitioners may also experience conflict within or between such roles, which is also likely to impact on meaning making regarding phenomena such as spiritual distress. Societal values, assumptions and narratives, such as the on-going debate regarding assisted-suicide and euthanasia, are also likely to influence individual meaning making, as are the NMC Code of conduct, which effectively sets boundaries of acceptable behaviour and practice, providing powerful societal and professional narratives.

The values and ethos of organisations such as the NHS and individual hospices also provide other contextual narratives and expectations, potentially impacting how such meaning should be 'lived out' in terms of employee behaviour.

Pessin et al. (2015, p.3) highlight how 'existential distress' may also significantly affect professional health care (PHC) providers within palliative contexts and therefore the process of meaning making. The authors also suggest that 'providers awareness of, reactions to, and processing of these themes are often under-recognised and variable' (Ibid).

Failure to cope with existential distress often leads to anxiety, avoidance, burnout, and disengagement, whilst self-reflection and meaning making appear to contribute to overall well-being amongst PHC providers (Melo and Oliver, 2011; Peters et al., 2013; Gama et al., 2014; Potash et al., 2014). Because practitioners must be both competent and skilled, they are required to find ways to effectively manage their everyday work. Allowing existential anxieties to be overtly expressed is clearly unhelpful, particularly whilst caring for patients who are facing death. Encouraging and assisting practitioners to find meaning within such contexts and to effectively manage anxiety/stress is therefore important.

6.9 Other intended research outcomes

Integral to the study were several other intended research outcomes. These were:

- To produce research which informs current practice (i.e. ‘actionable intelligence’).
- To produce research findings which are comprehensible to practitioners.
- To produce research findings which are applicable to the community-based contexts utilised within the study.
- To produce research findings which may facilitate changes in practice within these contexts.
- To provide recommendations for nursing education and ongoing professional practice which may help improve nursing care within EOL community-based care.

My hope is that the perspectives and insights of participants offer a rich data source that is both comprehensible and accessible to practitioners (i.e. the study’s findings represent a source of ‘actionable intelligence’) which, if implemented, could improve the care of EOL patients within the community-based contexts highlighted in the study. I also believe the study offers valuable insights to practitioners in other non-community EOL contexts. However, none of the above outcomes can be realistically assessed at present, as the specific dissemination strategy outlined in 7.4 has yet to be actioned. My hope is that the findings, if disseminated appropriately, will impact practice within relevant community-based contexts, and influence both undergraduate nurse education as well as the continuing professional development of existing practitioners. In this way, I believe the nursing care of patients experiencing spiritual distress may be significantly improved.

7 Chapter 7: Project Summary and Conclusion

7.1 Summary

This UK based study sought to address the following research questions:

1. How are the terms spirituality, spiritual care and spiritual needs perceived by community nurses within the different care settings?
2. How is spiritual distress perceived by community nurses within the different care settings?
3. How is spiritual distress identified by community nurses in the different care settings?
4. What specific interventions (forms of practice) are utilised by community nurses in the different care settings to help alleviate spiritual distress?
5. Is there any commonality of practice between the different care settings?

The study also had several other intended research outcomes. These were:

- To produce research which informs current practice (i.e. 'actionable intelligence').
- To produce research findings which are comprehensible to practitioners.
- To produce research findings which are applicable to the community-based contexts utilised within the study.
- To produce research findings which may facilitate change in practice within these contexts.
- To provide recommendations for nursing education and ongoing professional practice which may help improve nursing care within EOL community-based care.

The study arose out of my own experience as an NHS community nurse and appears to have confirmed my initial observations regarding the recognition and alleviation of spiritual distress within community contexts. Spiritual distress describes 'a state of suffering relating to the impaired ability to experience meaning in life through connectedness with self, others, world or a superior being' (Caldeira et al., 2013, p.82).

The initial literature review highlighted the conceptual ambiguity relating to key concepts such as spiritualty, spiritual care, spiritual needs and spiritual distress. This ambiguity would appear to impact both meaning making amongst practitioners and the nursing management of EOL community-based patients who may be experiencing spiritual distress.

Attempting to address the central research questions of this study was problematic and questions posed within semi-structured interviews frequently proved challenging for participants, the majority of whom struggled to articulate workable definitions of spirituality, spiritual needs, spiritual care and particularly spiritual distress. No participants could offer literature-based definitions of any of these concepts. This was concerning but reflects current nursing literature, where similar conceptual ambiguity is evident.

If practitioners find these central concepts difficult to comprehend or articulate, it is unlikely they will be addressed in practice; this was my initial observation within community nursing which provided the motivation for this study. Ambiguity was evident in responses from both hospice and NHS participants. Surprisingly, there was little difference in participant perceptions of spiritual distress between both settings, even though hospice participants encounter significantly more EOL patients during everyday practice. Conceptual ambiguity combined with a lack of knowledge would also appear to undermine attempts at meaning making for practitioners, again impacting the delivery of holistic palliative care.

Current practice is also likely to result in a medicated, sedated death: whether such deaths constitute ‘good deaths’ is debatable and currently lacks international consensus. No participants described quality standards utilised to evaluate the death experience of patients, though no specific questions sought to address this issue during interviews.

The area of assessment of spiritual distress was also problematic. Interviews reflected a lack of awareness of specific assessment tools, particularly so with NHS participants. The only participants who mentioned assessment tools were hospice-based; this was the IPOS tool. However, the IPOS assessment tool is not specific to spiritual distress and was not universally recognised as valid or useful by all hospice-based participants, some of whom showed a reluctance to utilise the tool. It is difficult to see how spiritual distress can be effectively recognised or assessed within palliative settings if practitioners lack awareness of suitable assessment tools, or if practitioners believe such tools lack validity, or if practitioners lack motivation to assess for spiritual distress. Further, due to lateness in referral, patients were frequently either profoundly unwell, semi-conscious or indeed unconscious, and therefore unable to contribute to any assessment process. This situation was more common amongst NHS participants, in contrast to hospice-participants who generally met patients earlier in their disease trajectory and therefore had greater opportunity to develop therapeutic relationships with them. Additional training would appear to be urgently required in this area.

A range of specific interventions to help alleviate spiritual distress were identified by study participants. Most common were the use of medication, talking with patients and referral to specialised talking therapies, such as counselling. There was a clear and significant mismatch between available resources for hospice-based and NHS participants, with hospice-based participants sharing a proximity to other MDT colleagues simply not available to NHS participants. This made referral to other services such as counselling, art therapy, massage, and other sensory interventions far easier for hospice-based participants and meant that NHS community-based patients rarely received such interventions. This discrepancy was further enhanced by patients' proximity to death at the time of referral to NHS community staff. Typically, this was very late in the disease trajectory and significantly limited patient accessibility to interventions.

7.2 Conclusion

In conclusion, within the two community settings it appears that for participants spiritual distress was difficult to define, difficult to identify, difficult to assess (or not assessed at all) and that interventions display a degree of commonality in both hospice and NHS contexts.

No published studies to date appear to address spiritual distress specifically within UK community-based settings, particularly where patients are dying within their own homes. Without further research, it is impossible to reliably ascertain if such patients are experiencing spiritual distress and whether such distress is recognised or simply suppressed using medication. Other interventions may seek to distract patients but leave the possible cause(s) of distress unaddressed. Interventions which seek to specifically target causes of possible distress appear underutilised, particularly as the use of medication was by far the most common intervention identified by participants. This seems to reflect a lack of knowledge/awareness regarding spiritual distress amongst community nursing practitioners.

This study has been challenging, predominantly due to my own inexperience as a researcher. The predominantly white British ethnicity of participants is also a limitation in terms of generalisability of the study's findings, although this ethnic profile would appear representative of both Pilgrim's Hospices and KCHFT community nursing staff.

Nevertheless, I believe the study offers practitioners a source of actionable intelligence to influence current practice. To improve the recognition and alleviation of spiritual distress amongst community-based practitioners will require further education and reflection, both within undergraduate programmes and as part of continuing professional development. As practitioner awareness is enhanced, hopefully EOL community-based patients suffering spiritual distress will receive more effective care which both recognises and seeks to address the specific causes of such distress.

7.3 Recommendations for community nursing practice

A central aim of this study was to attempt to improve practice within this area of patient care, by the generation of 'actionable intelligence'. Below are some realistic, key recommendations which I hope may help achieve this:

1. Teaching regarding spirituality, spiritual needs, spiritual care and spiritual distress should form part of undergraduate nursing curricula and be re-visited during all years of undergraduate study.

2. Input regarding spirituality, spiritual needs, spiritual care and spiritual distress should also form part of post-registration training, particularly in those contexts where this phenomenon is more likely to be observed, such as community care, palliative care and care of the elderly.

3. Assessment tools for spiritual distress and their use should be considered as part of both undergraduate and post-graduate nursing education, to raise awareness of spiritual distress and how such distress can be identified in patients.

4. Allowing practitioners opportunity to reflect upon how their own backgrounds, spirituality, spiritual needs and beliefs are likely to inform and influence their practice should form part of undergraduate and post-graduate nursing programmes.

5. Education regarding possible interventions for spiritual distress should form part of both undergraduate and post-graduate nursing programmes, to raise awareness of how spiritual distress can be alleviated.

6. Urgently establishing a national protocol for best practice in how spiritual distress can be best identified and alleviated (e.g. NANDA or equivalent) that is both accessible and achievable, should be a priority for the NMC.

7. Advanced communication skills should form part of all post-registration mandatory training, particularly in those areas where spiritual distress is likely to be more prevalent. Combined with recommendation 3 above, this will hopefully allow practitioners to identify spiritual distress more effectively.

7.4 Dissemination strategy

It is hoped that feedback to participants in all six data collection areas will be a further outcome of this study. Opportunity for such feedback was offered to all managers/gate-keepers prior to data collection and all participants stated they would value the opportunity to discuss spiritual distress and its alleviation further.

It is also my intention to present the findings of this study to the School of Nursing within the Faculty of Medicine, Health and Social Care at CCCU, as an attempt to influence undergraduate nurse education.

An additional hope is that several articles for publication may result from this study, highlighting key findings and suggesting ways in which community-based practice can be improved in caring for EOL community-based patients experiencing spiritual distress.

7.5 Recommendations for further research

Research could be viewed as incomplete if no further questions arise from it. It is hoped that further post-doctoral research involving patients and their families will be a direct outcome of this study. This additional research would focus specifically on the home environment of individual patients and the variables which may influence the experience of spiritual distress within that context for both patient and family. Other possible additional research areas include:

- The use of palliative sedation in community EOL contexts.
- The symbolic meaning(s) of the syringe driver and its use.
- Meaning making amongst practitioners in community-based palliative care.
- The impact of increasing medicalisation upon hospice care
  (Li and Mokrycke, 2017).

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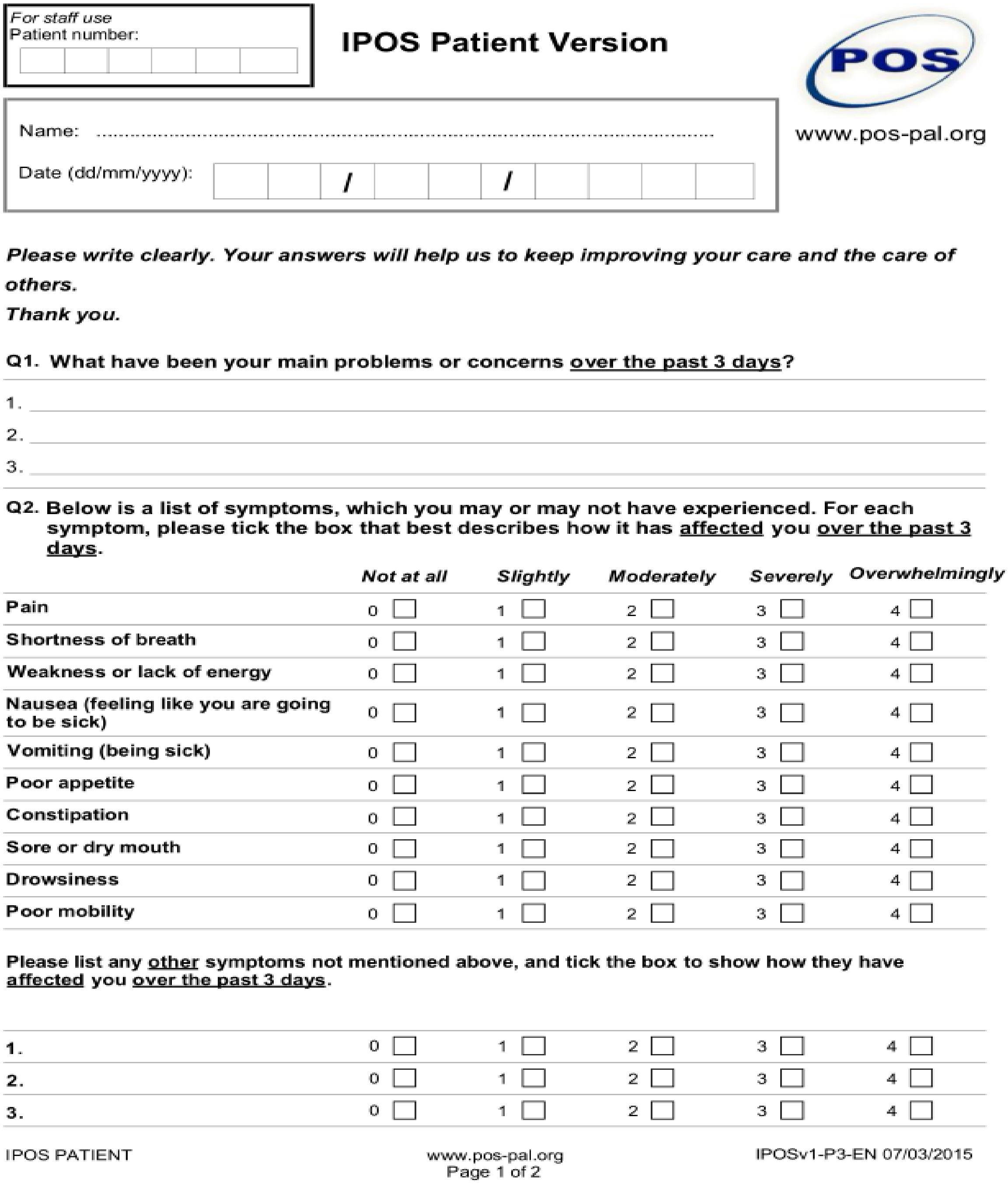
9 Appendix 1: Spiritual assessment models/tools

9.1 Integrated Palliative Care Outcome Scale (IPOS) (patient version)



For staff use
Patient number: ☐☐☐☐☐☐

IPOS Patient Version

POS
www.pos-pal.org

Name: ....

Date (dd/mm/yyyy): ☐☐ / ☐☐ / ☐☐☐☐

Please write clearly. Your answers will help us to keep improving your care and the care of others.
Thank you.

Q1. What have been your main problems or concerns over the past 3 days?

1. ____________________
2. ____________________
3. ____________________

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past 3 days.

	Not at all	*Slightly*	*Moderately*	*Severely*	*Overwhelmingly*
Pain	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Shortness of breath	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Weakness or lack of energy	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Nausea (feeling like you are going to be sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Vomiting (being sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Poor appetite	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Constipation	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Sore or dry mouth	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Drowsiness	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Poor mobility	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

Please list any other symptoms not mentioned above, and tick the box to show how they have affected you over the past 3 days.

1.	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
2.	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
3.	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

IPOS PATIENT
www.pos-pal.org
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Over the past 3 days:

	Not at all	*Occasionally*	*Sometimes*	*Most of the time*	*Always*
Q3. Have you been feeling anxious or worried about your illness or treatment?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Q4. Have any of your family or friends been anxious or worried about you?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Q5. Have you been feeling depressed?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

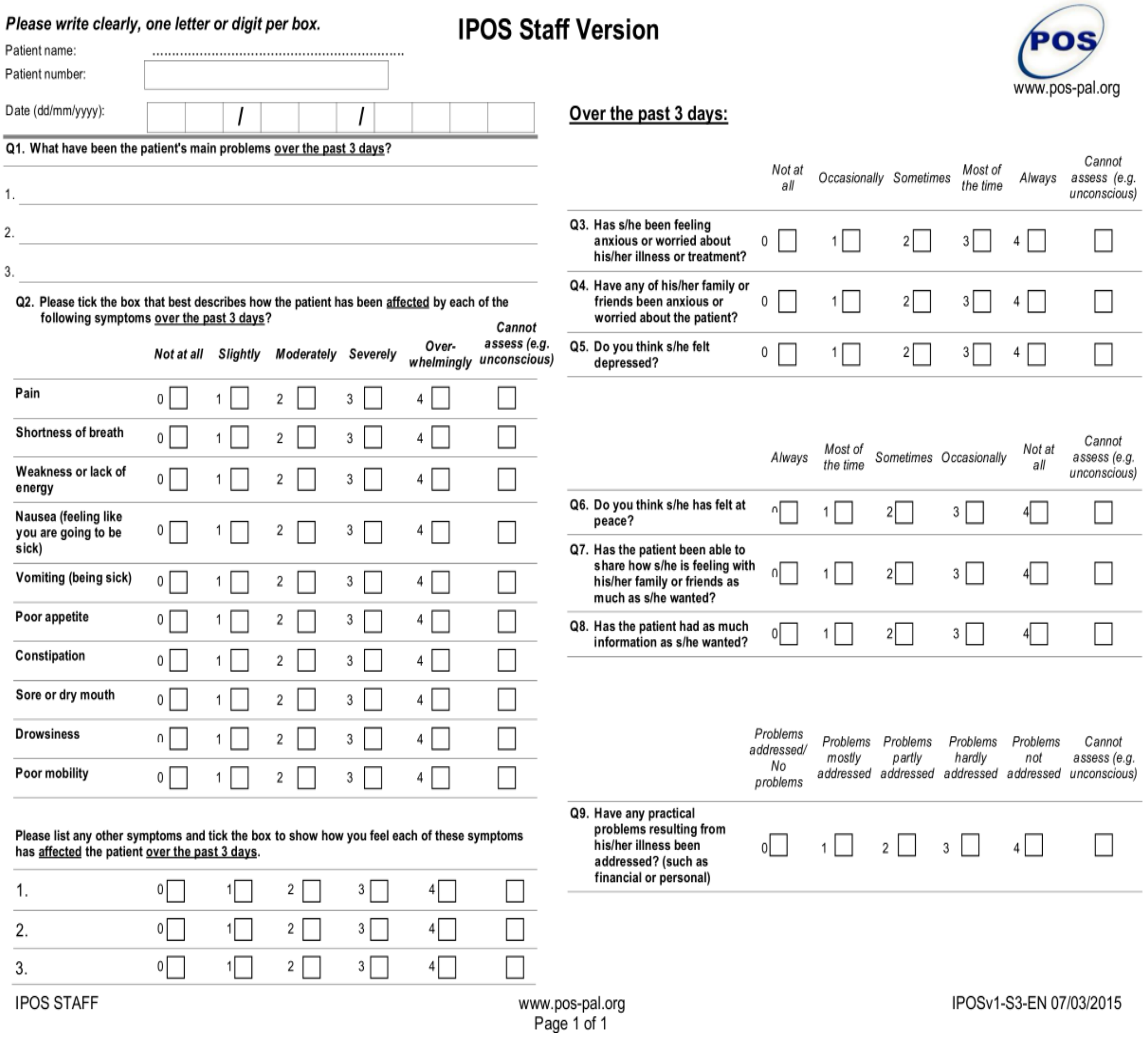
	Always	*Most of the time*	*Sometimes*	*Occasionally*	*Not at all*
Q6. Have you felt at peace?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Q8. Have you had as much information as you wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

	Problems addressed/ No problems	*Problems mostly addressed*	*Problems partly addressed*	*Problems hardly addressed*	*Problems not addressed*
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

	On my own	*With help from a friend or relative*	*With help from a member of staff*
Q10 How did you complete this questionnaire?	☐	☐	☐

If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse

9.2 Integrated Palliative Care Outcome Scale (staff version)



Please write clearly, one letter or digit per box.

IPOS Staff Version

www.pos-pal.org

Patient name: ....

Patient number: ☐

Date (dd/mm/yyyy): ☐☐ / ☐☐ / ☐☐☐☐

Q1. What have been the patient's main problems over the past 3 days?

1. ______________________________

2. ______________________________

3. ______________________________

Q2. Please tick the box that best describes how the patient has been affected by each of the following symptoms over the past 3 days?

	Not at all	*Slightly*	*Moderately*	*Severely*	*Over-whelmingly*	*Cannot assess (e.g. unconscious)*
Pain	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Shortness of breath	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Weakness or lack of energy	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Nausea (feeling like you are going to be sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Vomiting (being sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Poor appetite	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Constipation	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Sore or dry mouth	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Drowsiness	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Poor mobility	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

Please list any other symptoms and tick the box to show how you feel each of these symptoms has affected the patient over the past 3 days.

1.	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
2.	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
3.	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

Over the past 3 days:

	Not at all	*Occasionally*	*Sometimes*	*Most of the time*	*Always*	*Cannot assess (e.g. unconscious)*
Q3. Has s/he been feeling anxious or worried about his/her illness or treatment?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q4. Have any of his/her family or friends been anxious or worried about the patient?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q5. Do you think s/he felt depressed?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

	Always	*Most of the time*	*Sometimes*	*Occasionally*	*Not at all*	*Cannot assess (e.g. unconscious)*
Q6. Do you think s/he has felt at peace?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q7. Has the patient been able to share how s/he is feeling with his/her family or friends as much as s/he wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q8. Has the patient had as much information as s/he wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

	Problems addressed/ No problems	*Problems mostly addressed*	*Problems partly addressed*	*Problems hardly addressed*	*Problems not addressed*	*Cannot assess (e.g. unconscious)*
Q9. Have any practical problems resulting from his/her illness been addressed? (such as financial or personal)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

IPOS STAFF

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9.3 FICA, FAITH, SPIRITual and HOPE assessment tools

FICA Tool: assessment questions

F – Faith, Belief, Meaning

- What is your faith or belief?
- Do you consider yourself spiritual or religious?
- What things do you believe in that give meaning to your life?

I – Importance and Influence

- Is it [faith or belief] important in your life?
- What influence does it have on how you take care of yourself?
- How have your beliefs influenced your behaviour in this illness?
- What role do your beliefs play in regaining your health?

C – Community

- Are you part of a spiritual or religious community?
- Is this of support to you and how?
- Is there a person or group of people you really love or who are really important to you?

A – Address

- How would you like me, your healthcare provider, to address these issues in your healthcare?

(Puchalski and Romer, 2000)

FAITH Tool: assessment questions

F – Faith ⁄ spiritual beliefs

- Do you have any particular faith, religious or spiritual beliefs?
- What gives your life meaning?
- What helps you cope in times of stress or illness?

A – Application

- In what ways do you apply your faith in your daily life?
- Do you belong to a particular church or community?
- Is prayer or meditation important to you?

I – Influence ⁄ importance of faith in life, in this illness and on healthcare decisions

- How do your faith and spiritual beliefs influence your life?
- Are they important to you?
- How do your faith and spiritual beliefs influence you in this illness?
- Have they altered your attitude or behaviour?
- Has this illness influenced your faith?
- Do your beliefs influence or affect your healthcare decisions that would be helpful for me to know about?

T – Talk ⁄ terminal events planning

- Do you have anyone you can trust to talk to about spiritual or religious issues?
- Do you have any specific requests if you were to become terminally ill? (e.g. terminal care options, living will or end-of-life requests)

H – Help

- Is there any way I or another member of the healthcare team can help you?
- Do you require assistance or help with prayer? (e.g. facilities or accompaniment)
- Would you like to speak to a chaplain?
- Would you like to discuss spiritual issues or your beliefs with your doctor?

(Neely and Minford, 2009)

SPIRITual tool: assessment questions

S – Spiritual belief system

- Do you have a formal religious affiliation?

- Can you describe this?

P – Personal spirituality

- Describe the beliefs and practices of your religion that you personally accept.
- Describe those beliefs and practices that you do not accept or follow.
- In what ways is your spirituality/religion meaningful for you?
- What is the importance of your spirituality/religion to daily life**?**

I – Integration with a spiritual community

- Do you belong to any religious or spiritual groups or communities?
- How do you participate in this group/community?
- What importance does this group have for you?
- What types of support and help does, or could this group provide for you in dealing with health issues?

R – Ritualised practices and restrictions

- What specific practices do you carry out as part of your religious and spiritual life?
- What lifestyle activities or practices does your religion encourage, discourage or forbid?
- To what extent have you followed these guidelines?
- What significance do these practices and restrictions have to you?

I – Implications for medical practice

- Are there specific elements of medical care that your religion discourages or forbids?
- To what extent have you followed these guidelines?
- What aspects of your religion/spirituality would you like to keep in mind as I care for you?
- Would you like to discuss religious or spiritual implications of healthcare?
- What knowledge or understanding would strengthen our relationship as physician and patient?

- Are there any barriers to our relationship based on religious / spiritual issues?

T – Terminal events planning

- Are there particular aspects of medical care that you wish to forgo or have withheld because of your religion/spirituality?
- As we plan for your medical care near the end of life, in what ways will your religion and spirituality influence your decisions?

(Maugans, 1996)

<u>HOPE tool: assessment questions</u>

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

- We have been discussing your support systems. I was wondering, what is there in your life that gives you internal support?
- What are your sources of hope, strength, comfort and peace?
- What do you hold on to during difficult times?
- What sustains you and keeps you going?
- For some people, their religious or spiritual beliefs act as a source of comfort and strength in dealing with life's ups and downs; is this true for you?
- If the answer is 'Yes', go on to O and P questions.
- If the answer is 'No', consider asking: Was it ever? If the answer is 'Yes', ask: What changed?

O: Organised religion

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

P: Personal spirituality/practices

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

E: Effects on medical care and end-of-life issues

- Has being sick (or your current situation) affected your ability to do the things that usually help you spiritually? Or affected your relationship with God?
- As a doctor, is there anything that I can do to help you access the resources that usually help you?
- Are you worried about any conflicts between your beliefs and your medical situation/care/decisions?
- Would it be helpful for you to speak to a clinical chaplain/community spiritual leader?
- Are there any specific practices or restrictions I should know about in providing your medical care? (e.g. dietary restrictions, use of blood products)
- If the patient is dying: How do your beliefs affect the kind of medical care you would like me to provide over the next few days/weeks/months?

(Anandarajah and Hight, 2001)

10 Appendix 2: Participant recruitment documentation

10.1 Nurse participant information letter (KCHFT)

Nurse participant information letter

Canterbury Christchurch University (CCCU): Faculty of Health and Wellbeing

School of Nursing, Midwifery and Social Work

Research Project Information

Study Title: '<u>An exploration of Spiritual Distress in End of Life Community-based patients</u>'

IRAS Project ID: **251598**

Thank you for taking the time to read this information relating to the above MPhil/PhD research project. I would like to invite you to take part in this exploratory study. Your service manager has agreed to my contacting you and this information sheet is to help you decide whether you wish to take part. The CCCU Ethics Research Committee has also given approval for me to access a sample of nurses currently caring for community-based EOL patients.

To help you decide if you wish to participate, I have summarised below why the research is being undertaken and what would be involved for you personally. It is important that you are fully informed before deciding whether to take part. I would also advise you to speak with your line manager before deciding to ensure they are aware of your involvement.

Please do contact me if any of the following information is unclear.

Background to the study

High quality end of life (EOL) care requires a range of holistic approaches. Patients approaching the end of their lives often experience a variety of debilitating and distressing symptoms.

Collectively, these symptoms may constitute spiritual distress: a multi-faceted form of existential anxiety which can include fear, regret, loss of connection, loss of hope and loss of meaning. Spiritual distress remains a neglected concept within end-of-life care, principally due to confusion regarding definitions, a lack of conceptual understanding, variation in assessment tools and their use and the evaluation of specific interventions currently used to help relieve such distress.

The assessment of spiritual distress in a community context is also problematic: most published studies to date which seek to address the issue of spiritual distress are based either within a hospital or hospice setting. None would appear to describe how spiritual distress is perceived/experienced by community nurses within different care settings or attempt to evaluate spiritual distress as experienced by patients dying within their own homes. Likewise, literature describing the use of specific assessment tools within a community setting is scarce.

Aims of the study

This study explores perceptions of community nursing staff within two different care settings to the phenomenon of spiritual distress, as observed in end-of-life community-based patients.

The study will seek to address the following research questions:

1. How are the terms spirituality, spiritual care and spiritual needs perceived by community nurses within the different care settings?
2. How is spiritual distress perceived by community nurses within the different care settings?
3. How is spiritual distress identified by community nurses in the different care settings?
4. What specific interventions (forms of practice) are utilised by community nurses in the different care settings to help alleviate spiritual distress?
5. Is there any commonality of practice between the different care settings?

This study is not receiving external funding.

What would you have to do?

For this exploratory study, I aim to interview band 5 or 6 nurses from two different community contexts: namely, community (NHS) and hospice, so that perceptions and experiences of caring for EOL community-based patients can be compared.

Interviews would be carried out at a suitable venue within Kent Community Health Foundation Trust (KCHFT), hopefully with as little inconvenience as possible. At this stage, I am asking you to commit no more than 1 hour to the project. I hope very much that you might be willing to do this.

Why I am writing to you

I am attempting to recruit community (NHS), hospice and specialist palliative care community nurses to take part in this exploratory study. Participants need to be band 5 or 6 community nurses within KCHFT who have at least six months experience involving caring for EOL community-based patients.

Procedures

Interviews would be audio recorded and subsequently transcribed for analysis. Any information that might identify yourself, service users, other staff or your organisation will be removed from the transcripts. Participant anonymity would be maintained throughout, and no data subsequently used within the study would be identified by name or place of work.

Feedback

I would welcome the opportunity to present the findings of this exploratory study to an appropriate forum at KCHFT. The final thesis will also be available on-line via the CCCU website.

Will the study be confidential?

Absolutely. All electronic copies of personal information and research data will be stored securely using CCCU cloud storage in accordance with General Data Privacy Regulation (GDPR), the Data Protection Act 2018 and CCCU policies and procedures. Hard copies containing any personal information (e.g. consent forms) and anonymised hard copies of interview transcripts and thematic analyses will be stored in a locked filing cabinet in my home. No unrelated or unnecessary personal data will be collected or stored. Personal data will be used only to provide appropriate background information to the study (e.g. the average number of years participants had been involved in EOL care) and to provide summaries of participant responses within the final thesis. Data access within CCCU will be limited to myself and my supervisors: Professor Doug McInnes and Dr Harshad Kaval. Their role is to supervise the research project and associated data collection. No data will not be transferred out of the European Economic Area.

Audio recordings of interviews will be immediately transferred to a pass coded laptop computer and deleted from the recording machine utilised for the interview. The interview recording will then be uploaded to secure CCCU cloud storage. This recording will be subsequently transcribed by myself or a professional transcriber to ensure that confidentiality is maintained. All transcripts will be anonymised using appropriate letter or numerical codes to avoid identification of yourself, your service area or employing organisation and any patient identifiable information will be redacted. No respondents would be identified by name, age, gender or work location within the final thesis.

CCCU will keep identifiable information about you until completion of the study. After the study is completed, all personal information associated with the data will be removed. The remaining data will then be securely stored for a period of five years at CCCU before being destroyed in line with CCCU's confidential data management policies. All hard copies of data will be destroyed at the completion of the study.

Data protection Regulations

As a university we use personally identifiable information to conduct research to improve health, care and services. As a publicly funded organisation, we must ensure that it is in the public interest when we use personally identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

CCCU will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded to oversee the quality of the study. Individuals from regulatory organisations may look at your research record to check the accuracy of the research study (e.g. external examiners). The only people in CCCU having access to information that identifies you will be myself or those who audit the data collection process (e.g. my supervisors). No one else who analyses the research data will be able to identify you or have access to your name or contact details. CCCU will keep identifiable information about you until the end of the study.

CCCU is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.
Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. You can find out more about how we use your information by contacting the CCCU data protection officer at dp.officer@canterbury.ac.uk.

Health and care research should serve the public interest, which means that we must demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research. If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. Our Data Protection Officer can be contacted at dp.officer@canterbury.ac.uk

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

Dissemination of results

Our intention is that results of the study will be disseminated via:

1. Peer reviewed publication in appropriate journals.
2. Research paper/poster presentations at suitable Nursing related conference(s).
3. Publication of the final thesis in the CCCU library.

Deciding whether to participate

It is entirely up to you to decide whether to take part in this research. This participant information sheet describes the project and what you will be asked to do should you agree to participate. At this stage, the only commitment required is to be interviewed for no more than 1 hour at your place of work. At the beginning of the interview, you will be asked to sign a consent form to confirm your willingness to take part.

If you have any questions or concerns about the nature, procedures or requirements for participation please do not hesitate to contact me. I have included my contact details at the bottom of the sheet. Should you decide to participate, you will be free to:

1. Withdraw consent at any time without having to give a reason.
2. Request to see all your personal data held in association with this project.
3. Request that the processing of your personal data is restricted.
4. Request that your personal data is erased and no longer used for processing.

Process for withdrawing consent

To withdraw from the study, simply contact me by any of the means listed below, stating your decision to withdraw [before 30th November 2020]. Two options are available:

1. Withdrawal of consent to participate
2. Withdrawal of consent in association with deletion of data already gathered.

Having received your request, I will then respond via e-mail confirming your withdrawal and the deletion of any data pertaining to your participation (if requested).

Are there benefits to taking part?

I hope that the research data obtained will contribute to an enhanced understanding of spiritual distress as seen in EOL community-based patients. In that sense, you will be contributing to a study that aims to help improve both current knowledge and community nursing practice. There are no financial benefits from taking part.

Are there any risks?

There are no risks associated with participation in the study. However, the nature of the topic means that previous experience of caring for patients who were manifesting visible signs of spiritual distress may have been challenging or upsetting: also, talking about this may generate potentially difficult emotions. I would hope that both the context and the way in which interviews were conducted would help to minimize any potential upset and allow participants to openly discuss their experiences.

In the very unlikely event that anything be disclosed during interviews which may constitute criminal or professional misconduct, your employer's appropriate policies and procedures would be followed. I would also consult with my supervisors and CCCU if this were deemed necessary.

Who has reviewed this study?

All research undertaken on behalf of CCCU is subject to ethical review, to protect your interests as a participant. This study has been reviewed by the NHS Health Research Authority (HRA). The research proposal has also undergone internal independent assessment at CCCU.

What do I need to do if I am willing to participate?

If after reading this information letter you would like to take part in the study, please could you contact me using either the attached nurse participation sheet and pre-paid envelope or by either of the contact means listed below. It would be very helpful to receive an indication of your interest by **24/05/19**. I do hope you will be willing to participate.

Any Questions?

If you have any further questions or would like the opportunity to discuss the project further, please do not hesitate to contact me using either of the contact means listed below.

Thank you for taking the time to read this information.

Yours sincerely

Clive Laker

MPhil/PhD Research Student

Faculty of Health and Wellbeing

School of Nursing, Midwifery and Social Work

Canterbury Christchurch University

North Holmes Road, Canterbury CT1 1QU

E-mail: cl350@canterbury.ac.uk
Mobile: 07745579927

Project Primary Supervisor
Dr Harshad Keval
E-mail: harshad.keval@canterbury.ac.uk

10.2 Nurse participant information letter (Pilgrim's Hospice)

Nurse participant information letter

Canterbury Christchurch University (CCCU): Faculty of Health and Wellbeing

School of Nursing, Midwifery and Social Work

Research Project Information

Study Title: '<u>An exploration of Spiritual Distress in End of Life community-based patients'</u>

IRAS Project ID: 251598

Thank you for taking the time to read this information relating to the above MPhil/PhD research project. I would like to invite you to take part in this exploratory study. Your service manager has agreed to my contacting you and this information sheet is to help you decide whether you wish to take part. The CCCU Ethics Research committee has also given approval for me to access a sample of nurses currently caring for community-based EOL patients.

To help you decide if you wish to participate, I have summarised below why the research is being undertaken and what would be involved for you personally. It is important that you are fully informed before deciding whether to take part. I would also advise you to speak with your line manager before deciding to ensure they are aware of your involvement.

Please do contact me if any of the following information is unclear.

<u>Background to the study</u>

High quality end of life (EOL) care requires a range of holistic approaches. Patients approaching the end of their lives often experience a variety of debilitating and distressing symptoms. Collectively, these symptoms may constitute spiritual distress: a multi-faceted form of existential anxiety which can include fear, regret, loss of connection, loss of hope and loss of meaning. Spiritual distress remains a neglected concept within end-of-life care, principally due to confusion regarding definitions, a lack of conceptual understanding, variation in assessment tools and their use and the evaluation of specific interventions currently used to help relieve such distress.

The assessment of spiritual distress in a community context is also problematic: most published studies to date which seek to address the issue of spiritual distress are based either within a hospital or hospice setting. None would appear to describe how spiritual distress is perceived/experienced by community nurses within different care settings or attempt to evaluate spiritual distress as experienced by patients dying within their own homes. Likewise, literature describing the use of specific assessment tools within a community setting is scarce.

Aims of the study

This study explores perceptions of community nursing staff within two different care settings to the phenomenon of spiritual distress, as observed in end-of-life community-based patients.

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1. How are the terms spirituality, spiritual care and spiritual needs perceived by community nurses within the different care settings?
2. How is spiritual distress perceived by community nurses within the different care settings?
3. How is spiritual distress identified by community nurses in the different care settings?
4. What specific interventions (forms of practice) are utilised by community nurses in the different care settings to help alleviate spiritual distress?
5. Is there any commonality of practice between the different care settings?

This study is not receiving external funding.

What would you have to do?

For this exploratory study, I aim to interview band 5 or 6 nurses from two different community contexts: namely, community (NHS) and hospice, so that perceptions and experiences of caring for EOL community-based patients can be compared.

Interviews would be carried out at a suitable venue(s) at Pilgrim's hospice, hopefully with as little inconvenience as possible. At this stage, I am asking you to commit no more than 1 hour to the project. I hope very much that you might be willing to do this.

Why I am writing to you

I am attempting to recruit community (NHS), hospice and specialist palliative care community nurses to take part in this exploratory study. Participants need to be band 5 or 6 community nurses within Pilgrim's who have at least 6 months experience involving caring for EOL community-based patients.

Procedures

Interviews would be audio recorded and subsequently transcribed for analysis. Any information that might identify yourself, service users, other staff or your organisation will be removed from the transcripts. Participant anonymity would be maintained throughout, and no data subsequently used within the study would be identified by name or place of work.

Feedback

I would welcome the opportunity to present the findings of this exploratory study to an appropriate forum at Pilgrim's. The final thesis will also be available on-line via the CCCU website.

Will the study be confidential?

Absolutely. All electronic copies of personal information and research data will be stored securely using CCCU cloud storage in accordance with General Data Privacy Regulation (GDPR), the Data Protection Act 2018 and CCCU policies and procedures. Hard copies containing any personal information (e.g. consent forms) and anonymised hard copies of interview transcripts and thematic analyses will be stored in a locked filing cabinet in my home. No unrelated or unnecessary personal data will be collected or stored. Personal data will be used only to provide appropriate background information to the study (e.g. the average number of years participants had been involved in EOL care) and to provide summaries of participant responses within the final thesis. Data access within CCCU will be limited to myself and my supervisors: Professor Doug McInnes and Dr Harshad Kaval. Their role is to supervise the research project and associated data collection. No data will not be transferred out of the European Economic Area.

Audio recordings of interviews will be immediately transferred to a pass coded laptop computer and deleted from the recording machine utilised for the interview. The interview recording will then be uploaded to secure CCCU cloud storage. This recording will be subsequently transcribed by myself or a professional transcriber to ensure that confidentiality is maintained. All transcripts will be anonymised using appropriate letter or numerical codes to avoid identification of yourself, your service area or employing organisation and any patient identifiable information will be redacted. No respondents would be identified by name, age, gender or work location within the final thesis.

CCCU will keep identifiable information about you until completion of the study. After the study is completed, all personal information associated with the data will be removed. The remaining data will then be securely stored for a period of five years at CCCU before being destroyed in line with CCCU's confidential data management policies. All hard copies of data will be destroyed at the completion of the study.

Data protection Regulations

As a university we use personally identifiable information to conduct research to improve health, care and services. As a publicly funded organisation, we must ensure that it is in the public interest when we use personally identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. CCCU will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded to oversee the quality of the study. Individuals from regulatory organisations may look at your research record to check the accuracy of the research study (e.g. external examiners). The only people in CCCU having access to information that identifies you will be myself or those who audit the data collection process (e.g. my supervisors). No one else who analyses the research data will be able to identify you or have access to your name or contact details. CCCU will keep identifiable information about you until the end of the study.

CCCU is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.
Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. You can find out more about how we use your information by contacting the CCCU data protection officer at dp.officer@canterbury.ac.uk.

Health and care research should serve the public interest, which means that we must demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research. If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. Our Data Protection Officer can be contacted at dp.officer@canterbury.ac.uk

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

Dissemination of results

Our intention is that results of the study will be disseminated via:

1. Peer reviewed publication in appropriate journals.
2. Research paper/poster presentations at suitable Nursing related conference(s).
3. Publication of the final thesis in the CCCU library.

Deciding whether to participate

It is entirely up to you to decide whether to take part in this research. This participant information sheet describes the project and what you will be asked to do should you agree to participate. At this stage, the only commitment required is to be interviewed for no more than 1 hour at your place of work. At the beginning of the interview, you will be asked to sign a consent form to confirm your willingness to take part.

If you have any questions or concerns about the nature, procedures or requirements for participation please do not hesitate to contact me. I have included my contact details at the bottom of the sheet. Should you decide to participate, you will be free to:

1. Withdraw consent at any time without having to give a reason.
2. Request to see all your personal data held in association with this project.
3. Request that the processing of your personal data is restricted.
4. Request that your personal data is erased and no longer used for processing.

Process for withdrawing consent

To withdraw from the study, simply contact me by any of the means listed below, stating your decision to withdraw [before 30th November 2020]. Two options are available:

1. Withdrawal of consent to participate
2. Withdrawal of consent in association with deletion of data already gathered.

Having received your request, I will then respond via e-mail confirming your withdrawal and the deletion of any data pertaining to your participation (if requested).

Are there benefits to taking part?

I hope that the research data obtained will contribute to an enhanced understanding of spiritual distress as seen in EOL community-based patients. In that sense, you will be contributing to a study that aims to help improve both current knowledge and community nursing practice. There are no financial benefits from taking part.

Are there any risks?

There are no risks associated with participation in the study. However, the nature of the topic means that previous experience of caring for patients who were manifesting visible signs of spiritual distress may have been challenging or upsetting: also, talking about this may generate potentially difficult emotions. I would hope that both the context and the way in which interviews were conducted would help to minimize any potential upset and allow participants to openly discuss their experiences.

In the very unlikely event that anything be disclosed during interviews which may constitute criminal or professional misconduct, your employer’s appropriate policies and procedures would be followed. I would also consult with my supervisors and CCCU if this were deemed necessary.

Who has reviewed this study?

All research undertaken on behalf of CCCU is subject to ethical review, to protect your interests as a participant. This study has been reviewed by the NHS Health Research Authority (HRA) and by the Pilgrim’s hospice research committee. The research proposal has also undergone internal independent assessment at CCCU.

What do I need to do if I am willing to participate?

If after reading this information letter you would like to take part in the study, please could you contact me using either the attached nurse participation sheet and pre-paid envelope or by either of the contact means listed below. It would be very helpful to receive an indication of your interest by 15/04/19. I do hope you will be willing to participate.

Any Questions?

If you have any further questions or would like the opportunity to discuss the project further, please do not hesitate to contact me using either of the contact means listed below.

Thank you for taking the time to read this information.

Yours sincerely

Clive Laker

MPhil/PhD Research Student
Faculty of Health and Wellbeing
School of Nursing, Midwifery and Social Work
Canterbury Christchurch University
North Holmes Road, Canterbury CT1 1QU

E-mail: cl350@canterbury.ac.uk
Mobile: 07745579927
Project Primary Supervisor
Dr Harshad Keval
E-mail: harshad.keval@canterbury.ac.uk

10.3 Nurse participant contact sheet

Canterbury
Christ Church
University

Canterbury Christchurch University (CCCU): Faculty of Health and Wellbeing

School of Nursing, Midwifery and Social Work

Research Project Information

Study Title: '<u>An exploration of Spiritual Distress in End of Life community-based patients</u>'

IRAS Project ID: **251598**

Contact sheet to register interest in becoming a participant in the above study

Thank you for taking time to read the attached information letter. If you are willing to become a participant in the above study, please would you complete the following details: I can then contact you directly.

Name	
Job title and band	
Workplace address	
Preferred method of contact (please provide details of e-mail address, mobile number, etc)	
Preferred time/day of contact if by phone	

Could you please return the sheet in the pre-paid envelope provided by Monday March 18th 2019.

Alternatively, please scan and return the contact sheet to me via e-mail, if this is more convenient.

Thank you.

Yours sincerely.

Clive Laker

MPhil/PhD Student
Faculty of Health and Wellbeing
Canterbury Christchurch University
School of Nursing, Midwifery and Social Work
E-mail: cl350@canterbury.ac.uk
Mobile: 07745579927

10.4 Nurse participant consent form

Canterbury
Christ Church
University

CONSENT FORM

Title of Project: ‘An exploration of Spiritual distress in end of life community-based patients’

(IRAS Project ID No: 251598)

Name of Researcher: Clive Laker

Contact details:

Address:
Faculty of Health and Wellbeing
School of Nursing, Midwifery and Social Work
Canterbury Christchurch University
North Holmes Road
Canterbury CT1 1QU

Tel: 07745 579927

Email: Cl350@canterbury.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that any personal information that I provide to the researchers will be kept strictly confidential ☐
4. I agree to take part in the above study. ☐
5. I agree to the interview being recorded and later transcribed. Once transcribed, the interview will be deleted from the audio recorder. ☐

________________________	________________	____________________
Name of Participant	Date	Signature
_________________________	________________	____________________
Name of Person taking consent (if different from researcher)	Date	Signature
__________________________	________________	____________________
Researcher	Date	Signature

Copies: 1 for participant
1 for researcher

11 Appendix 3: Questions used for semi-structured interviews

Study Title: '<u>An exploration of Spiritual Distress in End of Life community-based patients'</u>

IRAS Project ID: 251598

<u>Questionnaire for semi-structured Interviews</u> (additional prompts are shown in italics)

Could you tell me how long you have been a nurse?

How long have you been involved in the care of community-based end of life patients?

What led you to this type of nursing?

Why did you choose a nursing context which involved caring for patients who are dying?

What kind of issues emerge in your work with end of life patients?

Are there particular areas in your work with EOL patients that you find troubling/challenging?

The term 'spiritual care' appears in the nursing literature. What's your understanding of this?

What do you understand by the term spirituality?

Is this a term you are familiar with?

Do you have a favourite definition of spirituality?

Are there particular components that you see as important to spirituality?

The term 'spiritual needs' also appears within a nursing context? What do you understand by 'spiritual needs'?

Can you give me an example?

Is there a way to make an initial assessment of spiritual needs for EOL?

For example, during any initial holistic assessment?

How do you do this practically?

For example, do you use any specific assessment tools to help you identify spiritual needs?

Would you say that spiritual needs form part of your ongoing assessment when caring for EOL patients?

How do you do this practically?

What do you understand by the term spiritual distress?

Is this a term you have heard or read about?

How would you define spiritual distress?

Do you have a working definition?

How would you identify spiritual distress in community-based EOL patients?

Are there specific manifestations that you look for?

In your opinion, can spiritual distress be measured or quantified?

For example, can spiritual distress be measured in a similar way to physical pain?

Are you familiar with any specific assessment tools to help identify spiritual distress in a community setting?

Are there tools that you currently use or have used in the past?

Could you describe them?

How do you use these in your care of EOL patients?

Have you used any specific interventions to help alleviate spiritual distress?

For example, talking with patients or drug therapy?

Other interventions?

How would you measure how effective those interventions were?

How did you do that?

Do you have standardised methods which attempt to measure efficacy?

Is there anything in your work context that would enable you to engage more effectively with the spiritual distress when caring for EOL patients?

Anything that would make your job easier? Or better?

Is there anything else you would like to say or add?

Male/Female/prefer not to say?

Approximate age?

20-30

30-40

40-50

50-60

Prefer not to say?

Ethnic group

12 Appendix 4: McKinley T34 Syringe Driver

The current operating manual for the McKinley T34 can be accessed at:

https://tam.nhsh.scot/media/2391/06-mckinley-t34-syringe-pump-manual.pdf