

Dedication

In memory of my beloved grandmother, Anastasia Pentari

&

To my family and friends

Acknowledgements

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Abstract

This thesis explores the challenges and controversies that healthcare professionals who work in death and dying settings face when working with service users with religion, belief, and spiritual identities. The secular-minded modern history of the nation has left people precarious of religion and belief, lacking religious literacy (i.e. the ability to talk about it) (Dinham & Francis 2015). Religious literacy is a contested concept which is used as a lens through which this thesis is framed. The study was undertaken in hospices while it reports on data from a triangulation method, including participant observation, interviewing, and focus groups.

Healthcare professionals appear to have lost the ability to engage adequately with religion, belief, and spiritual identities of service users. Religion and belief have been approached as problems to be solved, rather than aspects to engage with. Solutions to deal with the religiously diverse service user population include equality and diversity laws that underpin respectful and non-judgmental attitudes, yet mask *inclusivity* with *neutrality*. Findings show that healthcare professionals are ambivalent toward discussing religion and belief related issues while the preference is to signpost service users to religious leaders or communities. Additionally, hospice organisations are currently undergoing many and various changes that are often washed down to professional practitioners. The changes include the removal of religious adornments from within the space, as well as amendments in relation to language on signs. The space is more like the portrayal of a largely secular nation that lacks proper abilities to engage with religion and belief.

This study is merely opening up the dialogue in end of life care about adequate accommodation of religion, belief, and spiritual identities of service users in professional practice. This is paramount in order to fulfil requirements toward a fundamental aspect of hospice care; comforting service users from a holistic approach, beyond the bio-medical.

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Acronyms and Abbreviations

APA	American Psychological Association
ASA	American Sociological Association
BR	Beveridge Report
BSA	British Sociological Association
CAQDA	Computer-Assisted Qualitative Data Analysis
CDP	Community Development Project
CTE	Churches Together in England
DDB	Death, Dying and Bereavement
DoH	Department of Health
EDS	Equality Delivery System
EHRC	Equality & Human Rights Commission
EOAP	Equality Objectives Action Plan
EOL	End-of-Life
HCP	Health Care Professional
HCPC	Health and Care Professions Council
HEI	Higher Education Institution
HELP	Hospitalised Elderly Longitudinal Project
LCP	Liverpool Care Pathway

LGA	Local Government Association
MDT	Multi-disciplinary team
NCPC	National Council for Palliative Care
NEoLCIN	National End of Life Care Intelligence Network
NHS	National Health Services
NHS	National Health System
NICE	National Institute of Health and Care Excellence
NIH	National Institute of Health
NRES	National Research Ethics Service
NRR	National Research Register
ONS	Office for National Statistics
PHE	Public Health England
PIE	Person in Environment
QDA	Qualitative Data Analysis
QSR	Qualitative Social Research
SRA	Social Research Association
STaCS	Social, Therapeutic and Community Studies
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment

Key definitions

End of Life Care

End of life care refers to the caring of the dying when they are nearer to the end of their lives. Simultaneously, it refers to the care of the bereaved associated with the dying person. End of life care is multi-faceted and can be explored in several different contexts; e.g. hospices, community and people's homes, hospitals, elderly homes, and so on. This thesis is reporting on findings from within hospices.

Religious literacy

Religious literacy is a fluid concept that can only be examined within its context. It refers to the ability to comfortably engage with religion and belief (also see Dinham & Francis 2015).

Religion, belief, and spiritual identities

The terms religion, spiritual, and belief or faith are often used interchangeably. In this thesis I am using this phrase to refer to all faiths and none as individual identities. Reference to 'religion and belief' is only made when necessary to emphasise the marginalisation of the two from the discussion while 'spirituality' and 'spiritual care' are predominant.

Health Care Professional (HCP)

Professionals that are qualified by the Health and Care Professions Council are identified as health care professionals, including physicians.

Service User

The Equality Act 2010 describes service users 'those accessing or using a particular service' (volume 5). The term is used in this thesis to describe patients, family members and friends who become users of hospice and end of life services.

Introduction

My thesis regards the intersection of two fields. These are death studies and religious studies. I am taking my knowledge and background in death studies, coupled with social work as my occupational background, and examine professional practice in relation to one aspect of end of life (EOL) care: religion, belief, and spiritual identities of service users. This is where religious studies become relevant to the thesis. I am using religious literacy (Dinham & Francis 2015) as a lens through which I am exploring the challenges that health care professionals (HCPs) face with regard to how religion and belief are integrated in hospice care. In this chapter (i.e. introduction), I am sketching out the progression of my thinking as I outline step-by-step the themes that will be unpacked in the following chapters.

In accordance with Martin Heidegger's thoughts, one's conception of life in the knowledge of death is a liberating one (Heidegger 1962; also see Edwards, Freeman & Sugden 1979). However, death has for a long time not been a subject welcome at the dinner table. Until the mid-twentieth century, most of the people would die at home. This tendency has changed since in the western world. The death site is no longer in the comfort of one's home; it is placed in hospitals, hospices or elderly homes (over 80% of deaths in 2013 – see www.ons.gov.uk). Our detachment from death has led to a lack of conversation about death, as this is now a rather medicalised subject.

Philippe Aries (1974) accentuates the philosophical belief that death, toward the second half of the twentieth century, is merely a reminder of our mortal selves, and 'foreign to our existential pessimism' (p.44). This perception and ambivalence to touch on this subject has changed throughout modern history. About twenty years earlier, in 1955, Geoffrey Gorer challenged death talk in public, though without significant impact until the 1980s. With his *The Pornography of Death*, Gorer (1955), describes societies being ambivalent to accommodate

death talk, death being an issue that has had an immense impact on society after the World Wars I and II. The same ambivalence has been overseen for half a century as death in the 21st century is a subject for studying, but not necessarily a part of life that people talk about comfortably. To fully appreciate the course that death talk has taken in time, and the ways in which that has influenced EOL care, it is important to familiarise with death studies and hospice care, with their history and development.

Reminiscent of Weber's identification of the scientific era, technology and science have dominated in modern societies about death and dying; prolongation of life became more important than acceptance of the end of life. Death began to be considered a failure, a weakness of the body, and a state of imperfection that is certainly related to ageing (Elias 1985; Morin 1951; Feifel 1959; Kastenbaum 2000). Biomedical approaches to death have been gaining ground all through the twenty-first century (ibid.; Kastenbaum 2007), with the grief models highlighting the dominance of clinical classification of the meaning-making process and experiences of dying and grieving. Concurrently, the psychosocial study of DDB was ignored (Fonseca & Testoni 2011-2012).

Simultaneously, there are at least two repositories of conversation about death and dying that are happening separately. Existential philosophers have been developing discussions about DDB while the conversation is prompted by the wars in the first half of the twentieth century (also see Walter 1994). Important works of these philosophically driven discussions about death include the following. The American psychologist Herman Feifel (1959), one of the pioneers in death talk in the mid-twentieth century, and the well-renowned Austrian neurologist Sigmund Freud, who became the founder of psychoanalysis.

A second discourse is taking place in Theology and Religious Studies about death and the experience of life existence. Pattison (2013) offers a critical theological reflection of death, the

meaning of death in modern societies, and the afterlife. Pattison (2013) bases his analysis on Heidegger's philosophy about DDB.

The review of religious discourse about death shows us that concerns about the meaning of death in life, post-death experiences and resurrection have always been present in the discussions (Van Baaren 1967). Westphal (1984) identifies two main problems with human life as those link to religious discourse too; guilt and death. In his theological analysis, he explains what it means to be religious while attempting to resolve guilt and death.

The discourse about death in Theology, parallel to Christian values and the Church, has informed Cicely Saunder's aspirations when introducing hospice care (Saunders 2005). Hospice care became a movement (ibid.) that had received immense influence by theological understandings of spiritual care; drawing from the values of social solidarity and humane approaches to life.

The conversation has separated and scientific observations and explanations about death dominated while ontological interpretations are avoided and pushed into the existential realm of human life (Becker 1971). This split of the conversation also splits the experience of the patients in healthcare. The first signs of awareness of this problem are the medical model, which gives way, first of all, to Social Work theories in the 1980s.

In his work, Carl Rogers (1979) expanded on a person-centred approach, namely the client-centred theory. Since its beginning, the social work profession has followed the principles of a person-centred approach, based on the observations of social work practitioners that an individual's correspondence to life is unique and individualistic. Nelsen (1980), in *Communication Theory and Social Work Practice*, underscores the fragility of human beings in a complex environment, and the extensive need for a more humane, holistic and compassionate approach toward vulnerable situations. According to Donnison (1980), social

work became a beacon of principles toward well-being of individuals. Herbert (1980) suggests ‘informed eclecticism’ for social workers, alongside the wide range of professions that aim toward social and health well-being of individuals and communities.

Professional literature on death studies starts reflecting on general policies, such as the service user empowerment and the children’s rights. This consideration translates into death policies in the twenty-first century that are challenging the medical model and clinical approaches in hospice and palliative care. The End-of-Life Care Strategy 2008 in the UK comes first to explicitly identify the needs of patients toward the end of their lives. The strategy also signifies the importance of a holistic approach to care, beyond medical ones, and enhancement of the experience of patients, while involving compassionate perspectives in care. In the prime of this discourse, death policies are now informed by conversations about spirituality, compassion, and well-being, all introduced as remedies to psychosocial, emotional and religious needs of patients. NHS Improving Quality of care is issued for the first time in 2012 in the UK to assess and improve the quality of healthcare. This initiative promotes the principles of well-being and spiritual understanding of patients by HCPs.

Spiritual care is recognised largely in the healthcare system (DoH 2009) while its presence has been challenged (Walter 2002). The last twenty years, professional literature has focused on spiritual needs of patients (Stanworth 2004; McSherry & Ross 2010) and well-being as a core principle of offering quality care (Jewell 2004). This recognition is magnified in End-of-Life care (Kuebler, Davis & Moore 2005).

Policies are reflections of the understanding of spiritual needs, well-being, and compassion, as it will be further explored in the literature review. On top of that, general policies and death policies in the UK have recently started recognising religion and belief as new strands for integration in health and social care (also see PHE 2016). The Equality Act 2010 identifies religion and belief as one of the nine strands of equality. This has a large effect on death policies

as well (e.g. End of Life Care Strategy, Improving Care, Compassion in Practice). The Act introduces religion and belief in the conversation, but the levels of knowledge and understanding to do so are questionable.

According to Dinham (2015), professionals and policy-makers struggle to have that conversation because of lack of religious literacy. There is an ill understanding of religion and belief which undermines the principles of holistic care and well-being in healthcare in general (also see Dinham & Francis 2015), and in hospice care in particular (Pentaris 2013). Religious literacy is a contested notion that can only be understood within context. It refers to better skills and abilities to engage with religion and belief (Dinham & Francis 2015). This argument, as highlighted in the second chapter, needs to be complemented by the history of religious change in the UK. This is a necessary task toward the knowledge that there is lack of religious literacy and the need for effective health and death policies, and implementation of practices that meet individual needs on a holistic level.

Bryan Wilson (1966) suggested that religion lost its social significance as society modernised. This started what is known as the secularisation thesis. Since the mid-twentieth century, secularisation theories took hold, and secularism and the argument that religion and belief have been absent from the public sphere informed policy and practice. Nonetheless, suggested by many including Berger (1999), Dinham (2012) and Davie (2007), religion has maintained its social significance, both on an individual and societal level, regardless of the perceptions of the opposite.

At a time when religion and belief, after having experienced a prolonged period of public unidentification, are resurfacing in the public sphere, this study focuses on the influences that the secular characteristics of today's society have had on the health care service delivery system, and more specifically on service provision in hospice care. In more detail, it aims to explore religious literacy of HCPs in hospice settings in Britain. The hypothesis that HCPs in

Britain tend to be or are illiterate concerning religious matters, emerges in the context of religion in relation to the state, in post-war Britain (Wilson 1976), the trend of privatisation of religious affairs over the same period of time, the relationship between the state and the church (Davie 1994), as well as the emergence of social welfare and the state as the commissioner of welfare services (Dinham 2015).

Within this largely secular society in Britain and the secular character of social policy, it only seems rationally expected that HCPs lack knowledge, understanding, abilities, and skills in regard to religion and belief, both in theory and practice. On the contrary, it becomes a tremendous challenge when service users are more religious than one thought, and especially in death and dying settings (Curren 2001).

Overview of the Chapters

The structure of the thesis includes seven chapters. After the introduction, **chapter 1** discusses the approaches on DDB, as well as the emergence of religion in EOL care. In particular, health care practice is examined in parallel with current social policy and planning relating to qualitative services at hospice settings, and in connection with how *religion* is embedded within the guidelines for hospice care. This is the space where the meaning and value of death are discussed. Hospice care is laid out in more detail, and content analyses are provided for the reader to enhance better their understanding regarding hospice care's history and development. Moreover, this chapter explains the importance of religious literacy when working with DDB related issues in EOL care and fully identifies the rationale for undertaking this study. Last, the chapter includes an overview of current and effective social policies in EOL care.

The **second chapter** refers to secularisation theory, secular identities of the British society, and the impact of secularisation on social policy and the welfare state. Through the chapter, modernisation, westernisation and globalisation are discussed as well, in juxtaposition with

secularisation. The chapter focuses on social policy and the state since the post-war periods. Also, attention is given to the significant changes from a Christian society, to a Christian plural one, to Religious Plurality and Secularism. The chapter attempts to highlight the importance of becoming aware of where *religion* and *faith* stand today, the relevant changes, and how those play out in practice. This discussion bridges the literature review with the findings from the main study, as well as the conclusions from it.

Chapter three is the methodology chapter. The chapter provides a comprehensive sequence of ontology, epistemology, methodology, and methods. This chapter also clarifies the researcher's positionality, in addition to identifying and highlighting challenges, biases, and expected outcomes of the research project. Moreover, the pilot study is discussed in this chapter. Last, this chapter explores and discusses practical and ethical considerations of the study, inclusive of limitations that have been identified.

The **fourth, fifth and sixth chapters** provide a structured and comprehensive analysis of the findings of the study, supported by the secondary research for this project (literature review).

Chapter 4 reports on findings from participant observation. Vignettes from fieldwork are used to demonstrate the claims from the findings as well while all emerging themes are extensively discussed. **Chapter 5** adds value to the reporting of the findings. This chapter reports on findings from interviews and focus groups. This chapter has a main focus on findings that relate to HCPs' perceptions of religion and belief in society and in healthcare in general. It also pays attention to how HCPs understand and appreciate the links between DDB experiences and spiritual care that involves religion, belief, and spiritual identities in all. Similarly, **Chapter 6** draws from the same methods and reports on findings directly linked to the exploration of religious literacy in EOL care. It is concerned with how HCPs understand the integration of religion and belief in professional practice at thanatological settings. The discussion is

exhaustive about the skills and abilities of HCPs to engage with religion and belief, as those are emerging from the data.

Chapter seven concludes the thesis. The final chapter will be a commentary for the whole project, all the learning outcomes and future trends in research. It consists of one main section. It is concerned with the results and conclusions of the research findings and discussion. Next, recommendations for future research are made.

Chapter 1

End of Life Care: from Religious to Scientific modes

In this chapter I will explore the shift from explanations of death in the religious mode to explanations in a predominantly scientific mode. Within that, I will explore the changing discourses of religion, the medical and society, and the relationship between them, and will consider a tension between the increasing medicalisation of death on the one hand and a growing emphasis on spirituality in death and dying settings on the other. I will also consider the changing relationship between spirituality, which appears to have traction as a proxy for religion, and religion and belief themselves, with which professions seem less comfortable., despite continuing and increasing religion and belief diversity. This will enable me to explore the issue of the religious literacy of health professionals in hospices.

I start with an exploration of death and dying as socially constructed concepts, and an examination of contestations and ideas of death itself. The exploration of death as a contested concept assists in highlighting the various and changing discourses of religion, medical approaches, and society. It also contributes to the argument that dying has been appreciated through religious and philosophical modes, which have informed the conception and development of hospice care in the 17th and 18th centuries and its later formation in the 1950s. After that, I introduce hospice care and expand on its development in contemporary practice, and focus on the presence of spirituality in hospice ideology. This will explore the context in which this project is researched. I then explore whether ultimately current approaches in EOL care seriously narrow the space for discussion about the spiritual aspects of death and dying in healthcare practice.

The chapter will conclude by setting out the key parameters of contemporary policy about healthcare practice in hospices, as well as drawing on the literature to suggest that policy and

practice in this area reflect medical, clinical, and bureaucratic model dominance, and a need for religious literacy. The conclusion poses the key question of the thesis: how well equipped are HCPs to engage with religion, belief, and spiritual identities of service users in death and dying settings?

Introduction

Despite the unique and individual character of the experiences of DDB, research has primarily focused on generalised attitudes toward death and dying, all toward improving quality of care for the dying and the bereaved. From the Greek Philosophers Plato, Socrates and Aristotle, to the modern work of Kamath (1978) and Feifel (1959) a philosophical understanding of the role of death in life prevails in the discussion. Socrates suggests that ‘death is the separation of the soul from the body’ ‘but also the answer to an illness’ (in Plato: *Phaedo*: 61c-69e). Aristotle has said ‘Το να πεθάνω θα είναι μια πολύ μεγάλη περιπέτεια’ [To die will be an awfully big adventure] (384BC – 322BC) (Lear 1988; also see Sutton 1991). He viewed death as the outcome of life; an inevitable consequence of an individual’s life course. Moreover, the big adventure refers to the experiences before and after death, but not mortality itself.

Parkes et al. (1997) take a different approach and suggest that death can be viewed on the grounds of logic:

Maybe we are right to ignore death. If there is nothing we can do about it perhaps, we should treat it as if it doesn’t exist....This is the logical view. It accords well with a pragmatic view of life which seeks practical solutions to practical problems. It is very different from the superstitions of religion (p.5).

On the other hand, religion is essential to understanding and experiencing DDB (Leming & Dickinson 2011). In their introduction, Parry and Ryan (1995) have also stressed the importance of considering culture, religion, and tradition when working with the dying and the bereaved. Nevertheless, one should be mindful of religious difference within similar beliefs;

an aspect that only perplexes the picture more. According to Parkes et al. (1997), ‘people who subscribe to a particular religion in one part of the world may have very different beliefs and rituals from those of people of the same religion who live in other places’ (p.21). Such suggestions inform the current study, and it explores how HCPs in EOL care understand and respond to religion, belief, and spiritual identities of service users.

Between the main contemporary scholars who identified the need for responding to religion, belief, and spiritual identities in EOL care are Daaleman and VandeCreek (2000). They hold the view that ‘an understanding of religion and spirituality within the context of end-of-life care, quality of life, and patient-clinician interactions may illuminate the problems and potentialities for both patients and clinicians’ (Daaleman & VandeCreek 2000, p.2514). Nonetheless, the core challenge in this attempt is whether religion and spirituality are perceived as part of the problem or part of the solution. Some examples follow to illustrate this. The approach that Daaleman and VandeCreek followed (2000) had been influenced by the SUPPORT method (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment). This method refers to a project beginning in the 1990s which surfaced and identified, among others, aspects of religion and belief in the needs of terminally ill patients. The core objective of the study, similar to other studies at the time, such as HELP (Hospitalized Elderly Longitudinal Project), was to improve decision-making in order to address national concerns over the loss of control that patients experience toward the end of their lives. Further, it sought to eliminate the frequency of a prolonged, painful and complicated process of dying (SUPPORT 1995). The project suggested characteristics of care, treatment and decision-making patterns of critically ill patients (Daaleman & VandeCreek 2000), while the current project has gone beyond those aspects of care. With this study, the aim has been to improve the quality of end-of-life care, as well as promote – not necessarily in a direct manner – a

readdressing of the balance in the relationship between health care, and religion, belief, and spirituality. These are valuable aspects of EOL care:

The goal of a quality comfortable death is achieved by meeting a patient's physical needs and by attending to the social, psychological, and the now recognized spiritual and religious dimensions of care (ibid., p.2514).

This approach of quality care to institutional dying recalls previous examples regarding the enhancement and enrichment of health care. One example is that of the United States. In the late 1980s, a consensus statement included the embedding of religious and spiritual needs of patients in health care, however, referred to them as problems: 'assess and manage psychological, social, and spiritual/religious problems' (Cassel & Foley 1999, p.6). An additional remark regarding the approach informed by the quote above is that it had reinforced the management of 'religious and spiritual problems as core principles of professional practice and care at end of life' (Daaleman & VandeCreek 2000 p.2514). This has largely informed death policies, as discussed later in the chapter, as well as attitudes toward spirituality in EOL care. An example of the latter is Daaleman et al. (2008); in their explanatory study at nursing homes, they conclude that nurses and doctors still believe that spiritual and religious needs of their patients are merely fluid processes of their personal development toward the end of their lives. Outside of the institutional context of a hospice or an elderly home, and beyond their social and collective dimensions (Smart 1996), religion and belief are matters subject to individual consciousness. Nonetheless, this seems to be overly challenging to HCPs within institutional care, perhaps due to lack of confidence in engaging with aspects of care about which one may not have authority over (Yardley et al. 2009). For example, a physician would monitor and audit pain management but would find themselves professionally vulnerable in the face of needs that derive from spiritual suffering.

Further to the discussion, the UK End of Life Care Strategy 2008 highlights spiritual needs as being coupled with emotional needs, alongside implications of religious needs. Nevertheless, this is neither addressed in the guidelines for improving health care with the dying and/or the bereaved (NHS Improving Quality) nor expanded in its pragmatic dimensions (i.e. addressed in professional practice). In other words, spiritual care is included in the principal responsibilities of HCPs, as it is an integral part of the holistic care the National Health Services (NHS) have always striven to offer (DoH 2003). This was predicted by Walter in the 1990s. He predicted that ‘spiritual care will become indistinguishable in practice from emotional/psychological care’ (Walter 1997, p.29). His prognosis has come true to a wide extent, as the example of the End of Life Care Strategy reveals.

There is not only a dearth of literature in the area of ethics and spirituality in EOL care, but also unclear social policy (see *Spiritual Care in End of Life* by DoH 2009). The literature largely confines itself to discussions of spirituality while religion and belief are marginalized. This undermines the demand for engagement with religion, belief, and spiritual identities, and suggests in any case that talk of spirituality does not translate into commitment and practice.

Many scholars affirm spirituality to be a contested notion. In his view, Walter (2002), suggests alternative approaches and challenges the assumption in the palliative care literature; namely the claim that all patients have spiritual needs and that HCPs have the right skills and knowledge to provide spiritual care.

If all patients have spiritual needs, if the palliative care unit is committed to holistic care, and if all members of the multi-disciplinary team can deliver this kind of spiritual care, logic then requires that they ought to deliver it (ibid., p.3).

Research that focuses on spirituality (see Puchalski 2013; Ferrell, Otis-Green & Economou 2013), however, shows that spirituality has not been successfully integrated into end of life care, neither has it found its ethical embedment in the professional lives of health care staff.

On the other hand, both chaplains (Nolan 2012) and nurses (McSherry 1998) have, by and large, contributed to the delivery of spiritual care.

Wynne (2013) develops the claim that ‘there is a lack of awareness of the importance of spirituality in patients’ lives, and how good spiritual care can enhance quality of life and improve patient outcomes’ (abstract). According to Puchalski (2013), there is a lack of understanding of what spirituality entails when it comes to palliative and EOL care in general. In my argument, the spectrum of religion, belief, and spirituality reflects the real religious landscape according to the social scientific evidence while policy confines itself to discussions only of spirituality. This leaves religion and belief as neglected aspects of identity or identities in EOL care. That said, the marginalisation of religion and belief from EOL care is thought to be foregrounded in the experiences of dying people themselves.

Bio-medical and clinical approaches are taking hold in EOL care (Fonseca & Testoni 2011-2012; Hollins 2006; also see Paley 2007 for jurisdictions of care in hospices), which poses the challenge of how to integrate religion, belief, and spiritual identities of service users in policy and practice. Since the development of the hospice movement in the late 1960s, EOL care has seen numerous challenges along with a fast-changing society, with its composition, complications, and contested notions. So according to Daaleman et al. (2008), multiple ethical and pragmatic issues emerge from the conversation regarding integrating religion, belief, and spiritual related needs into health care in general, and in EOL care in particular. ‘Should physicians identify patients’ spiritual and religious needs and intervene in clinical settings?’ (Daaleman & VandeCreek 2000, p.2514). This is a key question that could apply to all healthcare professions as well as allied professions in health care. This was noted by Puchalski et al. (2006) who claim that ‘in order to provide excellent palliative care physicians and other healthcare professionals must be able to address all these dimensions of care [physical, emotional, and social], including the spiritual’ (p.398).

The current study goes beyond identifying needs and appointing professional responsibilities. Since Saunders' perception of spiritual care in hospices (Saunders 1988; also see Clark 2002a), which will be addressed later in the chapter, and until the recent review of the emergence of spiritual dimensions in EOL care in 2011 by the Department of Health (see end of chapter 1), the discussion and the intentions remain the same. Saunders opened up the dialogue about spirituality, and this has surfaced and resurfaced ever since in a variety of policies and guidance. However, the conversation appears not to have matured or evolved in keeping with developments in understanding the sociology of religion: specifically, religion, belief, and spirituality are not well understood and even less well operationalised. This study aims to move the debate on by exploring, not only spirituality but the specific categories of religion, belief, and the spiritual as they play out in policy and practice. I do this through the analytical lens of religious literacy (Dinham & Francis 2015).

Contestations of Death

Changing discourses of religion, medical and society

Death is a contested idea with a natural scientific factuality, alongside a plethora of interpretive analyses. These include culturally shaped attitudes toward death and dying, self-awareness and dying, immortal selves, death as an untouched subject, death as part of life, meaning-making and multiple social identities, and meaning-making and death sites. All the above culminate in a major key theme: death is a highly contested concept and an utterly subjective experience that is shaped by personal and social characteristics. In this section, I am reviewing the literature and reporting on previous analyses about DDB. Literature in this area often stems from a religious mode that explores the meaning of life. This is important as it directly links to the following argument. While the scientific mode or medical model attempts to operationalise

an overly individualised and subjective experience, it fails to respond or poorly responds to needs beyond the bio-medical (i.e. religion, belief, and spirituality).

A great number of historians, social scientists, medical scientists and philosophers have contributed to the definitions and explorations of the nature of death (Kamath 1978; also see Lear 1988). Similarly, scholars have focused on the definition of death, as well as how people and communities experience it (Glaser and Strauss 2005; Walter 1994; Aries 1974; Becker 1973; Kübler-Ross 1969). In the book *The Birth and Death of Meaning* (Becker 1971), the search for the meaning of human life can best be explained by the 'ultimate fear of death' (p.82). This responds to the human quality of having self-awareness (Taubman-Ben-Ari 2011). The self-awareness of our inevitable death shapes perceptions of meanings of death. Another source of the exploration of the nature of death is John White (2004), who focuses on the higher human development and elaborates on the factors that closely associate with DDB. In his guide toward death and dying, White (2004) talks about self-awareness in the way we die using the example of the Western world and the Himalayas. He talks about the interconnection between the nature of objective death (Cicirelli 1998) and the meanings that subjectively form and guide us through the experiences of DDB (Riley 1983). Death is a composition of two parts; the objective event of death, which is inevitable, and the subjective interpretation, and emotional and psychosocial reaction to the event: before, after and at the event. The latter is coined subjective death, and will be referred to in that term from now on.

There is no universal definition of the nature of death, and there cannot be one, for such definition would require a harmonious balance between the possibilities and limitations of life. This is likely to be linked with Becker's exploration of human nature and the heroic. The narcissist behaviour, as described in the following quote, demonstrates the tendency to oversee the limitations of life, as well avoid coming face-to-face with reality:

When we are young we are often puzzled by the fact that each person we admire seems to have a different version of what life ought to be, what a good man is, how to live, and so on. If we are especially sensitive it seems more than puzzling, it is disheartening. What most people usually do is to follow one person's ideas and then another's, depending on who looms the largest on one's horizon at the time. The one with the deepest voice, the strongest appearance, the most authority and success, is usually the one who gets our momentary allegiance; and we try to pattern our ideals after him. But as life goes on we get a perspective on this, and all these different versions of truth become a little pathetic. Each person thinks that he has the formula for triumphing over life's limitations and knows with authority what it means to be a man, and he usually tries to win a following for his particular patent. Today we know that people try so hard to win converts for their point of view because it is more than merely an outlook on life: it is an immortality formula (Becker 1973, p.255).

However, the tendency not to talk about, see or feel (through mourning and grief) death in many societies (Kastenbaum 2007; also see Walter 1999 for different types of grief expression) has become core principle and a norm. According to Feifel and Strack (2001) and Feifel (1992), a distinctive characteristic of human beings is the ability to conceptualise the idea of the objective death – 'understand its limitations' (Cicirelli 1998, p.713) –, and emotionally react to it. Human beings often hold strong beliefs about their immortality, for example, a certainty of eternity (Becker 1973; Aries 1974) and heroism (Becker 1973).

Also, the nature of death cannot be comprehended outside of life, as it is a vital part of it (DeSpelder & Strickland 1999). According to Taubman-Ben-Ari (2011), understandings of the meaning of life have highly complex philosophical implications for one's subjective death. Kastenbaum (2007) suggests that death and life come into close relation with society; the living are the means to experience death. As Freud claims (1915), death had always been there before it even occurred, and Feifel (1959) proposes that 'it is a myth to think that death is just for the old. Death is there from the very beginning' (p.234). The above sources mostly support the

highly contested notion of death and its individualised nature. These are important aspects when considering the operationalisation of care for the dying.

Understanding death and dying, and meaning-making may be an intense and frustrating process that might increase the risk of death anxiety (Yalom 2008; de Hennezel 2007; Byock 2002; Campione 2004), an experience that influences the tension between religious and philosophical explanations of dying, and medical or clinical approaches to it (also see de Hennezel 2007). Tomer and Eliason (1996) suggest a comprehensive model of death anxiety; it consists of three constructs: past-related regrets, future-related regrets and meaningfulness of death. The latter refers to the understanding that one has of death, which in turn mirrors the importance of life course, toward the dying process and finally objective death, i.e. the death of the body. An event in life can be perceived as meaningless only if it has subjectively been recognized as such (Weber 1966). In their model of death anxiety, Tomer and Eliason (1996) talk about anxiety levels of an unknown event in life. In contrast, Becker (1973) suggests that the tendency of the human beings not to accept their mortal nature enforces the lack of meaning in the event of death. Along with the death anxiety model, this relates to the process of refusing the parts of life that indicate the end of it.

In overall, it is in the human nature, the need to construct meanings of death and dying that affects the way we run our lives (Becker 1971). There is the need to make meaning, but there is also frustration and anxiety in the process, and those two can become counterproductive.

Since the 18th century, and up until the end of the 20th, the fear of the death of the other predominated in people's lives (Aries 1974; Becker 1971; Freud 1915). This has enhanced the tendency to refuse the acceptance of the vulnerable nature of human beings and future death. Times of war have also affected attitudes toward death and increased the fear of the death of others, also described by Freud (1915). However, in the contemporary world and globalised

societies of the 21st century, attitudes toward death have and are shifting directions. There is improved familiarity with one's death (Gunaratnam & Oliviere 2009) as well as awareness of potential vulnerability (de Hennezel 2007). This in response to Gorer's work (1955); *The Pornography of Death* (1955) makes an interesting contrast between sex and death. Sex had been an unmentionable subject in polite societies. It was a private matter, not only in terms of private desires but also in connection with what we today call sex education. In the same fashion, he presented death as pornographic material. Death was actively privatised (Enright 1987), and it became an unmentionable subject, along with sex. Gorer (1955, p.52) contests that, suggesting that 'if we dislike the modern pornography of death, then we must give back to death...its parade and publicity.' Some sixty years later, death is discussed openly and publicly in western societies, nonetheless, the conversation is focused on institutional death and its commodification.

An additional aspect that influences the contested notions of death relates to both primary and secondary death sites. Attitudes toward death have changed a lot, especially after hospitals were considered to be the main site for death (Aries 1974; Feifel 1959; 1977; also see Walter 1994 for more phenomenological approaches). From a time when home was the primary death site, and the public was invited to celebrate the death of the loved one, death became a private matter that took place behind hospital walls, and away from the public eye. De Hennezel (2007) observed how the meanings of death may change depending on the death site. Her work was mainly focused on deaths in institutions. However, she explored individuals' desires on where they would prefer to have been instead; a principle well discussed and centralized within death policies in the UK currently. The majority of the patients expressed their desire for a painless but comforting at-home death. It is a general tendency that when the individual approaches death, it seeks for comforting environments that will not be constant and everyday indicators or reminders of their imminent death (ibid.).

Tensions between medicalisation of death and growing emphasis on spirituality

In an attempt to understand the nature of death, it is necessary to understand the series of changes that perceptions of death endure. Death cannot be understood by its non-state – objective death (Cicirelli 1998). Objective death, as discussed earlier, is merely the fact of death: the cessation of all bodily functions. This is the concept that medicine extensively examines. It is focused on preserving life, and on delaying the objective death of an individual, for as long as possible.

Death inclines into a contested concept when its subjective nature surfaces. The nature of death is clearer for an individual when they are fully familiarised with the core of the meanings they make for death (Feifel 1959; Kastenbaum 1996; Byock 2002; Pentaris 2011). Such meaning is constructed by several aspects of the individual's identity (Pentaris 2015): a social constructivist perspective (Burr 1995). 'Meanings for most of what happens in life is provided by the individual's cultural worldview, which offers a framework for understanding the world and our place in it' (Taubman-Ben-Ari 2011, p. 395). It seems that without this framework the individual is challenged to clearly perceive their lived experiences.

Death reflects limits of life (Sergeev 2007), which in the context of an institutionalised dying process diminishes the quality of the remaining life. As I was carrying out field work (2013), in one of my conversations with a spiritual care manager of an English hospice, I was told that the hospice is struggling to gain "a language relevant to death", and struggling to talk about the limitations that are on the one hand identified, but on the other not addressed (J.D. 2013, pers. comm., 17 October). The above is evidenced by research as well. In their grounded theory study, Zambrano and Barton (2011) underline the relationship between the fear that GPs experience of their patients' death and their resistance to talking about it. Following the above, the question is whether the lack of language implies ambivalence or the opposite.

Death is valued differently than it was prior to the emergence of scientific and philosophical interpretations (Aries 1974). More and different customs and rituals are witnessed in societies, and individuals become acculturated and/or enculturated to the ideas that different cultures and religions introduce (Sue & Sue 2008). Ritualistic behaviours and mourning tend to be influenced by spirituality and religion (Van Gennep 1960). It seems that the value of death is now more spiritually oriented than it was ever before. Spirituality here would serve as a safety net one can thread through in order to gain understanding of his/her individuality and the process of dying.

Additionally, with regard to meaning reconstruction (Neimeyer 1998; 2001), changing attitudes toward DDB in the contemporary world can only be studied in connection with the environment (Kastenbaum 2007). There are different perceptions of DDB among different cultures and subcultures. Campione's (2004) study illustrates this. He describes how death is still unmentionable in Italian hospices. In his study, he concludes that patients in Italian hospices refuse to talk about death or highlight indicators of their imminent death. This also relates to Feifel's (1959) reference to a comment made by people who are opposed to paying attention to death; 'I'm interested in life, not death' (p.xi).

In overall, the concept of death can be controversial. Contemporary societies are now more complex than ever. It may now be difficult to grasp the meaning of death when meanings of life in the same society differ significantly. The plural context in which contemporary society is depicted raises more challenges not only in understanding death but also in understanding the importance of having a meaning of death and how that is integrated into the meaning we make of life.

Feifel (1977) simplifies how death is perceived. He suggests that people discern death either as a door or a wall. The event of death may either be the end of everything, or the beginning of

something new, commonly related to afterlife beliefs (McClain-Jacobson et al. 2004). Corr, Nabe and Corr (2009, p.555), when they review this same text, suggest that ‘most people hold one or the other of these beliefs’, but often link this to perceptions of life and living.

Changing relationship between spirituality, and religion and belief

Explorations of death evolved from religious to scientific modes. Death, life, and existentialism have all been discussed in relation to religion (Benatar 2009) prior to medical, clinical and technological approaches (Walter 1994). The study of death and end of life care challenges the dominance of the medical model, opening up space for alternative logics, such as religion, belief, and the spiritual. The predominance of the medical model has left the essential components of that part of care unpacked. Alternatively, religion has been replaced with spirituality: another contested concept that HCPs are still struggling to deal with (Puchalski 2013). On the other hand, according to Walter:

If religion puts you in touch with a God out there and with meaning and mores external to the self, spirituality puts you in touch with your inner self and with the God within (Walter 1994, p.28).

Nonetheless, if spirituality is contested, as well as the means to get in touch with the inner self at the time of grief or death, then the following questions are raised. How is this method measured in order to avoid the medicalisation and pathology of dying and grieving in modern societies? Is this ambiguity of the concept of spirituality there to enhance what Foucault refers to when talking about normality and the individual experience?

The judges of normality are present everywhere. We are in the society of teacher-judge, the doctor-judge, the educator-judge, the social worker judge; it is on them the universal reign of the normative is based; and each individual, wherever he may find himself, subjects to it his body, his gestures, his behaviour, his aptitudes, his achievements (Foucault 1977, p.304).

There is a general tendency to rely on the medical or clinical interpretation of the experiences of dying and grief (Walter 1994; 1999; Wasner et al. 2005), and disengage from religious modes of approaching death and dying (Levine 1989; Kastenbaum 1999). This may certainly serve the purposes of a technocratic healthcare system; it clashes, however, with the individual service user's perceptions of life and death, and their preferences in dying, were these to have a religious or spiritual-oriented language.

This section is used as a theoretical framework through which hospice care developed. The review of this literature assists the development of the conversation toward hospice care and spiritual care as one of its core aspects. It is presented in order to explore the predominance of the medical and clinical models in EOL care, and the professionals' language and skills to properly address religion, belief, and spiritual identities.

The following section presents hospice care in detail, and unpacks its historical developments, as well as the shift in how hospice care approached religion, belief and spirituality and what the focus has been over the decades. It begins with locating the roots of hospice care in the UK, and moves on to identify areas of spiritual practice and approaches to spiritual care in the 21st century. This explicitly sketches out the role of spiritual care in hospices and the services delivered today.

Hospice movement

It is impossible to talk about religion, belief, and spiritual identities of service users in EOL care without reviewing the history and development of the hospice movement. It would also be unorthodox to set out exploring professionals' attitudes and experiences about delivering care regarding these identities without first properly introducing the context in which this takes place. Before I embark with this task, however, it is worth noting that while the vision of hospice care travelled across the globe over the decades, I will only be focusing on its

development in the UK, with occasional references to the US, as the UK is the social context that has been the main canvas for this study.

Caring for the dying is part of humanity. Nevertheless, the last nearly sixty years have seen an increase in the care afforded to the terminally ill and to pain management. Medicine has expanded on researching symptomatology and new treatments have emerged for pain control. Simultaneously, scholars from sociology and psychology further developed their interest in death studies, and provided critical thinking that 'has reshaped contemporary views of death' (Forman et al. 2003, p.1). An example of the latter is Philippe Aries, whose work was influenced by Gorer's (1955) argument about the pornography of death. Aries (1981) explored western death attitudes and suggests that death was a concealed matter in the twentieth century as sexuality was in the nineteenth. Another example includes Herman Feifel (1959), whose work not only influenced professional practice with patients with terminal illnesses, but also inspired Cicely Saunders, one of the key figures in the development of hospice care. Despite all the achievements until the third quarter of the twentieth century, 'it was the work of two physicians, Elisabeth Kübler-Ross and Dame Cicely Saunders...that began to change the way society and health professionals perceived terminal disease, death, and dying' (Forman et al. 2003, pp1-2).

Cicely Saunders is well renowned for her work with patients with terminal illnesses. She is also acclaimed to be a pioneer of modern hospice care. She set out to contribute in this area in the late 1940s with a single vision in mind, and her work has since influenced the care system for the dying largely across the world (Clark 2002a). It is in that vision that one can locate the beginning of the modern history of hospice care.

Saunders's work has been reviewed, among others, by Clark (2002a). He provides a neutral account that lays out the progression of Saunders's thinking when conceiving her vision of

hospice care. Clark's work introduces a considerable amount of the correspondence that Saunders had sent to a large number of colleagues, friends, and members of the Church since she began envisioning her goals, up until the early 1990s, when St. Christopher's hospice had already become the beacon of care for the dying and palliative care was taking hold in policy and education.

Cicely Saunders was a highly devout Christian, British with strong strings with the Church of England, and, according to Clark (2002a), had a special connection to God. She was a qualified nurse, who had also practiced as an almoner. Due to her keen interest in caring for patients with terminal cancer, she undertook medical education and qualified as a medical doctor in her late thirties. She was to become one of the first modern doctors with a special interest in end of life care, an area that had yet seen scant attention.

Her vision becomes clear from her very first publication in the *St. Thomas's Hospital Gazette* in 1958, in which she argued for new approaches to the care of the dying:

It appears to me that many patients feel deserted by their doctors at the end. Ideally the doctor should remain the centre of a team who work together to relieve where they cannot heal, to keep the patient's own struggle within the compass and to bring hope and consolation to the end (Saunders 1958, p.46).

The vision was clear; the new approach would aim to care for dying people, easing suffering and pain when treatment was not available. This was envisioned as a task for a whole team and not for individual professionals. Saunders spent some years volunteering for the St. Joseph's Hospice in Hackney, London, from where her ideas of how to pursue this teamwork approach were informed. Those experiences helped her grasp the purpose of a team of healthcare and allied professionals that will together provide support to alleviate the *total pain* of the patients (Clark 1999).

Across the span of approximately fifteen years, Saunders sought advice and guidance from a large number of individuals from both sides of the Atlantic. Much of her influence came from nuns from the Irish Sisters of Charity at St. Joseph's Hospice, the psychologist Herman Feifel, the psychiatrist Colin Murray Parkes, the evangelical Christian lawyer Jack Wallace, and the theologian Olive Wyon, among others. Yet, her biggest influence in setting out to explore the idea of caring for the dying was her own religious faith practiced in the Church of England. Drawing from one of her letters dated on 9 February 1960, as published by Clark (2002a, p.20), Saunders writes to the Lord Bishop of Stepney: 'I am very anxious that this work should be a Church of England one, and that it should be broadly based in the Church'. There are numerous examples that suggest that Saunders acted as a Christian believer when approaching end of life care (ibid.; Clark & Seymour 1999; du Boulay 2007). Her Christian beliefs became paramount in the development of St Christopher's hospice in the late 1960s, the physical space in which her vision would come true. By that time, the NHS was involved in supporting this initiative, despite its newly established status.

The commencement of service provision at St. Christopher's Hospice in 1967, was led by the following principles:

- Death must be accepted,
- The patient's total care must be managed by a skilled interdisciplinary team whose members communicate regularly with one another,
- The common symptoms of terminal disease, especially the palliation of pain in all its aspects, need to be effectively controlled,
- The patient and family as a single unit of care must be recognised,
- An active home-care programme should be implemented,
- An active programme of bereavement care for the family after the death of the patient must be provided,

- Research and education should be ongoing (Forman et al. 2003, p.5, revised from Torrens 1985).

In the same period, Elisabeth Kübler-Ross was striving to introduce to the public and professionals the very first framework through which the stages of dying process would be operationalised. Even though Bowlby's work in the late 1940s about attachment and loss was already adding to the conversation, it was not explicitly operationalised for professionals to integrate into their everyday practice. Kübler-Ross, having interviewed dying patients, published *On Death and Dying* in 1969. With this book and her now popular 5 stages model, despite the critiques it has received (also see Parkes 2013), she managed to breach the public silence over the subject of death and dying. Her arguments travelled across the world and her work influenced professional practice in many nations; and it is still widely influential today. After that, it opened up the space for more robust initiatives in the USA that would follow the work of Cicely Saunders, including hospices and palliative care units within hospitals (Clark & Seymour 1999).

There is one paradox worth noting in the history of the hospice movement in the UK. This is most clearly described by Clark and Seymour (1999):

One of the paradoxes of the history of the modern hospice movement in Britain is that it was to originate in the shadow of a new, inclusive system of socialized medicine and welfare which would care for all in need, 'from the cradle to the grave'...Like the voluntary hospices which had preceded it, however, the priorities of the British National Health Service...were with acute illness and rehabilitation. This, coupled with an ideological rejection of charity as the appropriate source for the provision of health care, did not create an auspicious environment in which voluntary hospices might be expected to develop (p.69).

Also worth mentioning is that the terms *hospice movement* and *palliative care* were not used until the 1970s (Forman et al. 2003). By the beginning of the twenty first century there were numerous hospices and palliative care units across a plethora of nations, including examples

from Australia, New Zealand, Western Europe, Eastern Europe, Asia, and North America. The World Health Organization (WHO) recognised its importance and emphasized its attention to clearing the definitional boundaries. A clear-cut definition of palliative care was attempted, which would incorporate all aspects of a patient's needs:

Palliative care is the active, total care of patients whose disease is not responsive to curative treatment. Control of pain, other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of illness, in conjunction with anti-cancer treatment (cited in Forman et al. 2003, p.8).

This definition has changed a few times over the years, however, and its current form is as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (Available at: <http://www.who.int/cancer/palliative/definition/en/>, accessed on January 12th, 2016)

Despite the disparities in the two versions, which are approximately fifteen years apart, both imply a multi-dimensional patient for whom a team will care. Also, in spite of the identification of the patients' needs as problems, each of which poses different challenges, both definitions recognise spirituality and the professional need to attend to those aspects of the patient's care. It is that aspect of hospice and palliative care that this project is concerned about, but broadening the scope and addressing religion, belief, and spiritual identities of service users altogether, and not spirituality in isolation.

The following two sub-sections will explore the term 'total pain' that has led the principles of hospice care into their current form (Clark & Seymour 1999), and the interdisciplinary

approach that is used in hospice care (Saunders 1991; Eustler & Martinez 2003). This will lead to a discussion about the presence of spiritual care in EOL care, as well as the absence of religion and belief.

‘Total pain’

Total pain is a term coined by Cicely Saunders in the 1960s. Informed by the stories she had heard from her patients at St. Joseph’s Hospice since the late 1950s, she developed the concept of total pain to introduce the multifaceted character of pain as patients experience it:

By the time that Cicely Saunders left St. Joseph’s in 1965, she had collected detailed descriptions of the cases of 1,100 patients, and there was clear evidence of a sustained and determined attempt to understand pain as a multidimensional phenomenon in which physical and mental suffering were inseparable, and in which pain relief required something more than mere attention to medical treatments (Seymour, Clark & Winslow 2005, p.9)

There are four components to this formulation: physical, mental, spiritual and emotional/social suffering (ibid.). Saunders’ understanding of total pain, Clark (2000, abstract) claims, was the product of her own professional background as a nurse, almoner, and physician: ‘it emerged from Cicely Saunders’ unique experience as nurse, social worker, and physician – the remarkable multidisciplinary platform from which she launched the hospice movement’. According to Saunders (1996), total pain is also a process during which a person’s life is reflected in their own dying, which in turn causes multiple suffering.

Saunders (2001) recognised the importance of allowing the patient to be involved in defining their own suffering, while professionals advocate a holistic approach to that suffering, regardless of its particular dimension (also see Clark 1999). In other words, through the concept of total pain, the need for an interdisciplinary approach was as pertinent as it was pressing (Bonica 1953; ibid.).

Interdisciplinary team

Some twenty years after the establishment of St. Christopher's Hospice, Saunders (1990) wrote about her ideal of an interdisciplinary approach in hospice and palliative care. She did this through impressionistic metaphors in which a patient is surrounded by his home, work, and other aspects of his/her life. 'It is this scene that we are addressing...We are a collage comprised of all the different professions involved in the total care of the person who is approaching death' (Saunders 1990, p.v).

In its modern history, the healthcare system is characterised by holistic care, which in turn has adopted an interdisciplinary approach 'for addressing patients' complex health care needs' (Eustler & Martinez 2003, p.13). Eustler and Martinez (2003) argue that each profession and discipline has a different set of knowledge and skills to contribute in the care of the dying. Similarly, Puchalski et al. (2006, p.398) suggest that '...physicians and other healthcare professionals must be able to address all these dimensions of care, including the spiritual'. An example of how this works in practice is Howard (2001) who explicitly identified the different dimensions of the total pain of a patient, and thereafter linked its part to the discipline that could ease that pain.

According to Eustler and Martinez (2003, p.13), 'the goal of the interdisciplinary team is to work with patients to identify their specific needs and health goals within a holistic framework'. Each member of the team contributes in a unique way and supports the alleviation of the suffering of the patient, and this has been central to hospice care since the beginning of its vision (Clark 1999).

The previous subsections have introduced the history and development of hospice movement, as well as highlighting key concepts in hospice and palliative care; those of *total pain*, and the interdisciplinary approach. In other words, we now have a platform (hospice care) with

particular characteristics ('total pain' and interdisciplinary approach) in which the discussion about spiritual care, one of the 'total pain' dimensions, can develop.

Spirituality and hospice care

It is clear by now that one of the main dimensions of hospice care, which is a component of 'total pain', is spiritual care. The intention is to alleviate spiritual pain and suffering. This is a much different concept than physical pain where administration of the appropriate drugs can make all the difference. How does one go about relieving someone from spiritual pain? Many proposed answers are available in scholarly work, and some will be discussed later. However, it is worth noting here the following, as a starting point. Both Saunders (1990; 1988) and Kübler-Ross (1969) suggest listening to patients is the essential act in providing spiritual comfort and comfort in general. Beyond the bio-physical symptoms and needs, patients want to have their feelings and emotions heard, and the opportunity to discuss existential issues with their healthcare provider: often a nurse (McSherry 2001). Spiritual care provision is time-consuming and requires intensive engagement, which are two aspects of promoting care we shall return to in the findings and conclusion chapters of this thesis.

Until the late 1980s the spiritual dimension of hospice care made reference to Christianity only (du Boulay 2007). The Church of England played a critical role in the development and formation of hospice care, while Saunders, according to her own letters, had been guided by God to undertake this task (Clark 1999). Saunders (1988) introduced and made Christian concepts central in her work; she made reference to the Bible in her writings, and recognised St. Christopher's Hospice as a Christian Institution:

The Christian and medical foundation of St. Christopher's was concerned with the response to these costly demands, as it set out in the belief that God would provide both people and resources if we worked the plan out in the right way. We believed that in this response we would learn to be the instruments of His care for the suffering and

bereaved, and show our patients and their families the care by deeds rather than words which would help them into a healing relationship with Him and also help to encourage new skills and attitudes far more widely (Saunders 1986, cited in Saunders 2006, p.42).

It is appropriate to consider how this Christian framework has influenced the hospice movement. Excellent examples are the names of hospices across the UK, e.g. St. Luke's Hospice or St. Ann's Hospice. Another example of how Christian beliefs have been present in the development and formation of hospices is the contribution of nuns. Both of these examples show the focus on Christianity and the lack of inter-faith approaches in EOL care that carried on until recent years.

Despite the highly Christian devotion and influence, Saunders was of the view that all patients and staff should have the opportunity for spiritual growth, regardless their faith, belief, or non-belief:

We are ourselves a community of the unlike, coming from different faiths and denominations or the absence of any commitment of this kind. What we have in common is concern of each individual...and our hope is that each person will think as deeply as he can in his own way' (Saunders 2006, cited in Coward & Stajduhar 2012, p.3).

Spiritual care is critical in contemporary practice in EOL care, and most relevant to scholarly work across different disciplines. Spiritual care is contested in its definition, as is the definition of its counterpart and instigator, spiritual need. Saunders defines spiritual needs as follows:

'Spiritual' concerns the spirit or higher moral qualities, especially as regarded in a religious aspect with beliefs and practices held to more or less faithfully. But 'spiritual' also covers much more than that – the meaning of life at its deepest levels as understood through our patients' different religions' (Saunders 1988, p.218).

Saunders continues, delineating the concept of 'spiritual pain':

The realization that life is likely to end soon may well stimulate a desire to put first things first and to reach out to what is seen as true and valuable – and give rise to

feelings of being unable or unworthy to do so. There may be bitter anger at the unfairness of what is happening, and at much of what has gone before, and above all a desolate feeling of meaningless. Herein lies, I believe, the essence of spiritual pain (ibid., p.218).

Being equipped well enough to identify spiritual needs and pain, also raises another challenge; identifying the appropriate care for those needs, or the readiness to do so, which is the concern of this project.

The Spiritual dimension of modern hospice care

There has been increasing concern since the mid-1990s; that the original hospice ethos is reforming and becoming subject to secularity and bureaucratisation (Bradshaw 1996; Clark & Seymour 1999). This change is evident in the care that hospices provide, as well as the carers.

The story of the changes in care for the chronic sick and terminally ill is also the story of the changes in nursing from altruism and service to the patient, derived from a spiritual ethic, to empowerment and liberation for nursing, derived from a concern with professional autonomy. It is the story of the twentieth century secularisation of care. The changed ethic of care runs deeply throughout the care services...and has obviously affected the ethos of hospice care... (Bradshaw 1996; p.410).

Bradshaw (1996) explored the 'routinisation' thesis to argue that from a hospice system of care, where a 'spiritual calling' was essential for the professionals (also see, du Boulay 2007), the secularisation thesis has led to 'an iron cage' of duty (Bradshaw 1996, p409). In other words, Bradshaw scrutinises the spiritual dimension of hospice care to find that '...traditional, orthodox spirituality, the human being in relationship to God, has been replaced by a conception of spirituality as a personal and psychological search for meaning' (ibid., p416) (also see, James & Field 1992). Also, she argued that Saunders 'was reviving an attitude to death as part of life at a time in the twentieth century when Aries argues, the desire was to hide

death away' (ibid., 413) (also see, Aries 1974). Death had been more routinely encountered until the twentieth century. During the twentieth and into the twenty-first centuries, however, public attitudes considered death to be a weakness. In light of that belief, medical approaches to the prolonging of life became more important than embracing the full circle of life, which would have been a more spiritual approach.

Spiritual care must be something different in twenty first century hospice care than what it was in the 1960s and 1970s. The care of the dying and the bereaved has always had a connection with religion, however, and Bradshaw examined the changes to this over the years. Death is no longer happening in the home (Walter 1997; 1999; Bradshaw 1996). 'Two-thirds of all deaths today take place in hospital – an institution dominated by science and medicine' (Walter 1997, p22). This creates further challenges in integrating spiritual care in practice, mostly stemming from the division between science and religion, or spirituality, especially after the shift from *terminal care* to *palliative care*:

The shift from terminal care to the much wider area of palliative care is a shift in emphasis which alters the original concept of improving care of dying people. Palliative care shifts the focus of attention away from death and there is a real danger that by talking about focusing upon palliation, people may stop talking about and confronting the fact that the individual is going to die (Biswas 1993; p.135).

Walter (1997) subjects spiritual care to extensive scrutiny. His work is concerned with what spiritual care might mean today, and how that fits into a highly secular context. He examines three options through which spiritual care might find a peaceful place under the highly bureaucratic, secular and institutionalised hospice care of today.

Drawing from Christianity's principal concerns about death [i.e. 'love of the neighbour and concern for the post-mortem destination of the human soul' (ibid., p.22)], Walter introduces

the hospice as a religious community. Both Bradshaw (1996) and Walter (1997) raise the point that spirituality may be the concern of only religious staff members in a hospice. What happens though when ‘secular’ staff are hired to deliver hospice care? Both argue that such expansion of care causes conflict and tension, which may undermine quality of care for the dying. If we accept that spiritual care can only be delivered by religious staff members, we are also challenging the concept of holistic care, as discussed earlier, that calls for an interdisciplinary approach and the care of the whole person by recognising their ‘total pain’. As Walter (1997) suggests, if spiritual care is enabled only by the “charisma” and “discernment” of religious people, there might be major deficits in the provision of spiritual care for many dying people outside of hospices, and within the contemporary secular and technocratic formation of hospice care (also see, Clark & Seymour 1999). The following quote depicts this in Walter’s words:

...how is this gift [gift of discernment], this charisma, to be routinized in the larger and more bureaucratic institutions that hospices may turn into, or in the large hospitals that hospices aim to influence? Can thousands be expected to have this gift? If not, can such a gift be taught? If all nurses are expected to provide spiritual care, how may those without this particular gift or indeed without religious commitment discern when a patient is raising spiritual issues and know how to respond? (Walter 1997, p.24).

The first option seems problematic in numerous ways, including a different stance on spirituality, and a much different definition from what Saunders intended. Further with the second option, Walter’s argument is straightforward; if this is the option we go by then spiritual care should naturally find a place under clergy and other religious leaders that are members of staff. Clark and Seymour (1999, p.110) claim that ‘spiritual is the same as religious; only some people are religious; non-religious and non-ordained staff are not competent to deal with spiritual needs’. Walter calls it ‘Calling in the chaplain’. Perhaps this approach is what Nolan (2012) argues for, however, he neglects to consider that this approach, while letting all other staff members focus on their own remit of practice, while chaplains undertake spiritual care,

the idea of true holistic care would be compromised. Perhaps this is a question of what spiritual care actually means, and who should be responsible for delivering it. Nursing literature has argued in abundance that spiritual care is the responsibility of nurses (Carroll 2001; McSherry & Draper 1998; Ross 2006; Paley 2008). Nevertheless, current practice has this dimension of hospice care as being the primary responsibility of chaplains (ibid.). The main disadvantage of this approach, as argued by Walter (1997), is that 'it implies that only some patients have a spiritual dimension, and is therefore incompatible with holistic care' (p.25).

The third approach identified by Walter appears to reunite holistic care with spirituality:

This identifies the spiritual with the search for meaning and has more to do with the human spirit as the animating or vital principle in a person – the 'breath of life' – than with religion, narrowly defined (Walter 1997, p.25).

Literature has shown that few patients are highly religious (Simsen 1986). However, a vast majority have spiritual concerns, and therefore existential questions to answer toward the end of their lives (ibid.). Walter revisits Saunders' intentions, i.e. to provide care for all, regardless of religion, and highlights that this option is most likely to meet these foundational objectives of hospice care, and minimise the risk of the institutionalisation of spiritual care.

This approach also contests the notion that spiritual care is the sole responsibility of one or two professions or disciplines. Nolan (2012) argued that it is the chaplains who should be providing it, whereas other literature, and notably James and Field (1996) and McSherry et al. (2004), claim that nurses should be the ones delivering spiritual care. It is important to highlight at this point that this thesis does not argue that one professional should be more responsible than the other, or advocating for one discipline over another. It draws from Walter's (1997) third approach and builds on the argument that all healthcare staff should be well-equipped to address religion, belief, and spiritual needs of the dying and the bereaved. Walter, in particular, suggests that:

In this third approach, spiritual care becomes the joint responsibility of all members of the multidisciplinary team. Any staff member can listen to patients and help them identify and articulate what is important to them personally. Indeed, a patient may select a nurse or aide who is not him or herself ordained or even overtly religious with whom to discuss existential issues (ibid., p.25).

Literature of the twenty-first century, by and large, reflects aspects of the medicalisation thesis (also see Kennedy & Kennedy 2014), which links to the idea of jurisdictional areas for practice in hospices (Paley 2008).

Twenty years after Walter's analysis, the hospice and palliative care sector appear to have embraced a mix of the three options. Gordon and Mitchell (2004) claim that the Marie Curie model of spiritual and religious competencies is critical and would only benefit professionals if it were to be applied across hospices. The model presents four levels of competency and classifies professionals in each level by their discipline. For example, level 4, the highest, consists of chaplains and other religious leaders (Walter's second approach). This assumes that no other professional but religious leaders and chaplains, could attain a level 4 competency. Furthermore, the classification of competencies presumes that spiritual needs can also be classified from high to low.

On the other hand, Kellehear (2000) suggests a theoretical model of needs. He identifies three blocks of needs within the spiritual dimension: situational, moral and biographical, and religious. This model may also be seen as an outline of the different ways in which spiritual care can be delivered. It also seems like a new perspective on the interdisciplinary approach, where each professional delivers the aspect of spiritual care they feel comfortable with or are most knowledgeable about.

In their report, Puchalski et al. (2009) summarised:

...the need for a commonly accepted definition of spirituality, the appropriate application of spiritual care in palliative care settings, clarification about who should deliver spiritual care, the role of health care providers in spiritual care, and ways to increase scientific rigor surrounding spirituality and spiritual care research and practice (p.885).

First, spirituality was identified as ‘the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred’ (ibid., p.887). This is a definition that most likely aligns with Walter’s (1997) suggestion of a searching for meaning approach. It openly invites all members of a team to be the deliverers of spiritual care. Nevertheless, as we move on in the report (Puchalski et al. 2009), more technocratic and goal-oriented approaches seem to have dominated hospice care. Following are a few examples.

Engel (1977) and White et al. (1996) proposed a biomedical model that includes spiritual care. Despite the intentions to embrace a focus on the being-in-relationship concept of the individual (Puchalski et al. 2009, pp.890-891), it is suggested that each aspect (i.e. biological, psychological and social) of the illness is informed by the spiritual. Nevertheless, the medical aspect of the illness drives the need for the spiritual to begin with (White et al. 1996). This causes confusion and misunderstandings as to whether the illness is seen through the lens of a patient’s religion or not.

Further, Puchalski et al. (2009) report on the general suggestions made at the Consensus Conference regarding spiritual care, that spiritual assessment is fundamental in order to meet the needs of individual patients. So how do HCPs at the conference suggest this be done?

Spiritual screening or triage is a quick determination of whether a person is experiencing a serious spiritual crisis and therefore needs an immediate referral to a board-certified chaplain. Spiritual screening helps identify which patients may benefit from an in-depth spiritual assessment. Good models of spiritual screening use a few

simple questions that can be asked in the course of an overall patient and family screening. Examples of such questions include, “Are spirituality or religion important in your life?” and “How well are those resources working for you at this time?” (ibid., pp.891 & 893).

This method draws from all three approaches identified by Walter (1997). Firstly, a full screening of spiritual needs requires a ‘board-certified chaplain’ who will provide care of the dying; a religious leader will support religious or spiritual needs (approach 1 in Walter). So ‘who is a board-certified chaplain and what is their role?’, undeniably this is a model that induces the ‘calling in the chaplain’ approach (option 2 in Walter). However, it is acceptable that any member of staff may ask the initial questions that will identify a spiritual crisis (option 3 in Walter) before calling in the chaplain who will undertake a full spiritual assessment.

In summary

The aforementioned examples are critical of the current approaches of spiritual care in EOL care, and especially hospice institutions, in which this study takes place. However, it would be wrongful to examine these examples outside of the policy context that informs and often dictates the different ways by which care is delivered. Before we move on to the last section of this chapter, which addresses policy, it is worth recapturing the core themes from this section which have informed the research question of this study.

Hospice care has its roots in religion, most notably Christianity. The care of the dying has been undertaken by religious people extensively in the past (e.g. the Sisters of Ireland) and Saunders’ vision did not deviate from that (Saunders 1958; 2000). The concept of ‘total pain’ emerged to educate professionals and policy-makers about the different dimensions of care necessary for the dying and bereaved. Spirituality was one of the dimensions and the term was used to refer to any belief system. Spiritual care was an essential element of hospice care, which was further developed in the twenty-first century.

The delivery of spiritual care has caused distress and intensity within hospices (also see Cobb 2001). It causes the blurring of professional responsibilities as its delivery still lacks clarity. Secondly, spiritual care raises ethical concerns that are incompatible to the modern bio-medical approaches or methods through which it is understood (also see Carroll 2001). The need for measurable outcomes and results in practice, becomes imperative, and this may undermine the importance of respecting a person's religion, belief or spiritual identity.

An interdisciplinary approach that compliments holistic care is pertinent to hospices (McPeak 2003), but poses a number of challenges for professionals. The main challenges are identified by Yardley et al. (2009) who suggest that '...there are difficulties encountered in delivering optimal spiritual care: first, uncertainty about who should deliver spiritual care; second, lack of confidence and competence in delivering spiritual care in palliative settings and third, difficulty identifying specific spiritual needs' (p.601).

This project goes beyond the identification of those challenges in professional practice. It suggests that all HCPs should be prepared to support the dying and the bereaved regarding religion, belief and spiritual identities. Simultaneously it examines the current practices, skills, knowledge and understanding that HCPs demonstrate in this area, opening up the space for recommendations and the discovery of future trends.

What policy says about religion and belief in dying

The tensions I have been exploring between religious and scientific modes, and between religion and spirituality, find expression in the policies which relate to the practice of care in death and dying settings. In this section I will explore these policies.

Various disciplines are involved with EOL care delivery. End of life care is a wider field than just palliative care. Palliative care is an intervention that aims to eliminate pain and control symptoms (Saunders 1992) and in general increase the presence of medicine and pathology in

DDB (Walter 1994). However, palliative care is one of the reasons why EOL care is embedded in social policy. Moving forward from an NHS that promotes biomedical approaches and enhances opportunities for the prolonging of life. The NHS End of Life Care Programme 2004-2007, a programme launched in 2004, advances different perspectives. The programme aims to comprehend the need for future health care policies regarding EOL care and to set the boundaries between health care and palliative care.

In 2008, 60 years after the establishment of the NHS, the first death policy was inaugurated, explicitly regarding end of life care – End of Life Care Strategy 2008. Followed by a number of documents and complementary social policies and guidelines for EOL care (i.e. NHS Constitution in 2013, Liverpool Care Pathway (LCP) in 2009, End of Life Assessment annual documents, Better Care Better Lives 2008, to name a few), the emergence of the strategy acted as a milestone with regard to the care of dying adults.

The strategy is primarily led by the principles of the Modern Hospice Movement; the document begins with a quote from Dame Cicely Saunders. Nonetheless, the strategy goes beyond the care of symptoms and pain and intervenes toward the care of the psyche and psychosocial care. All patients, families and carers are involved in this strategy, however it is focused on the care of adults rather than children or minors. This is a death policy, which was developed around the idea that people do not experience death or the dead body until at least midlife, and it reflects the fact that British society does not discuss death and dying openly. It is specifically highlighted that health and social care staff fail to have discussions about the end of life (DoH 2008, p.23), which makes social policy planning even more demanding.

End of Life Care Strategy 2008

The strategy states that it is important to train HCPs who are in a relevant position to identify dying people ‘and initiating discussions about preferences for end of life care’ (p.11). There

are two components of care in this report. First, professionals are expected to become more competent in their skills, abilities, and values to welcome the dying of an individual, and not push toward life-sustaining medication. The second part of the report embraces discussions about end of life and death, and appreciation and respect for dying people's preferences. This is challenging for workers simply due to the fear of one's own death that many people have, and will always be reminded of this by the death of the other (Kamath 1993). Despite the challenge, it is suggested that preferences should be taken into consideration, and skills and abilities should be further developed and maintained in order to meet the needs of dying people (also p.17 §§1, 2 & 5). HCPs should have necessary skills and knowledge toward 'assessing needs' (p.11), so that EOL care is addressed with inclusiveness and 'excellence' (also highlighted by the National Institute of Health and Care Excellence at <http://www.nice.org.uk/>).

Underlined in the EOL Care Strategy 2008 is that HCPs should have 'right attitudes' and skills to develop attitudes appropriate to everyone who needs care (pp.12-13). This is expected regardless of service users' personal characteristics such as culture, language, gender, religion, to name a few. The strategy refers to 'high quality services' (p.13) in EOL care. Of great importance are the following: a) in §19 it is suggested that a carer's care plan should always be in place as well, because 'carers might also have emotional needs', b) considerations are given to what should be included in end of life care education (§§20-21), c) there is inadequate training of staff, and d) there is insufficient support for carers.

The UK Strategy has adopted principles and priorities by the EOL Care strategies in Australia (2000), Canada (2000), and New Zealand (2001). All strategies had a special focus on identifying preferences toward the EOL, as well as providing adequate resources to meet those preferences and promote quality services. Despite the principles, the substitution of the term 'terminal care' with 'palliative care' in the 1980s was a milestone at a time when EOL care

was leaning toward medicine and life-sustaining interventions (Walter 1994). After that, alongside the change of roles of religion and belief in society (Chapter 2), spiritual care took hold in EOL care and acted as a proxy for religion and belief.

Spiritual care at the end of life: a systematic review

With numerous references to the hospice movement and Dame Cicely Saunders, the systematic review on spiritual care at the end of life (DoH 2009) reviews hospice care and the responsibility for a holistic approach, which includes spiritual care for patients and carers. The authors of the report suggest that due to deficiencies in service provision and professional practice, patients and/or carers may experience unnecessary spiritual suffering. The latter term however, lacks description and definition, thus vague in interpretation. Despite the clear intentions of the meaning of spiritual suffering, the authors imply that emotions are as well included in spiritual care, which might be, however nowhere across the review is spiritual care explained or defined. On this note, and as spiritual care in EOL care appears to act as emotional and psychosocial care, this challenges the HCPs' roles and responsibilities (i.e. social work roles, psychology).

Attention is paid to spiritual care for patients and their families, and there is a strong link between the care pathways and, in particular, the LCP. The sixth step in the LCP suggests that all staff should be responsive to cultural, religious or spiritual needs. As with many other policy documents, these clustered needs are framed in an un-measurable and opaque way. It is advocated that people 'have spiritual, religious or emotional needs' (p.75), this being one of the only times the term 'religion' appears in the document.

Next, I will look at when and how the terms *religion*, *spirituality* and *faith* have been used in the review.

Religion

Although both documents, EOL Care Strategy 2008 and Spiritual Care at the EOL, are circulating information with regards to respective attitudes towards diverse populations, high-quality hospice services, and the need for spiritual care provision, the matter of religious beliefs is rarely introduced, or discussed. ‘Spiritual/religious’ needs are listed with the factors that influence needs and preferences of patients and family or friends (p.45, §3.2). Table 1 lists the mentions of religion and religious needs in the document.

Table 1: Systematic review: Mentions of ‘religion’ and ‘religious needs’

‘Religion’
<ul style="list-style-type: none">• High quality care for all people approaching end of life should be irrespective of...religious belief and ethnicity... (p.10, §7).• ...high quality care for all people approaching end of life should be irrespective of...religious belief and ethnicity... (p.33, §1.33).• ...raising awareness of death and dying can also be taken forward by religious organisations. Those can promote understanding and information. (p.39, §2.8).• ...it is suggested that in the 6th step all staff should be responsive to cultural religious or spiritual needs. (p.67).• ...religious beliefs to be respected when it comes to organ donation... (p.71, §3.83).• ...body to be handled according to any religious beliefs... (p.72, §3.84).• ...disposal of the body: be aware of different religious perspectives. (p.73, §3.85).• Spiritual care services recognise that individuals may hold to a religious or non-religious belief system. (p.75, §3.98).• ...organization must obtain consent before sharing information on religious affiliation with chaplains. (p.76, §3.102).• Healthcare chaplains to have network of other religious ministers in the community. (p.77, §3.105).• ...religious competencies in all core training... (p.77, §3.107).• Religion and belief to be included in the demographics/stats collection. (p.82, §4.11).

In all, the paper introduces religion in the following ways; in relation to organ donation, as affiliation and demographics, and as an impacting to care factor with limited expansion on the latter.

Further, the systematic review addresses references to both spirituality and faith often used interchangeably with the term 'religion'. This makes the process of identification and definition giving a lot harder as it mixes meanings and concepts, which might as well be cultural-religious- or personally-bound. This indecisive attitude towards language, definition and concept is a struggle in itself. There are elements to it that go against the clarity of what religious creeds have historically offered; 'defence against death' (Walter 1994, p.14). Religious creeds have framed an afterlife in heaven and a well-developed exploration of the soul and eternity. References to spiritual care that includes religious needs, emotionality, psychosocial aspects of care, and a general understanding of belief are merely not clear enough. Such matrix offers lots of contradictions and controversies, all of which are subject to further exploration.

Spirituality

Table 2 shows a few examples of when and how the term 'spirituality' is used in the systemic review on spiritual care in EOL care. In overall, it is communicated throughout the report that patients and family or carers have or may have spiritual needs. The reference to these needs, however, lacks definition or guidance for the HCPs to be well equipped to provide such services and meet those needs but also be in the right place to measure the outcomes of service provision, toward the improvement and development of the services.

The document also supports that hospices are the rightful institutions to be delivering spiritual care while at the same time it is highlighted that each person has spiritual dimensions. Also, spiritual suffering is identified as the outcome of deficiencies in service provision or

professional practice, while spiritual care is to offer to the individual the opportunity to express anger, sadness and guilt.

Table 2: Systematic review: Mentions of ‘spirituality’

‘Spirituality’
<ul style="list-style-type: none"> • Over the past 40 years hospices...have demonstrated what can be done to provide physical, psychological, social and spiritual care for people and their families. Hospices are the good example of how to deliver qualitative spiritual care (p.7 forward). • Due to deficiencies in service provision and professional practice, patients and/or carers may experience unnecessary spiritual suffering (p.24, §1.5). • ...past work taught us that paying close attention to spiritual needs of patients and families, can improve end of life care. (Saunders’ quote: p.28, §1.16). • Ensuring access to spiritual care. (p.33, §1.34). • Spiritual care is integral to the end of life care pathway. (p.49, §3.13). • ...spiritual dimension of each person... (p.49, §3.99). • Spiritual care is to allow the ‘person to express anger, guilt, sadness and reconciliation.’ (p.49, §3.100). • Chaplains provide spiritual care to all staff as well. (p.49, §3.101). • ...spiritual competencies in core training... (p.49, §3.107). • Hospice care includes and always included spiritual care (§p.95, §4.40). • ...carers of the dying face spiritual consequences. (p.107, §5.1). • Staff providing bereavement services to family –after death – should have access to spiritual support. (p.107, §5.18).

This rather puzzling mixture of arguments raises numerous questions, as well as promotes a challenging attitude towards policy planning around this area. If spiritual suffering is the result of poor service provision and professional practice in hospice care, is this why hospices are the right places to deliver spiritual care? Are hospices responsible for causing spiritual distress and then providing services to remedy the situation and comfort the patients? Is spiritual care

merely an approach for the individuals to express their disappointment in the face of deficiencies of service provision and professional practice? All these questions and many more come to the surface in light of what language is used in the document and how it is used.

Faith

The term ‘faith’ is used in the document three times. Most importantly what is mentioned in the review is that ‘lenders of different faith groups were included in the consultation process’ of the development of spiritual care in EOL care (p.34, §1.36). The latter raises questions around the politics of planning a relevant policy. If the language used still seems Christian-centred or secular, how is the contribution of the different faith groups obvious? What is meant by faith here?

This review is of utmost importance to this thesis as it depicts how religion and belief are reflected in practice. A year after the systemic review an action plan with equality objectives became effective. This plan is designed to influence front line EOL care, nonetheless with no immediate effect.

Religion and belief in health care: A new design

In October 2012, the Department of Health first published the Equality Objectives Action Plan (EOAP) [September 2012 – December 2013]. Only in recent decades have equality and diversity issues become major topics for social policy and politics. The EOAP’s aim is to highlight the importance of embracing the differences between majority and minority populations. An additional aim is to underline the limits and strengths that dominate in current social policies across health and social care (DoH 2012).

EOAP promotes three principles; better health, better care and better value for all (DoH 2012). The action plan opens up a discussion and suggestions for fundamental changes within the health and social care system, as it is recognised that it lacks expertise on equity and equality

issues. Derived from the EOAP, the DoH Business Plan 2012-13 developed priority principles and strategies, all based on and in line with the NHS' Equality Delivery System (EDS) goals. Those are improved health outcomes, patient access and experience, inclusive leadership and empowered, engaged and included staff (DoH 2012). Similar to the NHS End of Life Care Programme 2004-2007, the Business Plan is looking to develop further, or generate if necessary, strategies that will promote the well-being of individuals and health equality.

For the business plan to be successful, NHS staff members from a variety of disciplines are required to participate fully in its recommendations (DoH 2012). The DoH is now working to 'ensure equitable policy-making and improved health outcomes' (DoH 2012, p.6). The new business plan also includes a supportive body, Public Health England (PHE). This body aims to collate all previous information and data from health and social care sectors in order to support equality in care and inclusive social policy-making. PHE assumed its responsibilities on the 1st of April 2013 and is working 'with stakeholders to promote good practice in dignity in care for all people' (DoH 2012, p.11). The importance behind this is the establishment of dignity as a key priority for the services in health and social care and the NHS in general (ibid.). One of the latest documents of the PHE, published after the submission of this thesis, is entitled *Faith at end of life*, and is a resource for professionals who practice in the community (PHE 2016). Embedded in the NHS Constitution 2013, the National End of Life Care Intelligence Network (NEoLCIN) promotes equality and equity in healthcare and end of life care, for both dying and bereaved individuals.

One of the core principles of the EOAP is the better value of the services. The equality objective here is to '...ensure, as a system leader allocating and distributing funding, that the drive to increase value, efficiency and productivity across the health and care system considers the needs of all people with protected characteristics' (ibid., p.13).

EOAP is not just an action plan in place, but a call for the reformation of the NHS. Within the report, suggestions for new policies and a 'new system' are made; 'equality and diversity is prioritised in the design of the new system' (ibid., p.15). Among others, with this report, the DoH recognises that inequalities within the NHS exist, and that a new design of the system is required, one that will focus on inclusive professional practice across health and social care. '...building and developing relationships with stakeholders including those that represent groups with protected characteristics as appropriate, in order to improve policy design and delivery' (ibid., p.17). It is encouraging to witness an inclusive attitude by the DoH and NHS, in the face of globalised communities, that offers opportunities for representatives from all subgroups of the community to have a regular participation with the National Stakeholder Forum which examines key issues in health and social care. This is known as 'new policy partner system' which was put in place in March 2013.

Effective social policy remains a legislative idea based on past events and data until future events may prove it as such. The new design for the NHS, which embraces minority groups in the community and adopts a further inclusive character to all in practice and service delivery, has yet to be fully assessed.

The above information on equalities and diversity relate to this thesis in an indirect way, nonetheless are necessary to mention. Equalities are part of the language in communicating religious plurality and the shifting needs associated to it. It is also the language used to interpret observations and explanations of secularity within a religiously plural environment, in social policy that can be well comprehended and established by health care.

A second key issue that is worth noting refers to the definition of 'personal characteristics'. Woodhead (2009), with her research report for the Equality & Human Rights Commission (EHRC), identifies and prioritises issues associated with religious and secular matters in

modern Britain. Religion has been included as an equality strand and discrimination on the grounds of religion and belief been denounced in the recent years (ibid.). The new design for health and social care services by DoH refers to ‘personal characteristics’ but does not define or name any of those. It suggests including stakeholders from minority groups from within the community, but does not identify the minority groups. It refers to dignity for all people, regardless of background, but without clarification of what kind of ‘backgrounds’ were in mind when the report was generated. We can assume that ‘personal characteristics’, as framed within the new NHS design, refer to the equality strands recognised by the government, including religion and belief. I will proceed based on this assumption.

This is a groundbreaking period for Britain, to start including religious matters in legislation and policy-making associated to healthcare. However, belief is not a mere indication of religion or religious affiliation. Beliefs may be non-religious too. The latter remains a matter of social policy and inclusion within DoH legislation.

Reference to the action plan that affects health care provision overall was necessary in order to lay the foundations for a discussion of EOL practices and religious literacy. Kübler-Ross (1972), in her discourse on a death-denying society repeats the question: ‘Why is dying different now?’ (p.174). People still hold the same unconscious thoughts on death and dying experiences. However, society is ever changing, alongside the settings that develop and deliver services to dying and/or bereaved systems. It is important, in consideration of providing quality services within NHS, to have assured first that the delivery system follows on successfully in light of the changes that globalisation, modernisation and secularisation bring within the community (Meister 2011). Shifting demographics signal the need for policy planning and organising according to shifting needs in the community. This thesis does not directly deal with changes in the composition of society. However, given these changes, and in particular the diversity observed in terms of religion and belief (Weller 2007), we may ask whether we still

possess the right language for the purposes of having this discussion. In consideration of this question, the next chapter will explore the changes in the role of religion and belief in society since the post-war years. It will further examine how these changes have played out in professional practice, and specifically in hospice care.

Chapter 2

Religion and belief

In the previous chapter, I have reviewed literature on the study of death, the history and developments of hospice care, and the dominance of the medical and clinical models at the expense of the psychosocial and religion. Moving on to this chapter, the exploration of the changing roles of religion and belief in society, and of how those changes have played out in professional practice is of particular importance to this project. This will assist with the further examination of how religion, belief, and spiritual identities are treated in hospice care today.

This chapter will review literature from the sociology of religion, as well explore literature that introduces religious literacy, which is the lens through which I shape my argument, influenced by an interdisciplinary approach. This chapter questions why the language of religion and belief have been off the radar in EOL care and hospice care in particular, while medical and clinical approaches have taken hold. Moreover, the focus on spirituality and spiritual care in recent years is referenced from a critical lens about their strengths and limitations in hospice care.

Religious literacy is a contested concept that may refer to numerous different ideas (Dinham & Francis 2015). With this in mind, religious literacy is not a skill easily obtained, at least partially because it is also not a concept that can be easily explained. This is another challenge taken up by this project.

If we want to explore the roles that religion and belief have acquired in contemporary society, and how these have played out in relation to professional practice, it will be necessary to explore a modern history of changes to religion and belief as delineated by several authors and researchers, which is what this chapter is doing. Also, the chapter concludes that professionals may have lost the privilege of language and understanding when responding to religion and belief related needs (Dinham 2015).

Introduction

Until very recently the dominant paradigm in which thinking about religion was that of secularisation. Redfield and Becker (in Winfield 1941) refer to the secular as the rational response to meeting needs and adapting to change. Since the 1960s, both secularity and the secular appear in the discussions of the sociology of religion. Wilson (1966) first explored the notion of secularisation, and suggested that religion lost its social significance as society modernised. This is known as the secularisation thesis. Wilson refers to people with declining religious thinking and practices as 'unchurched people'. He refers to religion as a social phenomenon, and to secularisation as the process whereby religious practices, thinking, and institutions lose social significance (also see Berger 1967). Some years later, Fallding (1974, p.210), claimed that secularisation 'is the analytical process that has sacralisation for the complementary synthesizing process'. This process is equally important across all areas of life in society. That said, and as long as secularisation is seen 'as one of the primary social processes' (ibid., p.210) it is relevant to be reviewing literature in this area.

When the discussion in the sociology of religion delved into the process of secularisation at length (Davie 2013), policy and practice were enormously influenced by its notions. Secularisation has an effect on health care practice at DDB-related settings, raising the necessary question; how do HCPs engage with religion, belief, and spiritual identities of service users? Religious, non-religious, spiritual (Canda & Furman 2010), or secular beliefs might act as predictors for how we perceive and interpret the nature of death. Also, they might be indicators of how we might perform our bereavement through mourning (i.e. rituals) (DeSpelder & Strickland 1999). Thus, it is essential that professional practice respond well to the needs of the changing religious landscape. Another concept that challenges EOL care is desecularisation; the reverse process of secularisation (explored later in the chapter) (Berger 1999). With that in mind, the overall challenges of hospice care in the contemporary society

are twofold. The standards of care for people who are experiencing death and bereavement are either secluded or implicit (Kastenbaum 2007). Either way, change is relevant to both in light of shifting challenges in society.

The changes that religion and belief are currently undergoing are intense and extensive, and, therefore 'difficult to gain a proper perspective on them' (Woodhead & Catto 2012, p.3). The need to gain as much knowledge as possible and integrate it into practice is pressing (Fonseca & Testoni 2011-2012).

Despite its predominant tradition being Christian, the UK is distinguished for its variety of religions:

The United Kingdom (UK) has a Christian inheritance that remains the predominant religious tradition, particularly in Northern Ireland, Scotland and Wales, but also in England. At the same time, in many other European countries, after Christians, Muslims form the largest religious group (Weller 2007, p.21).

In the case of the UK, however, there are also relatively large groupings of Hindus, Sikhs and Jews, together with smaller numbers of Buddhists, Baha'is, Jains and Zoroastrians. In terms of the range of world religious traditions with significant communities here, this gives the UK a greater degree of religious diversity than is found in any other country of the European Union (EU) (Weller 2007, p.21).

Heelas and Woodhead (2005) have explored the new composition of religions in England; they argue that the number of different religions, or alternative spiritualities is increasing rapidly (also see Warner et al. 2010). The duty of health care is to promote qualitative services in the best interest of service users and provide equal access regardless of personal characteristics (DoH 2012). Best interests ought to include religion, belief, and spirituality for those to whom this is significant, a direction that PHE has only recently taken into account (PHE 2016).

The work of a trajectory of thinkers has influenced many of the concepts introduced in this chapter. Some of those include Bryan Wilson (1966), Peter Berger (1967; 1999), David Martin

(1978), Grace Davie (1994), Danièle Hervieu-Léger (2000), Woodhead, Davie and Heelas (2003), Charles Taylor (2007), David Voas and Abby Day (2007), Linda Woodhead (2007; 2009), Steve Bruce (2011), Adam Dinham (2009; 2012; 2015), Abby Day (2011; 2010), Justin Beaumont and Chris Baker (2011), and James Beckford (2003). A distinguished contributor in the section is Jürgen Habermas (2002), who ranks as one of the most influential philosophers of his time, and who significantly added to the conversation around epistemologies and language in religion.

While the content is mainly packed with literature from the sociology of religion, this thesis is approached from an interdisciplinary perspective, including social work, sociology, psychology, death studies, and religious studies. The aim is to underline what religion is today, where religion stands today, and how those two facts have an impact on the levels of social functioning and service delivery in hospice care.

This chapter looks back in time, from the post-war period, and attempts to illustrate a comprehensive account of how the role of religion has changed over time. This discussion includes an exploration of three main areas: social policy and the restructuring of the nation after the end of WWII, religious diversification, and the secularisation thesis. While this narrative points out the transitions in the role of religion and belief over time, it also sets the context in which religion and belief have become absent from public life (Bruce 2011), and then present again (see Davie 2015), and finally, how our ability to talk about religion has been challenged (see Dinham 2015).

Shifting demographics in the population since the 1940s have led to a different religious landscape. When medical and clinical models were coming to dominate the discussion about DDB, a rich source of commentary and wisdom on religion and belief were also dropping out of the available public language of care. This chapter will further explore religious literacy,

including its limits, and it will define my use of the term in this thesis, and make clear why this is important in hospice care.

Religious literacy

I begin this chapter with an explicit account of religious literacy; the overarching lens via which I am framing my project. Dinham and Francis (2015, p.257) describe religious literacy as ‘a fluid notion’ that can be understood in the context in which it happens, as well a concept that ‘requires a willingness to recognise it as relevant’ (ibid., p.11). This poses two great challenges. How do we go about quantifying religious literacy? If “fluidity” describes religious literacy, then this is a concept that is probably not easily examined in policy or practice terms, two areas where unambiguous and explicit information and guidelines are necessary. Further, in order to meet the requirement aforementioned, by Dinham and Francis (‘recognising’ religious literacy); the recognition of it should appear in a tangible, more concrete form, so it can be comprehended more widely. Both these challenges will be explored in relation to the findings at the end of the thesis.

Next I will explore the many different conceptions of religious literacy (Dinham & Francis 2015), from which I draw to explore my research question, and operationalise my results.

Prothero and Kerby (2015) place religious literacy in the loss of religious tradition but not religion in itself. They delve into the history of protestant Americans and interrogate the absence of engagement with religious traditions in public life, with distinguishing examples from politics and school life. These examples are used to illustrate the point that ‘the devotion of Americans to tolerance and inclusiveness have caused them to forget much of what they once knew about their own religious tradition’ (ibid., p.57). However, ‘religious literacy does not have to come at the price of religious harmony’ (ibid., p.64). Their argument is compatible with the idea that people should re-engage with their traditions, and thus become more religious

literate, and explore the possibility of developing a more tolerant attitude toward minority religious groups; ‘religious literacy can also lead to a more robust tolerance, particularly for minority religious groups who do not fit into the Protestant model that has dominated American religious history’ (ibid., p.74).

According to Moore (2015, p.27), ‘an important dimension of diminishing religious illiteracy is to provide resources for *how to recognise, understand, and analyse* religious influences in contemporary life’. This is better understood if we look at her earlier definition of religious literacy. Moore’s interpretation is that religious literacy explores the intersected areas of religion, culture, political, and social life (also see Moore 2006). In other words, levels of religious literacy cannot increase, unless explored from the perspective that it is embedded and influencing each aspect of life, and primarily culture. It is fundamental that religions and religious influences are understood ‘*in context and as inextricably woven into all dimensions of human experience*’ (Moore 2015, p.31).

Another conception is offered by Dinham (2015) in his account regarding religion and welfare. Dinham uses the welfare lens to present the enigma of religious literacy in public life:

This is the conundrum of religious literacy as it presents through the welfare lens. It confronts the public sphere with the urgent need to re-skill its public professionals and citizens for the daily encounter with the full range of religious plurality (Dinham 2015, p.110).

Dinham’s argument is rooted in the post-war years, and notably during the fertilisation of the welfare state. The division between the state and the Church, as well as the differentiation of their roles have led to a newly formed context in which professionals are trained without the knowledge of the interplay of religion and belief in their practice. Dinham concludes that due to limited or no attention to religion and belief for a long period, professionals have lost their ability to talk about religion, and now find it hard to re-engage. Religious literacy for Dinham

(2015, p.110) is the engagement with a complex society, both secular and religious, and it starts with recognising the importance and relevance of this to public life.

On the other hand, Ford and Higton (2015) explore Theology and Religious Studies as tools that can be used in the journey toward religious literacy. They do not in any way suggest that these two areas are depicting religious literacy, but add value to the conversation about religion. They conclude that religious literacy:

Involves learning patterns of fruitful interaction – engaged, conversational, perhaps argumentative. It involves learning how religious communities argue, and how to join in with those arguments in order to explore agreements and disagreements, and the dynamics by which they can change. It involves engagement with questions raised about, between, by and with the religions (Ford & Higton 2015, p.52).

Religious literacy is a notion that is contested, and its contestations stem from the arguments that followed the theories of secularisation, as well as from the thesis that religion has lost significance. This presumption, i.e. the lost significance of religion, resulted in the classical secularisation theory (Wilson 1966; also see Tylor 2007) and prolonged discussions about religious decline and disengagement from the public. The consequences were many in public life, including lack of engagement with religion and belief (Dinham & Francis 2015). Public professions, in particular, have gradually lost literacy; the appropriate language to address religion and belief, whether in policy or practice (see Dinham 2015). However, religion and belief continue to have an enormous impact on individual consciousness and public life (see Davie 2015). The largest part of the population worldwide, 84 percent, reports religious affiliation (PEW Research 2012). On a parallel note, a readdressing of religion and belief in the public sphere is evident since the late 1990s (Berger 1999), but with tremendous challenges. At a time when people considered religion and belief as important aspects of life, they are also faced with their lost ability to talk about it. Dinham (2015, p.108) coins this as ‘anxious re-visibility’.

In underpinning religious literacy, it is also important to highlight the areas in which religion and belief have been misunderstood to be absent from public life recently. Often people might be religious and believe, but not by practicing or being affiliated with either religious establishments or religious activities (Davie 1994). As secularisation theories suggest, this is a case of private religious matters (Martin 1978). The Census data only depicts the answers of 1) people who decided to answer, as the question of religious affiliation is not mandatory and, 2) people who affiliate or do not affiliate themselves with a religious establishment, or activity, social action, or sense of belonging.

Even though people do not affiliate with religions as much as they did before (UK 2001 Census), the subject of religion is often included in public discourse (Dinham 2009). There is a universal lack of understanding of religion, its presence and interconnections with different walks of life (Garces-Foley 2006). At a time when religious diversity has increased (Weller 2007; Meister 2011) and as society becomes more complicated as it modernises, and while secularity (Wilson 1966; Bruce 2011), desecularisation (Berger 1999) and the post-secular (Beaumont & Baker 2011) coincide in the discourse, religious literacy has become more important than ever.

Religious literacy is a pressing need across society, in the full range of sectors and settings. Religion and belief, the private and the public, religion and the secular, are not separate but inescapably bound up – in law, in identities, in beliefs and in practices, not to mention the physical landscape, with its spires, mosques and temples (Dinham & Francis 2015, p.11).

The 2011 Census lists the minority religions in the UK, with five standing out with statistical significance, including other faith subgroups, with Christianity as the dominant religious affiliation in the Nation (ONS 2011). Respondents who claimed no religious affiliation constitute another unique category that should not be ignored in religious literacy discourses. Lack of affiliation with a religion may as well refer to spiritual meaning making through the

life course (Canda & Furman 2010), as opposed to following the readings of a particular creed (also see Woodhead & Catto 2012). Religious literacy is also relevant, in this case, to prepare professionals who feel uncomfortable engaging with religion, belief, and spiritual identities.

Nonetheless, secular ideas and secular beliefs increase ambivalence toward religion. ‘Resistance by secular partners to consultation with, and the incorporation of, faith groups in the policy frame may reflect ongoing mistrust as well as lack of religious literacy’ (Baker 2009; p.108). According to Berger (1999), ‘religion is the human enterprise by which a sacred cosmos is established’ (p.11), and by which people make meanings and sense of their communal, social, political and personal relationships and experiences.

According to Dinham and Francis (2015, p.11), ‘it is impossible to talk fully about the public sphere without talking about religion and belief’. Religious literacy requires as the first step recognition that ‘religion and belief pervade as majority, normal and mainstream, whatever one’s own position or stance’ (ibid, p.11). Drawing from Beyer’s (1994) typology of religion, religion may be a societal or a cultural system. People do not cope well with religion when it is treated as culture. In the space of professional practice, there are different theories and models when responding to cultural versus religious traditions and beliefs. Nonetheless, both are relevant to public professions that engage with service user identities.

Moore (2015, p.29) suggests that ‘religions are collections of ideas, practices, values and stories that are all embedded in cultures and not separable from them’. However, religion as a culture retains customs and rituals in one’s life despite the personal preference of non-affiliation (Parkes et al. 1997). For example, people still get married or celebrate Vesak: Buddha Day. These are all traditional forms of practice that represent religious doctrines, nevertheless not treated as such necessarily.

The contested notion of religious literacy may also be approached differently at different times and places in which it is contextually relevant (Dinham & Francis 2015). Some interesting accounts include Prothero and Kerby (2015), as explored earlier. They consider religious literacy the loss of knowledge about traditions, first located in Christianity. They suggest that religious literacy intends to increase tolerance in society. Similarly, EOL care involves approaches that find solutions to the challenging multi-faith service user population. Knowledge about religions will not result in religious literacy. Contrary to Prothero and Kerby (2015), loss of knowledge about traditions in hospice care did not lead to religious illiteracy, but rather facilitated the tendency to avoid the subject further.

Different to Prothero's and Kerby's (ibid.) conception, Barnes and Smith (2015, p.85) approach religious literacy as harmony: 'acquiring religious literacy requires a positive and relational encounter with people from different faiths and beliefs'. They suggest that diversity among people should not be suppressed, nor omitted. Public life should value difference and embrace the possibilities that will lead toward harmony. This is relevant to this thesis for it supports the argument that religious diversification in hospice care should be valued with acknowledgement and facilitation toward harmonious existence and understanding.

The modern history of the welfare state shows that religious language gradually disappeared from care, and a secular-minded dialogue took its place (Dinham 2015). 'Public professionals such as the new NHS doctors, social workers and state-employed teachers had taken on the care functions of the churches' (ibid., p.106). This supports the argument that professionals who practice in death and dying settings have received a secular-minded education that has left them precarious of properly engaging with religion, belief, and spiritual identities of service users.

Religious literacy, as described by Dinham and Francis (2015), integrates religion and belief as social aspects of an individual or community. Religious literacy is also inclusive of all faiths and none:

Clarity about the category of religion and belief is the beginning of religious literacy – it requires a willingness to recognise it as relevant. This precedes knowledge about specific religions and belief themselves, which can only effectively follow on from intelligent, thoughtful, informed understanding of ideas about religion and the secular - an understanding about how the conversation is framed. Further, religious literacy need not...exclude non-religious identities which are equally complex (ibid, p.11).

Religion and belief should be taken into account in all areas of public life, whether in policy-making or practice. Dinham and Francis (2015, p.23) suggest that ‘religious literacy is a multifaceted endeavour’. It is this concept and guiding notion that I am employing in analysing and interpreting research data, as well as identifying areas for future study, but always bearing in mind its limitations and the challenges that come with it, as outlined in the beginning of this chapter. The following is an account of migration in the post-war years; a matter of unquestionable pertinence in the current religious landscape, i.e. the much more plural and diverse social environment. This is highly relevant to this thesis as it explicitly describes the context in which religion and belief were gradually privatised before they emerged in the public discourse once again.

Religious Plurality and Diversification

England changed from an Anglican community to a Christian plural society, and finally to a religiously plural community. This frames the context in which secular practice has thrived. Religious plurality is the driving force of current social policy that directs service delivery in death and dying, and other settings. Religious diversification grew after the 1950s. From a Christian plural society, the UK and Britain became religiously plural:

It was also from the middle of the 20th century onwards that the size, distribution and significance of the other religious groups, such as Hindus, Muslims, Sikhs and Jains, grew in importance in the UK (Weller 2007, p.25).

Linking this enlargement and diversification of religious identities with migration and globalisation, defines it in secular terms.

Toward Christian Plurality

Before full religious diversity, including minority religions, migration led a diversified number of Christian beliefs to emerge to promote Christian values and beliefs in Britain. This emergence has eventually resulted in the development and maintenance of a Christian plural environment.

Thus the migration, settlement and development of new Christian communities has further diversified the profile of Christianity in England beyond even its relatively (as compared with many other European countries) pluralistic Christian inheritance of *Anglican, Presbyterian, Roman Catholic* and *Free Church* traditions (Weller 2007, p.23).

Apart from immigration, there are various reasons to justify the diverse Christianity that has been experienced and is still a feature of British society in the 21st century. Christianity has undergone serious transformations that have informed and promoted the emergence of new forms of Christian life, as well as *organisational life* rooted in Christian denominations (Weller 2007).

As a result, the Christianity of the UK in the early twenty-first century is much more diverse than many could have imagined, even half a century ago, both in terms of its ethnicity and the variety of its traditions, movements, denominations and other forms of organization and presence (Weller 2007, p.22).

Toward Religious Plurality

Weller (2007) suggests that the formation of religious plurality in the UK has taken a multifaceted course. It started from Christian plurality – ‘Christianity in these islands has developed into richly diverse forms’ (p.22) – and moved forward to a state that is Christian, plural and secular altogether.

Diversity within Christianity, among other religions, gained more attention in the public (Woodhead & Catto 2012). ‘Individuals and groups of people belonging to other religious traditions have come as visitors, or to live here’ (Weller 2007, p.23). Mayo (2005) best frames this presence of multiple religions in one space, based on globalisation theories and the notions of migration. ‘Globalization is not merely a matter of culture and communication. Globalization is also defined in terms of increasingly interconnected problems,...which give rise to the mass movements of people...’ (ibid., p.16). Social mobility, nonetheless, comes hand in hand with the migration of social identities and personal characteristics, but also with societal norms and beliefs that are embodied differently from the way they were expressed in the original societies.

In the post-war period, the Nation was experiencing significantly large waves of migrants who were either seeking asylum or migrating due to personal reasons or were refugees (Hansen 2000; Weller 2007). Migrants’ unique identities and demographic characteristics such as religion, migrated to Britain with them. The Nation faced the significant challenge of accommodating all kinds of different religious beliefs and practices in a Christian dominant context, a challenge that emerged in contemporary public life.

Today the UK is perceived as an environment of religious plurality and not as a dominantly Anglican place. Britain, along with France and Germany, has the most significant decline in

professed Christian believers. Scholars have noted that Christianity in Britain is in crisis since the 1960s (Meister 2011; Erdozain 2012; Green 2011; Prochaska 2006).

In contemporary Britain Christianity may be in crisis, as many historians and sociologists contend, but one should not assume that it is dead. There remains a goodly measure of belief, not least among Catholics and the expanding Pentecostal churches. But Christian belief is much less often expressed in church membership or in belonging to voluntary societies. To both believers and unbelievers today, the Victorian assumption that competing religious institutions could stem the tide of social distress is baffling (Prochaska 2006, p.25).

After WWII, British society started experiencing the trend of external diversification of religion, as opposed to the internal notions described above (Christian plurality) (Weller 2007). Many different groups of migrants, Sikhs, Muslims, Hindus, to name a few, were attracted into the labour force in the UK throughout the 1950s, 60s and 70s.

All the new religions that emerged in the nation at the time (Weller 2007) were initially distinguished by their race and ethnic diversity. Religious needs were not yet apparent to the government. The latter changed as the secondary wave of migration wave flew in between the 1960s and 1980s. Those migrants were the families (spouses and children) of the migrants from the first wave. The demographic changes, the increase in the number of people from certain religious movements or creeds led to the unavoidable need to accommodate individual desires associated with religious practices.

This phase of migration laid the basis for the development of a range of social, cultural and religious communities and institutions that would maintain and transmit their religious traditions. Mandirs, gurdwaras and mosques were founded and became an increasingly established part of community life (Weller 2007, p.25).

This identity shifts, as described above, highlight an enormous complexity of conscious notions within the individuals, families and smaller groups. Death studies attempt to capture the dimensions of a complex world. This is led by the idea that the needs of persons vary based on

perceptions and interpretations of their social reality, as well as the characteristics, values and beliefs that influence and guide them (Pentaris 2015b). Religious literacy in EOL care is not merely the knowledge and understanding of different religions, but the understanding of the complexity that the coexistence of different religions may bring to professional practice. It becomes an essential professional skill, for HCPs, to be able to understand and engage with religion, belief, and spiritual identities of service users.

Religious composition today

Britain is one of the most religiously diverse countries within the European Union. Britain has multi-faith societies, and people have the freedom to choose their religious beliefs. Although Christianity has been the dominant religion in the country and still is, other religions started taking significant hold too, such as Judaism, Hinduism, Sikhism, and Islam (Weller 2007).

Table 3: 2011 Census: Religion

Religion / No Religion	Percentage
Christian	59.3
Buddhist	0.4
Hindu	1.5
Jewish	0.5
Muslim (Islam)	4.8
Sikh	0.8
Other: Pagan	0.1
Other: Spiritualist	0.1
No religion	25.1
Agnostic	0.1
Atheist	0.1
Jedi Knight	0.3
Religion not stated	7.2

Source: Office for National Statistics (ONS), UK Census 2011, available at <http://www.ons.gov.uk/ons/datasets-and-tables/index.html?pageSize=50&sortBy=none&sortDirection=none&newquery=religion&content-type=Reference+table&content-type=Dataset>

Having unpacked the phases through which the state became religiously plural, it is appropriate that we now look at the most recent data in the UK, which reflects plurality and diversity. First and foremost, Table 3 details data from the UK Census 2011: religious affiliation in the UK. It is important to highlight that the question about religion and belief in the Census is voluntary, and therefore we are unsure how broadly the information can be generalised.

Along with the UK Census 2011 data, looking at the British Social Attitudes (BSA) about religious affiliations in Britain will also benefit our understanding of how people generally view religion and faith.

Table 4: Religious belonging in 2008 and 2009: “Do you regard yourself as belonging to any particular religion? Which?”

	2008		2009	
No religion	43.4%	1,937	51.0%	1,735
Christian – no denomination	10.0%	446	9.3%	318
Error! Hyperlink reference not valid.	9.3%	415	8.6%	294
Error! Hyperlink reference not valid.	22.6%	1,009	20.1%	684
Error! Hyperlink reference not valid.	0.8%	35	0.5%	18
Error! Hyperlink reference not valid.	1.9%	85	1.3%	44
Error! Hyperlink reference not valid.	2.9%	130	2.2%	77
Error! Hyperlink reference not valid.	0.0%	1	0.00%	2
Error! Hyperlink reference not valid.	0.1%	4	0.0%	1
Error! Hyperlink reference not valid.	0.3%	13	0.2%	8

	2008		2009	
Error! Hyperlink reference not valid.	1.6%	70	1.2%	40
Error! Hyperlink reference not valid.	0.5%	21	0.4%	14
Error! Hyperlink reference not valid.	1.5%	67	0.9%	31
Error! Hyperlink reference not valid.	1.0%	46	0.4%	14
Error! Hyperlink reference not valid.	3.0%	133	2.4%	81
Error! Hyperlink reference not valid.	0.3%	16	0.8%	27
Error! Hyperlink reference not valid.	0.4%	17	0.2%	7
Error! Hyperlink reference not valid.	0.5%	20	0.3%	12
TOTAL		4,466		3,404
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Source: British Social Attitudes, Retrieved (04/12/2012) from <http://www.britsocat.com/Marginals/RelRFW>

The 2008 survey had 4,466 participants, while the number was 1,000 less for the 2009 survey (3,404). 43.37% of the respondents in 2008 stated that they do not belong to any religion, while the percentage increased within a year (50.98% in 2009). The number of people who stated that they belong to particular religions, has declined through the time gap, between 2008 and 2009. In more detail, the number of people who declared affiliation with the Church of England dropped by 2.51% (20.09% in 2009). Roman Catholics fell from 9.3% in 2008 to 8.63% in

2009, and Christians with no stated denomination fell from 9.98% in 2008 to 9.34% in 2009. Regarding other religions, there has been a general elimination of feelings of belonging while Sikhs increased in 2009 to 0.81% from 0.35% in 2008.

The same statistics body has collected data over a series of years, up to 2011, asking the question: “Which religion or denomination do you consider yourself as belonging to?” In 2001, 54.51% replied that they consider belonging to Christianity, 4% stated other Religions, and 41.47% said that they do not think they belong to any religion or denomination. In 2011, the percentage of the people who found themselves Christians dropped by approximately 10% (46.36%), while 7.4% stated other religions, and 46.19% no religion. It is apparent that social attitudes are influenced by how we understand religious affiliations, as discussed earlier. However, the high number of people who state that they either belong or not to a religion or denomination, are part of the service user population seeking assistance and support at death and dying settings. This heightens the importance to address the challenges that HCPs face when it is necessary to engage with religion, belief, and spiritual identities of service users.

In light of the decline in religious affiliation, historians and sociologists are examining the future trends of religious connections and belonging. The estimates show that Muslims are a broad category of migrants in Britain, which continually grows and that growth indicates a significant increase in Islam affiliations in the future (Norris 2011; Meister 2011). Even though Christianity, and especially Anglicanism, is the core religious practice within Britain, other so-called *minority* religions co-exist and intersect with the dominant one.

The most common minority religions in Britain are Judaism, Sikhism, Islam, Hinduism and Buddhism (see Woodhead & Catto 2012). This religious diversification is the result of migration. A religion does not just transfer to a different Nation through the migration of its believers. It adapts to the societal, political and environmental circumstances of the host nation.

‘Religions change as they travel, and so do those who live by them’ (ibid., p.86). Furthermore, the dominant religion (in this case Christianity) of the location one migrates to is also changing and adapting to the new religious affiliations in its environment and to the impact the new religions have. This entails a whole process of inter- and intra-communication among faith groups and belief systems, to use the opportunity for increased knowledge and understanding of religion and belief within a multi-faith society. If we view secularisation as a reaction to those changes and the overall complexity of the religious composition in Britain, then we can speculate that religion has become privatised due to feelings of inclusion and respect for diversity (see Prothero & Kerby 2015).

This thesis is concerned with how well, or not, HCPs respond to religion, belief, and spirituality in relation to their professional practice. Further, explores the challenges, if any, that HCPs face about engaging with religion, belief, and spiritual identities of service users. In order to adequately explore this, it is important to consider what changes contributed to an environment in which religion and belief are marginalised.

Immigration & globalization: contributing to religious plurality

According to Meister (2011), migration is the primary reason for religious diversity and religious plurality in developed countries. Equally, Weller (2007) suggests that:

It was also the labour migration, ... that, in the 1950s and 1960s, led to workers of Hindu, Muslim and Sikh backgrounds from the Indo-Pakistani subcontinent becoming a permanent feature of UK life and bringing about the existence here of significant communities of Hindus, Muslims and Sikhs (p.25).

Diversity and plurality have both challenged politics, policy and practice. New measures were necessary to respond to the shifting requirements of the population (Timmins 1995).

Even though attention was given to the question associated with migration, it was still not asked in the 1951 UK Census. In the UK Census 1961, however, a question regarding previous addresses and number of years of residency in the UK had been added (Guide to Census Reports 1977). This was due to extended demands from local authorities and the government to be conversant regarding social mobility in the country (ibid.).

Immigration in Britain from the 1940s onwards had a tremendous impact on various areas (e.g. education, welfare services, crime rates, and worshipping) of the state. When WWII ended in 1945, the British economy was a priority, specifically the recovery from losses inflicted by war (Timmins 1995). To aid in this recovery, a large number of migrants were recruited for labour (Weller 2007). The Royal Commission on Population (Redington & Clarke 1951) reported that migrant populations can be of *good stock* and that they should be welcomed as labour into the country. That report raised the awareness of labour market needs in the UK and as a result immigration numbers increased.

Britain accepted migrants from several places with the Irish community being the largest until the 1970s (For further details on particular ethnicities and migration in the UK, also see Weller 2007). People migrated to Britain for various reasons. Nevertheless, apart from how and if immigrants' needs were met in their new nation, we cannot avoid the acculturation and enculturation processes that both the immigrant and the dominant populations had to go through. Immigration suggests a lot more than just a person moving from one place to another (Hansen 2000). It entails a complicated adjustment, which might take time and sometimes might not even be successful.

Part of what immigration brought in the UK was increased religious plurality (Weller 2007; Dinham 2009; Meister 2011). From an Anglican environment, Britain had now to accommodate the needs of many and different religions. The plurality that was raised then has

been apparent to date, but with a lot more legislation and awareness in place, that promotes and enhances equality within communities of multiple identities (Meister 2011). The following section reviews discourse on the religious decline, secularisation, and desecularisation as those are concepts that have been used to define the changes in the religious landscape of Britain.

Religious Decline, Secularisation and Desecularisation

Secularisation may have been assumed to be happening in the West, but not necessarily in the rest of the world, or at least in large parts of it. In the modernised and technological development of Western countries, a religious decline has been observed by theorists, but with limited generalisable effects. By religious decline, I refer to the tendency of people not to follow religious practices anymore, but to move toward a privatised mode of religious expression. Religion started to become more personal than public (Davie 1994). By believing but not belonging, participation in discussions about religion in the public space has declined.

Sociology has long reflected a widespread assumption of religious decline (Fischoff 1993; Luckmann 1990; Fallding 1974; Berger 1967; Wilson 1966), though the opposite has also been posited since at least the 1970s (Martin, 1978) and continuously ever since (Davie 1994; 2007, Berger 1999, Habermas & Seidman 1989, Hervieu-Léger 2000; Voas & Day 2007; Dinham 2009, Woodhead & Catto 2012, Dinham 2012).

Wilson (1966) suggests that the social significance of religion in the public domain has suffered in modernity and was eventually lost. In these terms, secularisation is a process of religious decline in public life, which in turn is an unavoidable consequence of modernity. Similarly, Berger (1967) identified that despite religion's importance in providing a unifying belief and worldview, the process of secularisation has had a conflicting impact on individuals and society. Berger (*ibid.*, p.107) defined secularisation as 'the process by which sectors of society and culture are removed from the domination of religious institutions and symbols', while later

he termed the freedom to choose affiliation to a religious denomination the *heretical imperative* (Berger & Luckmann 1981).

Fallding (1974) identifies inclusive and exclusive religion. The former is closer to the shapes of new religions and new spiritualities: a more individualised experience of belief. On the other hand, exclusive religion indicates decline, also as described above. Both Fischhoff (1993) and Luckmann (1990) suggest religious decline. Luckmann (1990), also, recognises the changes that modernity brought to the social construction of society and, therefore, suggests that religion is no longer the centre of attention due to these structural changes.

Martin (1978), however, argues that secularisation has served a primarily ideological purpose, with limited proof of religious decline. Beyond this point, Davie (1994) introduces her thesis on believing without belonging, arguing that ‘the majority of British people – in common with many other Europeans – persist in believing (if only in an ordinary God), but see no need to participate with even minimal regularity in their religious institutions’ (p.2). In contrast, Voas and Day (2007) identify religious changes as the corruption of religions in their proper form, into a “fuzzy” form which they term, *fuzzy fidelity* (also see Voas 2009). Over ten years after her ‘believing without belonging’ thesis, Davie (2007) moves beyond it, suggesting vicarious religion, which she defines as:

the notion of religion performed by an active minority but on behalf of a much larger number, who (implicitly at least) not only understand, but, quite clearly, approve of what the minority is doing (Davie 2007, p.22).

In other words, vicarious religion concerns religious practice by churches and church leaders on behalf of others. Examples of this include a marriage, a funeral, or a christening, all of which require a form of consent by the vast majority.

In a different approach, Rowan Williams’s (2006) observations include programmatic versus procedural secularisation. Programmatic secularism refers to a deliberate, conscious decision

to be secular; 'when the Church is regarded as an enemy...that must be resolutely excluded from public debate, liberal modernity turns itself into a fixed and absolute thing, another pseudo-religion' (ibid, p.79). On the other hand, procedural secularism can be seen as behaving on the assumption that things are secular.

Some thirty years after his first argument on the social reality of religion (Berger 1967), Berger (1999) suggests that his analyses have been misled by his own thinking. He suggests that society is as religious as ever. He does this by introducing the desecularisation thesis. Others (Hervieu-Léger 2000; Woodhead & Catto 2012; Davie 2013; Day 2010; Dinham 2009; Martin 2005), in various and different ways, but also for various reasons, suggest that religion never went away, but rather has changed.

Secularisation theories have suggested that while societies advance they will become more secular (Beyer 1994). On the same note, several commentators of sociology have noted that religion may be in a permanent decline. The founders of Sociology, Karl Marx (1818-1883), Durkheim (1857-1917), and Max Weber (1864-1920) have all noted this process of religious decline (also see Bruce 2011).

However, the examination of religious decline and modernisation has been undertaken by, and for, a Christian dominated world. These two terms - religion and Christianity - have the tendency to be linked in conversations and even used interchangeably. Bruce (2002) argues about secular beliefs based on Westernised communities and Christian-oriented ones. However commentary on minority religions is limited.

Despite its recent evidence, secularisation has already found its counter-process. Berger (1999) has discussed his thesis of how secular beliefs and privatised patterns of religious behaviours are turning around again, as people adopt more 'desecular' beliefs. As noted by Karpov (2010), Berger's thesis was expected to initiate an emergence of research questions and hypotheses,

and it did. It is worth noting here though, that desecularisation related research and theoretical approach rapidly became relevant to the sociology of religion but has not been used as much by research on public professions.

Berger (1999) describes the concept of desecularisation as ‘counter-secularisation’ and has ‘offered an innovative view of the vitality of religion vis-à-vis global modernity’ (Karpov 2010; p.232). Desecularisation implies that the secular assumptions have been wrong, and that communities as they modernise, remain as religious as ever (Berger 1999).

With desecularisation theories, predictions of inexorable secularisation have been undermined (Woodhead & Catto 2012). Karpov (2010) debates the latter suggestion by exploring the definition of Berger’s desecularisation thesis.

Theorizing desecularization does not involve an all-out refutation of the secularization thesis...a valid conceptualization of desecularization as counter-secularization rests upon acknowledging the presence of secularization trends and forces. Only in such a manner will we be able to approach the important task of studying the interplay between secularizing and counter-secularizing trends. Therefore, the development of a theory of desecularization will...benefit once this issue is detached more clearly from the never-ending debate on whether or not and to what extent secularization is a reality (Karpov 2010, p.237).

Desecularisation, in other words, is a process of reacknowledgement of the social significance of religion and belief, in the public sphere; it is the recognition that secularism is no longer pertinent to the 21st century societies, and that religion and belief are in the core of individual and public life.

Further beyond the discussion about the secular, Habermas (2008) argues that societies are now post-secular; i.e. concerned with the relationship between religious and secular beliefs. Beaumont and Baker (2011) present the post-secular city as a space where the role and

boundaries of religion are ‘no longer rigidly enforced..., and new relations of possibility are emerging’ (p.2). Preceding this claim is Beaumont’s (2010) suggestion that the postsecular:

...does not infer that we now live in a radically different age compared with half a century ago...the limits of the secularization thesis and the ever-growing realization of radically plural societies in terms of religion, faith and belief within and between diverse urban societies. If we consider postsecular as the indication of diverse religious, humanist and secularist positionalities...it is precisely the relations between these dimensions and not just the religious that are taken into account (p.6).

On the other hand, Beckford (2010, p.125) describes Habermas’s claims as ‘paternalistic’:

Habermas insists that religious contributions to public debate must be translatable into the supposedly neutral language of secular reason. He wants to exclude direct or untranslated religious voices from legislatures, courts of law and public bureaucracies. He accepts that public religions are enjoying a resurgence but he would also like to prevent them from exercising power where it really matters. This represents an emasculation of the public sphere (Beckford 2010, p.125).

In other words, according to Beckford (ibid.), Habermas describes the post-secular as a state in which religious contribution is communicated with neutral terms. I will share Beckford’s scepticism here, for neutral terminology and avoidance of religious character appear to facilitate religious illiteracy in different parts of public society, rather than being inclusive, acknowledging, and engaging with diversity, as the results of this study show.

Secularisation, however, is in the spotlight of sociology of religion, while research is attempting to examine the changes that cause this effect. In research, secularisation has been framing questions and methods while religion has become a significant variable (Karpov 2010).

‘Views on the causes of secularization abound...from the effects of scientific rationalism to social diversity, from modernization to Sunday shopping’ (Prochaska 2006, p.25). As societies modernise and develop, they view religion, along with race, ethnicity, and other matters, in a

different way. As social coherence evolves from multiple angles, and multiculturalism has settled in today's communities, religion is treated in the way expected to meet the needs of the new social structures and social functioning. According to Stackhouse (2011, p.239), 'religions have been moderated or otherwise manipulated by modern powers in various respects to suit various agendas'. In these terms, secularisation, desecularisation and the post-secular, may refer to a societal needs assessment and the necessity of adjusting religious beliefs and values to current public desires. Secularisation may as well refer to the desire for better adjustment to societal changes, as opposed to an informed individualistic decision to privatise religion.

Green (2011), based on his historical and more empirical evidence of religious change in the modernised religious world, argues that the process of secularisation commenced with the elimination of religious questions within politics. Also, the expulsion of those questions has had an important impact on the modern social history of religion. In support of my previous assumptions and also Stackhouse's work (2011), the privatisation of religion and the adoption of secular beliefs may be the product of the new challenges emerging in the multi-faith communities and multi-cultural contexts that shape modern societies.

The lack of causation of the secularisation paradigm is heavily critiqued by Bruce (2011), who 'complains' that he has presented enough statistical evidence, to answer the question 'why?' However, others do not share this view (Green 2011; Erdozain 2012; Warner et al. 2010). To theoretically illustrate a concept of the secularisation causality, it is necessary to combine a few different ideas (Erdozain 2012), and find the interconnections with the trends in secular beliefs. Following are the most important concepts for helping us understand the interconnections and the impact those processes had to the causality of secularization.

Secularization and professional practice

As we go through the causality of secularisation, it is important that links are made with the secular context of professional practice. The context wherein the expertise of HCPs is built, reflects secular characteristics, practices designed for service users under the assumption that individuals have become less and less religious, and do not to a great extent, interpret their life experiences (e.g. death) through their faith. Looking at the concepts that boosted the secularisation process in society will enhance our understanding of the current position of religious or non-religious matters within health care practice.

Some critiques of religious decline, nevertheless, recognise that religion has remained fully present in society though changing continuously in its effect, and that at the same time we have largely lost our ability to engage with them (Dinham 2015). Dinham (ibid.) articulates this as lack of religious literacy, highlighting its impact on an inability to produce appropriate language and policies that will respond to the needs of religiously plural service user populations. Lack of understanding of the role of religion and belief may lead to limited skills and abilities with which to engage with it, and result in poor quality of service delivery overall.

Religion has always been part of society in various ways (Ammerman 2007), and it has always given meaning to societal norms and institutions (Hervieu-Léger 2000). Since the mid-twentieth century, religion in Britain has undergone several challenges along with political and historical change (also see Bruce 1995). Wilson (1966) argues that technology, empiricism, and rationalism have come to substitute the religious perspectives of social norms and societal definitions, as he highlights the impact of modernity on the role of religion in the public realm:

The whole significance of the secularization process is that society does not, in the modern world, derive its values from certain religious preconceptions which are then the basis for social organization and social action (Wilson 1966, p.227).

The meaning of religion and belief, as well as its role in the public domain has, both publicly and privately, sustained its significance all along (Berger 1999, also see Davie 2013; 2015; Beckford 2010). Drawing from private, individual identities and individual consciously held values that drive people's perceptions in life; life experiences, such as DDB, are threaded through those values and help people make sense of their imminent death, grieving process, or a challenging health situation. (Feifel 1959; Walter 2006; Pentaris 2012; Hurding 2013).

In the rest of the chapter, following Dinham's (2015) description of religious literacy, and keeping in mind its limitations and barriers, I look at how the welfare state had the effect of transferring the language of care from religious to secular. This transfer shows the gradual division of the church and the state, while it underlines the imbalance between secular-minded practices versus religious language in practice, in the favour of the former.

Post-war Britain

According to Dinham (2015, p.101), 'World War II had formed a cauldron for rethinking society in the most ambitious of terms, and...the churches saw this too'. Starting from William Temple who introduced the term 'welfare state' in the 1920s, Dinham (2015) suggests that the War was a good reason for rethinking society and readjusting power and needs according to the shifting challenges in the post-war years. The Welfare State becomes the means for transforming the nation. Despite the different sources of welfare services, by both the Church and the State in Britain (Gladstone 1999; Prochaska 2006), it is argued that after WWII welfare was transferred from the Church to the State, however with an 'invisible presence' remaining:

This is a period in which the transfer from church to state is *assumed* to have resulted in the wholesale nationalisation, professionalisation and therefore secularisation of welfare. Public professionals such as the new NHS doctors, social workers and state-employed teachers had taken on the care functions of the churches. These were now the people to whom publics turned. Yet the point is that, despite the shift away from a

religious articulation of welfare, faiths continued to play a crucially important role, though one which was far less visible (Dinham 2015, p. 106).

William Temple envisioned these services for Britain along with William Beveridge, responsible for the Beveridge Report (BR) (Dinham 2015), which was largely influential in the founding of the welfare state (Timmins 1995). Focus was given to housing and for some years the welfare state delivered these services while other community services were neglected. After that, the attention of the state shifted toward community development and expanded on opportunities toward the improved social reformation of Britain. Despite the large amount of services provided by the state, the Church continues to provide services as well, which were not necessarily visible in the public (ibid.). The result was a public sphere that did not engage with religion anymore and gradually lost the ability to do so. The next time when religion is thought again very few people know how to engage with it, address it, or even talk about it (ibid.). Alongside the loss of religious literacy due to the transfer of care from church to state, there is a dramatically changing religious landscape in the very period when religion is being talked about the least.

After the election of the Labour Party in 1945, the Church became more involved with the welfare state and initiated philanthropic movements to reinforce the well-being of the community (Prochaska 2006). Until the late 1970s, the state was, however, the leading provider of the services (ibid.), and it was during that time, between 1950 and 1970, that ecumenism developed. Ecumenism was an attempt to unify all Christian churches, especially the Protestant denominations (discussed accordingly in a later sub-section). After the 1970s, the state became the commissioner of welfare service provision (Backstrom & Davie 2010), whereas Church became the main provider (Prochaska 2006). ‘Both voluntary and private sectors have taken on larger roles in partnership with the state, providing services totally or partially funded by the state’ (Backstrom & Davie 2010; p.116).

Taking a step back, Timmins (1995) writes a comprehensive narrative history of the development and establishment of the British Welfare State since the end of WWII. A thorough look at this will enhance our understanding about how the language shifted to secular from religious. Giant want, disease, ignorance, squalor, and idleness are the ‘five giants’ that Timmins (ibid.) writes about and shapes their historical overview starting from Beveridge’s report and moving forward.

When, in Keith Joseph’s final days as Secretary of State for Social Services, I first started reporting what the academics would call social policy, I had wished for a single volume which simply told the story of how we had got there – the events, ideas, personalities, issues and pressures which had taken the post-1945 welfare state to the point (Timmins 1995, p.1).

The welfare system in Britain, in addition to the aforementioned challenges, has ‘been put under considerable strain in recent decades due to a number of demographic and social factors’ (Le Mon 2010, p.116). Weller (2007) depicts two major waves of migration and how those influenced the demographics in the UK and England specifically. During the years of the unification of Churches, vast number of migrants arrived in the nation – ‘the labour migration’ (ibid., p.25). Furthermore, as migration for the labour force slowed down during the 1980s, the families of migrants started joining them; secondary migration (ibid.).

Post-war Britain is directly linked to religious plurality in contemporary societies. This is also illustrated by Grace Davie (1994) from a sociological perspective:

We live in an ageing society in which the nature of family life, including the traditional codes of morality, is altering rapidly. The related revolution in gender roles has, for better or for worse, penetrated the churches and influenced theological thinking. Similarly, the influx of immigrants in the post-war period, not all of them from Christian countries, has introduced significant other-faith communities into this country. The trend toward a greater religious diversity is unlikely to be reversed; it has

had, and will continue to have, a lasting effect on many aspects of British religious life (p.3).

Alongside the changes to the demographic landscape (Backstrom & Davie 2010), dependence on the voluntary sector (Prochaska 2006) and informal support systems increased. Church played and is still playing, a critical role in launching charitable organisations based on needs assessments run in the communities (Woodhead & Catto 2012).

The religious composition in Britain is great and varied (Weller 2007; Norris 2011). Due to the religious demographics of the state currently (Table 1) as well as social attitudes (Table2), several distinguished sources of faith play a role in relation to the welfare state. A good example is Churches Together in England (CTE). CTE is an ecumenical organisation that aims to bring all the churches together, reflecting ecumenism from the 1950s-1970s, to work collectively and be more efficient in their relations to the public realm. Other examples are the Muslim Council of Britain and the Muslim Welfare House Trust in London.

The Church of England, historically (Green 2011), has influenced not only the life of the nation (Welsby 1984) but its political development as well (Prochaska 2006; Backstrom & Davie 2010). It is worth noting here the report entitled *A Call for Action by Church and Nation* in 1985. The report illustrates the Church's wish to have an impact on the Nation as whole (ibid.). This is an example that clearly illustrates the intentions and the politics of working together.

The British Welfare State developed in a period when there was a need for it (Timmins 1995). All four countries of the UK were facing multiple challenges and needs in five main areas of concern. Those became the five areas of coverage for the BR, and, therefore, the 'Beveridge's Welfare State' (ibid.). The five giants were the five programmes for the nation to work on; social security, health, education, full employment and housing. The BR has, in general, seen glorious moments in the history of the nation, and it became a beacon for its reconstruction in the post-war period.

It is also worth mentioning that the meaning of the welfare state was established in the same way for all but held different aspects for many. Timmins considers that:

Over the years, the modern welfare state had meant many different things to different people. Its half-century had affected, broadly, four generations, but even within them had had different effects. To take my own family and friends, my grandparents' generation – the one that had fought the WWI and who were on their way to retirement in the later 1940s and 1950s – had been the first to gain. For them, the welfare state brought NHS care and a pension they might not otherwise have had (Timmins 1995, p.500).

This is important when setting out to understand what the welfare state meant to people and how it has been understood. Different experiences of welfare show different appreciations of the relationship between the state and the Church as well.

Religion and the State

The previous section set out the grounds for exploring the relationship between religion and the state; an account that further illustrates the context in which professional practice develops. The current section is important as it will highlight and round out the secularisation component, which sets an awkward tone for the conversation about religion and belief in particular settings, such as hospices.

A good starting point might be to look at the role of her Majesty the Queen of the UK. The Queen is Head of State in the UK, as well the Supreme Governor of the Church. These two facts alone could initiate a prolonged argument on what the relationship between religion and the state is. Being a constitutional monarch, her Majesty does not 'rule' the nation. However, the Prime Minister can, on her behalf, affect the Church, while, on the opposite side, 26 senior bishops hold positions at the House of Lords. This amounts to both a covert and overt, interrelation between religion and the state.

Another good reference point is Bruce (2003). In his book, he draws upon many religious traditions from around the world. He does this in order to explore the links between politics and religion but also to highlight the complexity of those relationships in contemporary society. Bruce (ibid.) shows that as long as economic, social and political aspects shape and often regulate the political choices of the believers in society; he then concludes that, based on this, religion still matters.

Religion and State have interconnected in the social and political life of the Nation. It is these facts that respond to the assumptions of secularist theorists, who have – some still do (Bruce 2011) – supported religious decline in social, political and personal levels. Secularisation theories support that societies inevitably become more secular as they modernise (Berger 1967). Based on these suggestions, secularity has become a characteristic of several levels of 'practice' in society today, one concerning the health care sector. Hence, elaborating on the relations between religion and state is as important as understanding what secularisation is. The former reflects the significance of religion and faith driven social action from within individual consciousness. The latter informs the patterns followed with regard to qualifications in health care professionalisms driven by the idea of secularity and non-religious exchanges with service users.

Despite the intentions of making a full understanding of what has happened to religion or faith, a fundamental characteristic has been left out of the discourse:

Christianity, especially in its established forms, still plays a preeminent role in the public religious life of the UK. Within this, the established Church of England has a special constitutional position with regard to the UK state as a whole that marks it out from other Churches (Weller 2007, p.48).

Prochaska (2006) reviews a series of Christian social actions that support the ongoing engagement of religious matters with politics. The same happens with Green's work (2011);

he unravels post-war perspectives of Christianity in a political Britain. Religion has been a significant part of the state's work and the welfare state is no exception (Prochaska 2006). After the disconnection of the parish from the state and vice versa, there is a shift in the 1960s in education; namely the recognition of 'World Religions'. The attempt was to maintain religious matters as being involved in social action, and education was one of the ways.

Current challenges about religion in the public sphere, such as Dinham's suggestion (2015) about the loss of the ability to talk about religion and belief, were consolidated and driven along by the transfer of care from church to state. Consequently, this represented a concomitant loss of a space for religious articulations of care – the language of care is effectively secularised. It is important to review the relationship between the church and the state, and how religion and belief have played out in politics and policy. One of the most direct ways to examine the interrelationship of the two is to review the developments of community development programs during and throughout the reconstruction of the state since the 1950s. Also, to explore the emergence of the concept of community cohesion, in the 21st century.

Social policy

Parsons (1993) suggests the Church has moved on from being predominantly concerned with 'churchy' issues, and developed its thinking beyond inward-looking matters. Despite the argument that faith-based provision was in the front line during and after the war ended (Green 2011), the state became the provider of services. Meanwhile, faith-based contribution to the reconstruction and reformation of the nation was still visible through volunteerism and philanthropy (Welsby 1984). The church retained its role to sustain and enhance community cohesion and social functioning, as it bonded and maintained relationships among the citizens; it became a means of communication and the sense of belonging.

This narrative, however, has multiple offshoots, and healthcare is one of them. While the state, after the 1950s focuses on housing and later on employment, community development is subsequently identified as a crucial matter (Timmins 1995; Prochaska 2006; also see Feifel's reflections on post-war social action 1977). This is well-presented in Dinham's (2015) account, in which religion exerts an 'invisible presence' after the WWII and until Thatcher gains power in politics. After the welfare responsibility was transferred from the Church to the State, welfare services started secularising to the point where policy makers and professionals have lost their ability to talk about religion. All attempts for community development were accompanied by a stance of non-religious language, i.e. Community Development Projects of the 1960s. It is important to unpack this in the current thesis as it complements the concept of religious literacy and the challenges around it, when later on religion is visible again but we do not know how to address it (Dinham 2009).

There was a realisation that rebuilding physically (housing) was not resulting in the rebuilding of communities (relationships) (Dinham 2015). The Gulbenkian Report (first report in 1968) highlighted this and led to community work, a great deal of which was done by churches. Despite the assumption that welfare secularised, faith groups remained highly active in society, although less visible (ibid.).

In 1969, the most prominent attempt at community development was the Community Development Project (CDP). CDP was a national government initiative, which in 1977 published the report entitled *Gilding the Ghetto* that seeks to make sense of the urban interventions from 1969 to 1976. The project showed how problems were conceptualised at different levels (national versus local):

Their brief rested on three important assumptions. Firstly, that it was the 'deprived' themselves who were the cause of 'urban deprivation'. Secondly, the problem could best be solved by overcoming these people's apathy and promoting self-help. Thirdly,

locally-based research into the problems would serve to bring about changes in local and central government policy (CDP Inter. 1977, p. 4).

The report looked at the CDPs throughout England, twelve at the time. Even though it identifies the problems, it does not meet the goal of balancing its critiques and recommendations (CDP Inter. 1977). The report elided addressing concerns about the church's contribution to community development.

In the 1980s, under the Conservative Party, the Single Regeneration Budget (SRB) ran the *City Challenge* project that would revise and recycle income sources in the community and potentially enhance community development (Craig et al. 2011). In the late 1980s and early 1990s, a joint effort by the state and the church, to explore and find solutions to inner-city problems, was initiated. The programme was the 1988 Inner Cities Religious Council (ICRC), which commissioned leaders from the five major religions in Britain and was chaired by a minister. The Interfaith Network follows in 1987 to promote knowledge and understanding of different faiths in the community, as well as embrace good relations among people from different faith groups in the community (also see Taylor 2002).

To follow that project came the *New Deal for Communities* by the Labour Government in 1997. It is a regeneration programme under the leadership of the government and some distinctive neighbourhoods of England. The programme aims at community development and neighbourhood enhancement through community-led regeneration. It was one of its goals to try and bridge the gap between different communities. Dinham (2005) shows critical evidence with regards to the effectiveness of the project from the participants' point of view, which revitalizes its purpose. In his article (ibid.), he highlights the contrast between the intentions and desired outcomes of the *New Deal for Communities* and the actual experiences of local participants in one of the areas. He argues that the Labour Government had an understanding

of community participation that was politicised, and which detracted from the grass roots participation it claimed to want to support.

Similarly, in the USA in 2001, President George Bush set up the White House Office of Faith-Based and Community Initiatives (OFBCI), today known as Faith-Based and Neighbourhood Partnerships. This was an initiative toward strengthening organizations and empowering faith-based groups in the community to deliver federally funded social services. At the same time, and right after the attacks of 9/11, a Prevent Strategy was launched in the UK. This strategy, also reformed and readdressed in 2011, aims to prevent people from becoming terrorists, or joining terrorist attacks.

Launched in 2008, the face to face and side by side framework for partnerships was launched to encourage interfaith dialogue, build up strong relations, and increase collaborative social action. The framework is based on three core principles: empowerment, partnership, and choice. Also, until recently the Local Government Association (LGA) was generating policies that suggested the state and church were working in partnership. The LGA had funded a research project in 2010, regarding the partnerships between faith groups and local authorities that were active at the time. That study focused ‘on the opportunities, challenges and methods of effective partnership and engagement’ (Chapman 2012, p.3). Two years later, Chapman (2012) reported that there is a willingness for collaboration among faith, religious, and governmental bodies. However, there is still a misunderstanding in how that partnership shall be organised and by whose authority. That said, religions, faith or humanist groups are still engaged with policy. On the other hand, politics and policy are still engaged with faith, as opposed to the tenets of secularisation. In other words, religion is not as privatised as has been speculated. Religious matters are still important to individuals. Chapman’s (2012) study (i.e. how a partnership can be established) also speaks to the challenge that the current thesis is

tackling: how can a religious literate approach be employed by HCPs at the request of service users.

Implementation of Butler's Act was to fall to Labour. But the issue which was to cause the biggest welfare state row immediately after 1945 was not to be education, Beveridge's social security plan, or even housing, though that too was to see its fair share of controversy. It was the National Health Service that took the lion's share of the headlines, despite proving the most enduring of the 1945 Labour Government's achievements (Timmins 1995, p.102).

The NHS became a milestone in social policy, as it would benefit the whole of society in Britain (Timmins 1995). Nonetheless, beneficiaries of the NHS would be asked to give back (prescription charge since 1952), in terms of building up a sustainable system.

The inclusion of *religion and belief* in the Equality Act 2010 and additional government agendas toward cohesion and empowerment of the community, have been partially responsible for the increased significance in issues of religion and belief in local and wider communities. Community cohesion has been a leading principle in the 21st-century society, and, therefore, an important aspect to examine on its own when exploring facets of public life, i.e. religion and belief. In the next section, I am exploring community cohesion as a government agenda and as a social process. Further on I am exploring how faith has acted as the means toward community cohesion.

Community cohesion

Community cohesion is a term coined after the 2001 riots in England (Bradford, Burnley and Oldham) by Ted Cante (2001) with the Independent Review Team. The vision was to build communities by breaking down stereotypes and embracing diverse identities. Cante envisioned a society where people from all backgrounds would co-exist together, valuing each other and enjoy similar opportunities in the community:

the aim of community cohesion is to tackle the ‘fear of difference’ more generally and to enable people to be more comfortable with all areas of difference,The community cohesion agenda can also be applied to all types of communities whether in town and cities, or in suburban and rural areas, where ethnic minority and faith communities are very small (Cantle 2008, p.171).

Ted Cantle was the chair for the Community Cohesion Review Team (Robinson 2005), which was established as to explore the opinions of the residents of the communities that had been affected by the riots. According to Cantle’s work later (2008) cohesive communities can only come together when they argue. The latter has been supported by Robinson (2005) as well, in the attempt to define social and community cohesion:

The stronger the ties that bind...local communities...the greater may be the social, racial or religious conflict between them. The result might be a city consisting of socially cohesive but increasingly divided neighbourhoods (Robinson 2005, pp.1416-1417).

The above firmly agrees with the conclusions that the Independent Review Team drew, with regards to where social cohesiveness may be found (Robinson 2005). One of the concluding lines suggests that cohesiveness may be found in very much ‘divided towns and cities’ (ibid., p.1417).

Suggested also by Robinson (2005, p.1411), community cohesion has not been included ‘in the lexicon of urban theory or public policy’ before the events/riots in England in 2001. The latter events triggered the community cohesion agenda that sought to review the government policy at the time and also encourage ‘good practice in community cohesion’ (ibid., p.1411).

The Community Cohesion Unit was established, located in the Home Office and charged with leading on a review of government policy and encouraging new learning at the local level through the Community Cohesion Pathfinder Programme (ibid., p.1412).

On the face of it, the emergence of community cohesion agenda would appear to be evidence – based policy-making in action (ibid., p.1412).

By ‘challenging the negative effects of globalization’ (Mayo 2005, p.1) it becomes clear how community cohesion and community action is a lot more complex to achieve. Nonetheless, and according to Mayo (2005), not a new trend in social reality. Cattle (2008) defines community cohesion as clustered groups of the society that self-identify by ethnicity or faith, but not social class. He suggests that ‘community cohesion has emerged...to describe the societal features which are based on identifiable communities defined by faith or ethnicity, rather than social class’ (p.50). To achieve cohesion in the commonwealth, values and challenges must be shared and understood as such by the whole community.

Suggesting that community cohesion is about helping micro-communities to gel or mesh into an integrated whole, the Independent Review Team’ in 2001 ‘argued that divided communities will need to develop common goals and a shared vision; to challenge to “them and us” attitude considered prevalent in situations of increasing division and crumbling cohesion (Robinson 2005, p.1413).

According to Robinson (2005) and Cattle (2008), the core value of building up communities that are cohesive was illustrated by the riots in England in 2001; at Bradford, Burnley and Oldham. Community cohesion in public policy was the response ‘to community conflict and unrest’ (ibid., p.50) after the riots.

According to Mayo (2009), community cohesion has become a critical component of social intervention and social policy. Following up with the riots that both Cattle (2008) and Robinson (2005) have explored, the London bombings (2005) is another example of the need for community cohesion (also described by Mayo 2009). The relevance for consideration of a mixed society and active social action is transparent if one considers globalisation (Mayo 2009; 2005), in addition to the culturally, ethnically, as well religiously diverse societies of the contemporary world in the 21st century.

Faith and community cohesion

In light of achieving community cohesion, new resources were sought by the government. Since the 2001 riots, the government sought to engage faith communities in bridging the gaps between ‘parallel lives’. Cattle (2008) describes as such the experiences of white people and Asians in Bradford and Burnley. These experiences are distant relationships among various sub-communities within the community. On that note, Dinham (2011) remarks that faith is seen as community cohesion in the arena of politics. Faiths can be repositories of values and beliefs that can work collaboratively toward a cohesive community (Dinham 2009).

Community cohesion as an output of religious and non-religious beliefs comes from an inter-relationship between the two, as they neighbour in the same community. Both, religious and the secular, contribute to the social functioning of the community as they go along ‘parallel lives’. One of the many ways to understand the idea of community is shared ideas, values and history (Robinson 2005; Cattle 2008; Dinham 2011). To a large extent, religious beliefs are part of the shared ideas or attitudes of a community. The same happens with secular ideas, represented by people with shared sets of values and historical beliefs. The development of community cohesion and the ‘parallel lives’ discussed above are experienced in the community as a whole, but not only there. What is experienced at death and dying settings reflects similar circumstances. A death and dying setting is the microcosm of a diverse and multifaceted environment (also see Walter 2011). Part of its diversity is emphasised in the now recognised religiously plural palliative patients (*ibid.*). An ambitious assumption, yet visible, is that given the connections made above, within death and dying settings the religious and the secular may coincide. However, religious change over the last sixty years has led to a poor understanding of its role by professionals in the field (Pentaris 2014). Further, it has left us, as noted in previous sections, with a secular vocabulary when talking about religion (also see Dinham 2015).

The Home Office (2007) made a new statement of purpose, which states the intention of working together to protect the public. Faith is one of many ‘contested ideas in policies’ (Dinham 2009, p.91) that contributes to the evolvment and maintenance of community cohesion. It is worth adding here that *faith* may refer to religious as much as non-religious groups and communities. Nonetheless, for social policies to effectively respond to the shifting needs of the population, the unpacking of such contested ideas is necessary. Essential is also the consideration of appropriate training and assessment of HCPs with regards to the active death and health policies.

Drawing from Mayo et al’s. work (2009), ‘If government policies to promote community engagement fail to take account’ of *parallel lives* of faith and secularism, in terms of end of life care, there is a significant risk of undermining key themes of the principles of professional practice in the health sector (Gunaratnam & Oliviere 2009).

Faiths and community development

Religious and non-religious matters have always remained present through faith-based social action (Dinham 2007) while it is the affirmation of its presence that brings it back in public space. From the shift of privatising religion (Casanova 1994; Davie 1994) we are now experiencing engagement of religious organisations with politics and social action from faith-based communities.

The make-up of religious plurality is a complex matter within a political context. The latter informs and commonly complicates faith in the public sphere (Dinham et al. 2009; Dinham 2009). Faith enhances community development. However, it requires community engagement to attain such goals.

One understanding of faith and community development is that it seeks to empower individuals and communities to engage but can do so only within the limited terms of

what is offered in social policy. In terms of faiths this translates into the ‘repositories’ discourse around which government wishes to see change (Dinham et al. 2009, p.81).

Faith-based social action is evidenced over the decades with lots of community work and organisational change (Green 2011). Community development and faith have gone hand in hand in the welfare state (Backstrom & Davie 2010). This is paramount to understanding the process in which religion and belief were given public visibility. Also toward gaining insight in regard to how religion and belief became active contributors to public life, despite the risk of causing frustration due to lack of religious literacy (Dinham & Francis 2015).

Concluding note

It seems that most of the CDPs failed to deliver their prominent goal, despite the good intentions. The Church had all along been doing community work (Dinham 2005), and this is where we can see what has been missing from policy-making. After Thatcher’s first General Election win by 1979, the welfare state was considered the problem and not the solution. That is when religion started gaining ‘accidental’ visibility in the public sphere again (Dinham 2015, p. 106). Despite the recognition of its importance, all the changes that have proceeded since the 1940s indeed left very few people with a fair knowledge, language, and understanding of religion and belief, in order to integrate this into policy and practice. The latter has led to religious illiteracy (ibid.). In other words, religion and belief never went away (Dinham 2009; Beckford 2010; Davie 2015). They rather privatised (Casanova 1994), and then later entered the space of deprivatisation (also see Beckford 2010), and gained public experience again.

This reveals a gap between pervasive religious identity and a social policy landscape, which seeks to get things out of faith groups without understanding, without the skills to engage, or being able to talk about them well in the context of hospice and EOL care. In most cases, the narratives of lost religious literacy, and change in the religious landscape, both enrich the discussion about how health care and hospice care precisely, have addressed religious plurality.

Looking at the history of religion in Britain (Green 2011), and also reflecting on its changes helps us understand how society became more secular and religious practices in public have declined in time (Woodhead & Catto 2012). Further, this review enhances our understanding of where the gaps between the secular society, individual religious consciousness and hospice care stand. With that knowledge, further actions and improved and better informed social policies can be planned.

Individuals facing DDB related experiences have the choice of a care pathway, which will allow them the space to declare their preferences toward the end of their lives. The latter empowers the service user to decide which, for lack of a better phrase, solutions might best serve his/her needs.

As a concluding note of this section, it is worth reiterating that religion and belief may be contested notions but still present in everyday life, maybe in different forms and shapes. This clashes with the secular professional practice, or lack of religious literacy by policy-makers and practitioners. The gap identified between the two is visible in the *Spiritual Care at the EOL* report by the Department of Health in 2009, explored in the previous chapter. The report surfaces the realisation that individuals still have religious needs that, to that extent, will have to be addressed and integrated into future policies and practices (Pentaris 2015a). Nevertheless, the skills and abilities of policy-makers and professionals in doing so have not yet been assessed in those terms. This leads us to look at the implications of religious plurality in professional practice and hospice care in particular.

Implications of religious plurality

Woodhead and Catto (2012, p.86) suggest that ‘when religions move, it is not merely a case of transporting a fixed body of beliefs and practices unchanged from a place of origin to a new location’. This plurality increased over the decades and caused irritation and conflict within the

community (Wohlrab-Sahr 2003). ‘The more this happens, the more important is the question of how we look at diversity, how we evaluate it and deal with it’ (Portmann & Plüss 2011, p.180-181). The emergence of multiple religions in the Nation caused an intense situation of acculturation of religion and belief. The government, however, did not account at the time the implications that such a religious movement would have:

Community is a fundamental dimension of spirituality and religion, not only as a beneficial factor for the individual engaging the world, but also while offering an alternative perspective or rather a different ‘focus’ on ways of engaging life. Groups of people sharing common values, sharing interest in particular spiritualities or sharing different worldviews and acting together toward a common goal, truly impacts their members (Champagne 2009, p.1).

According to Weller (2007), the core focus of social policy, upon the immigration waves and plural identities, was race and ethnicity, but not religion. More and more faith groups were included in the society (ibid.), and engagement in social action was cherished (Dinham 2012). However, such religious diversity brought up matters of adjustment in sectors such as health and social care, political, and so on (things that were not necessarily explored in the BR as it was thought through in the post-war period – also see Timmins 1995).

The End of Life Care Strategy 2008 is a good example to show how the Government identified the need for addressing the unique experiences of DDB in relation to individual identities and how those were taken into a considerate plan of social policy. This strategy suggests that individuals adapt their attitudes toward death, the process of dying and bereavement adjustments. These attitudes may be driven by multiple different factors; religion, culture, ethnicity, past experiences, and many more. The index for Personal Preferences recognises the above and integrates new dimensions in EOL care.

The Equality Act 2010 incorporated religion and belief as valuable factors of social justice and equality in society. The Commission is now working on multiple projects, which relate to

religious and spiritual beliefs intersected with various aspects of life. A very few good examples of such projects may be involved with the Muslim Women Power List. The List inaugurated in 2009 and celebrated the growing number of Muslim employed women in the UK at the time; it exceeded 100,000. Another example is the New Guidance on Religion or Belief, which was released in February, 2013 by the European Court of Human Rights, to be followed by the Human Rights Commissions including EHRC. The guidance document is based on four case studies from a Christian background, but its applicability goes across all religions and faiths.

Religious plurality has caused not only conflict and irritation within the community but also affected social cohesion (Cantle 2008) and had an impact on everyday practice (Weller 2007). Within the same context, Britain learned to cooperate with the dominant religion – Christianity – and Christian faith influenced social cohesion in numerous ways (Prochaska 2006; Green 2011).

The effectiveness of service delivery in hospice care, among others, comes in an inclusive set of beliefs, values and past experiences approach. HCPs who practice in death and dying settings aim to undertake sensitive and competent practices (Pentaris 2011; Sue & Sue 2008). Additionally, the relation to DDB issues requires religious-sensitive practice as well. Where the challenges come in it with the conflict of a secular society that addresses religious/non-religious matters as declining or private, and religious or non-religious individual consciousness. The recognition of religious plurality and awareness of personal identities has had broad implications (Woodhead & Catto 2012) and reflects the need to re-assess professional practice and its course within the experiences of DDB. Religious literacy of HCPs at death and dying settings does not suggest a withdrawal of secular identities if supported. On the contrary, it implies an increase in the awareness of religious and non-religious individual

aspects on DDB, as well as being appropriate to the challenges and shifting needs and approaches in EOL care.

Restructure, reform and cohesion: rethinking religion and belief in care

Despite the lack of visibility of religion in the public sphere throughout the decades and until the 1980s, matters of religion and belief were emphasised once again and considered in society (Dinham 2009). Since the mid-1990s, theorists and researchers have started to focus on the reality of religion and faith affairs in Britain of the 21st century. Professor Adam Dinham has extensively dedicated work related to faith associated with the public space and has argued in principle with regard to secularism. He concludes that faith has been part of the public sphere for a long time, but highlights that this is the time when people start observing this reality, and social policy is introducing faith-based implementations.

British society has developed in an environment where secular-minded ideas and beliefs have dominated. The trend has now changed. Religion is back on the table as a relevant subject, and it cannot be avoided (Dinham 2009). As long as individual consciousness remains religious (Beyer 2011) and personal beliefs overlap with the values of faith communities and religions, the levels of social life need to address the needs that relate to it.

Due to public religious consciousness during the last decade in Britain, reform of several services need be considered, among other public affairs. Healthcare reflects a significant part of society. In contemporary Britain, the healthcare sector is one of the largest areas of social policy that enables and embraces equality in service delivery (also reflected in Timmins 1995).

This chapter concluded that religious matters are present in contemporary Britain. The biggest challenge that derives from all refers to what I have already explored earlier in the chapter; the increase or development of religious literacy among HCPs, who are qualified for a secular-minded environment instead.

Observing the factor of religion and belief in the individual consciousness of dying and bereaved systems is an essential affair. However, the observation in itself will not increase the quality of services of the patients, for example at a hospital, but further explanations will need to be made. That said, HCPs who work in hospice care might show empathy to religious identities, or that service users may interpret their imminent death through religious texts and practices, but, at the same time, they might show lack of knowledge or skills as to how to integrate these aspects of the patient into care provision.

A most effective way of undertaking this challenge is to, first, measure and carefully examine the levels of religious literacy of HCPs who practice in hospices. This project commences its course with a cautious hypothesis that there is a predominance of religious illiteracy amongst HCPs who work with dying and/or bereaved people. It puts this hypothesis in the contexts of secularisation and religious plurality in Britain while it employs religious literacy in doing so. Part of the expected outcomes may as well answer the questions raised in practice (Jordan 2000). These may include the following: how can already developed skills of HCPs respond to the needs of religious or non-religious individuals and/or families that face DDB related challenges in their lives.

Chapter 3

Methodology

Research is not independent of its audience. At large, the researcher is expected to deliver a project that is reliable and valid, and in doing so his/her project will grow in viability and generalisability. In order to achieve this, the researcher ought first to justify the research design to their audience. This involves more than merely depicting how the data is collected and analysed. More importantly it includes the demonstration of understanding knowledge and how that is generated.

Hathaway (1995) argues that researchers often choose their methods at relative ease. The primary concern is to collect intended information, while commonly not much thought is given to underlying causations of the choices made. Similarly, Crotty (1998) suggests that ‘how the methodologies and methods relate to more theoretical elements [in research] is often left unclear’ (p.1). That said, this is not a chapter that solely sets out methods and methodologies. This would have been a misuse of this space on my part, and I am saying this drawing from Morris (2006), and Rooke et al. (1997). Both scholars contend the mechanical representation of methods and support a holistic demonstration of the researcher’s knowledge of epistemologies and methodologies. This chapter deals primarily with addressing three questions in relation to my position as a researcher. What choices do I have in undertaking this research project? Why is one choice the most appropriate when approaching my research question? How am I to do this? A better understanding of advantages and disadvantages of the methods I have used, will add legitimacy to my findings, and aid in identifying the limitations of the study.

In this chapter, I explore the methodologies and methods of this study. I do this via the lens of Crotty’s (1998) process of social research; ‘there are epistemologies, theoretical perspectives

and methodologies. If we add in methods, we have four elements that inform one another' (ibid., pp.3-4). In detail, the chapter begins with the developed research question and a rationale for the choice of hospices as the context in which the study takes place. After that, it moves to set out how ontology, epistemology, methodology, and method have been considered, and summarizes practical and ethical considerations, in addition to limitations of the study at the end.

Research question

When I started developing my research question I came across certain challenges. Most of them were concerned with ethics and proper language, but these are not to be addressed here, rather later, in my reflections on the project. What I want to set out here, as the beginning of this chapter, is my research question as it was finalised before I designed my research around it.

First and foremost, I want to accentuate what scholars in research have argued about; that the quality of the research design is dependent upon the quality of the research question.

Although it sounds like a simple thing to do, articulating a research question can be a challenge. Some scholars contend that research studies are only as good as the research question behind them, which can put a great deal of pressure on you [as a researcher] (Blakeslee & Fleischer 2009, p.14).

Designing a research project involves some obstacles. Along similar lines, Bryman (2004) suggests that a clear and straightforward research question will help the researcher overcome many of those obstacles. If the question is unfocused, then the design of the study lacks focus, as well, and to a further extent the results will be affected by it.

My research question is the product of a series of draft questions, all considered thoroughly prior to advancing to next steps of research design. The research question is as follows:

“What are the religious literacy challenges of health care professionals in EOL care?”

Many questions have been answered in research about DDB (Fonseca & Testoni 2011-2012), and extended understandings have been provided regarding the various meanings we give death and dying as human beings. The current study seeks clarity from a research evidence reference that can become empirical knowledge in both death and religious studies, and their intersection.

Despite the assumptions of secularity, religion in a great many forms persists across the world, including in Britain and Europe. Thus, it is paramount that professionals acquire appropriate skills and knowledge in order to respond to the shifting needs of service users. The institutionalisation and secularisation of death (Walter 1996; 1999) in modern societies of the western world, has overcome the importance of personal values and belief systems in one's attempt to make sense of one's life experiences.

The research question of this study aims to examine the religious literacy challenges that HCPs face when practicing in death and dying settings, notably hospices. Lack of research and a dearth of information on the subject, raises several problems and exposes gaps in service delivery when working with the dying and/or the bereaved. Therefore, the research question posed has informed the literature review of the study by stressing the social and religious history of Britain, which establishes the role of religion both from a religious and a secular standpoint.

The nature of the question posed provides a clear guidance on the research design and methodology that are employed. It is important to examine in-depth whether and how HCPs can and are taking religion and belief into consideration in their professional practice with DDB related issues. Qualitative methods seem the most focused strategy to the intended outcomes of the research design of this project. The research question reflects the choice of epistemological and ontological orientations in forming the research project. The induction of the collected data almost feels necessary in terms of conceptualising knowledge.

In social research, the questions that are laid almost always guide imperative decisions that need to be made by the researcher(s) further down the process (Silverman 2011). Briefly we can say that the research design of the current project is mainly a product of the nature of the research question that I am posing. In other words, the question reflects on the methods of collecting data, analysing data, interpreting them, writing them up and reporting on findings.

Ultimately, the current project seeks to examine evidence associated with religious literacy in hospice organisations and the challenges related to that. The nature of the project may have given the researcher a wide variety of directions to where the data could take him. However, it is important to maintain a clearly framed research question. Therefore, the researcher will not go off different orientations than the ones intended.

Rationale for undertaking this study in a hospice

Having presented the research question, and right before introducing the research design in length, it is important to justify the choice of a hospice for this study, and specify the context in which religious literacy challenges and controversies are examined.

Chapter 1 extensively introduces hospice care while it highlights the core values and principles it has espoused since its development (Clark 1999; Saunders 1958). It was made clear that the hospice ideology stems from religious beliefs (also see Clark 1999; Saunders 1990) while the caring of the dying has always been part of the work of the Church. Not surprisingly hospices developed as organisations highly influenced by religion and faith. They have also developed the principle of spiritual care (Saunders 1958) as a significant component of the care of the dying. The delivery of spiritual care progressed over the decades and into the 21st century professionals in hospices were assigned with the responsibility to provide, if not direct spiritual care, at least appropriate space for the service users to express their own beliefs and share their preferences toward the end of their lives (Forman et al. 2003).

It can be assumed at this stage that religion and belief have always played an important role in hospice care and the care of the dying. Drawing from Clark's (2002) claim that hospices are aiming to inform hospitals in how to deliver spiritual care, undertaking this research in a hospice setting and collecting data from hospice staff is logical; if religious literacy in DDB care is not found here, it is unlikely to be found elsewhere.

Ontologies and Epistemologies

Crotty's (1998) schema of social research embodies both ontology and epistemology. He is concerned with the challenge of distinguishing between the two.

Ontology is the study of being. It is concerned with 'what is', with the nature of existence, with the structure of reality as such. Were we to introduce it into our framework, it would sit alongside epistemology informing the theoretical perspective, for each theoretical perspective embodies a certain way of understanding what is (ontology) as well as a certain way of understanding what it means to know (epistemology) (Crotty 1998, p.10).

Ontological and epistemological issues 'emerge together' (ibid., p.10). This makes difficult to tell them apart. Ontological considerations are important in indicating how social entities are viewed and to understand those social entities alongside their interactions within the social world. Integral to this is epistemology. Maynard (1994, p.10, cited in Crotty 1998, p.8) highlights its relevance in that 'epistemology is concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate'.

Crotty's (1998) reference to Heidegger's and Merleau-Ponty's inferences of a world that exists outside of the existence of human beings makes for an example that illustrates the troubles in keeping ontology and epistemology apart. Following Crotty's work, realism is often taken for objectivism. There is a strong argument to support the opposite. Realism is an 'ontological

notion asserting that realities exist outside the mind' while Objectivism is 'an epistemological notion asserting that meaning exists in objects independently of any consciousness' (Crotty 1998, p.10). Following the concept of realism, the world would still be there if human beings were not (Macquarrie 1973).

Having said that, and via the lens of social ontology, religion and belief can be viewed as repositories of shared values and customs with which people find structure and meaning. The ontological notion of realism better suits the research question of this project, especially when referring to identities that are expressed as ontologies outside of the individual.

Epistemology: Constructionism (constructivism)

Having discussed the overlap area of ontologies and epistemologies, and having pointed the ontological perspective employed here, it is appropriate to link this choice with the epistemological perspective of this project. Realism accepts a world independent of people's consciousness. Nonetheless, and according to Guba and Lincoln (1994), meaning does not exist independent of the mind and consciousness (also see, Crotty 1998). That said, 'realism in ontology and constructionism in epistemology turn out to be quite compatible' (ibid., p.11). This harmonious relationship between the two also evidences the choice of the epistemological perspective of constructionism.

According to Bryman (2012), it is common that social research is designed based on either objectivism or constructionism. Crotty (1998) includes subjectivism, and all the variants of the three, under the category of epistemologies. The former, in Bryman's argument, suggests that social phenomena occur and exist beyond external influences. Constructionism (often mistaken for constructivism, Crotty 1998), on the other hand, supports that social phenomena 'can and should be considered social constructions built up from the perceptions and actions of social actors' (Bryman 2004, p.16).

Crotty (1998) suggests that constructionism claims that all meanings made by individuals are constructed as they are preoccupied with their environment:

It is the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context (p.42).

Constructionism suggests that we construct meaning. This is a position that suggests that social phenomena, and phenomena that are in general subjects for research, are living situations that continually result from the social relationships and interactions in society. Furthermore, constructionism views such phenomena as the attitudes toward DDB and the interpretation of those attitudes by HCPs, as being in a constant state of revision (see Bryman 2012; Burr 1995).

Comparing constructionism to subjectivism on the other hand, 'it is tempting to say that in constructionism meaning is constructed out of something (the object), whereas in subjectivism meaning is created out of nothing' (Crotty 1998, p.9). On the notions of socially constructed behaviours, attitudes, practices and policies, constructionism seemed the most appropriate of epistemologies to employ for this project.

Same as culture (Burr 1995; Feifel 1959), religion and belief are points of reference as to how society is constructed, and are constantly, 'in the process of being formed' (Bryman 2004, p.18; Gray 2009). As Burr (1995) suggests, it is cultural specificity that contributes to constructionism in general and the social construction of reality in particular.

Social reality is a constantly changing entity. It is defined by the ontological considerations discussed earlier, and various inferences can be drawn from social research, according to a research strategy. Related to epistemological considerations, the research strategy is shaped by the nature of social reality and its character, as viewed by the researcher (Silverman 2011).

It is important to link ontology and epistemology together more comprehensively: realism and constructionism. To the contrary of Giddens's (1976) position, that the natural and social world differ in that the former does not comprise meanings, I follow Crotty's work. Crotty (1998) suggests that if reality is socially constructed, that does not mean that it is not real as well. The world may as well be both, 'realist and relativist' (ibid., p.63). Both realism and constructionism confine reality in the same way, as perceived. Also, reality may be relativist due to the various and often contrasting ways that it is viewed.

Prior to advancing to the next element of Crotty's model, it is important to note that both perspectives, realism and constructionism, have complemented this project in the following ways. The research design has been based on the assumption that service users in EOL care are social constructions, and similarly that they have constructed meaning of their world and their experiences. Nonetheless, this does not make their reality any less "real." As discussed in the second chapter, it is this challenge that needs tackling, and not merely the acceptance of religion and belief as social identities. In doing so, an appropriate theoretical perspective is required to inform methodology and the methods.

Theoretical perspective: Interpretivism and hermeneutics

Interpretivism is a term that usually denotes an alternative to the positivist orthodoxy that has held sway for decades. It is predicated upon the view that a strategy is required that respects the differences between people and the objects of the natural sciences and therefore requires the social scientist to grasp the subjective meaning of social action (Bryman 2004, p.13).

As mentioned in previous sections, the research process takes its form while it forms what is acceptable as knowledge within it. A theoretical perspective is important as it pre-organizes the research outcomes. I am exploring the theoretical perspective of interpretivism here, essentially as a philosophical stance that will inform the chosen methodology.

According to Gray (2009), interpretivism contrasts with positivism; i.e. what natural sciences reflect. In opposition to Gray's view is that of Schwandt's (1994); interpretivism is the approach to interpreting the social world in a physical science way. These two perspectives – interpretivism and positivism – are not compatible in their way of perceiving reality. Positivism is concerned with objectified views of the world, interpreted in natural science terms. On the other hand, the interpretive approach 'looks for culturally derived and historically situated interpretations of the social-life world' (Crotty 1998, p.67). It is highly linked to the thoughts of Max Weber, who suggested that humanities and social sciences are concerned with the *Verstehen* (Understanding) of the world. This is a rather phenomenological perspective. Weber describes sociology as 'the science which attempts the interpretive understanding of social action in order to arrive at a causal explanation of its course and effects' (cited in Bryman 2004, p.13). It is based on these assumptions that phenomenology seeks to examine the person's lived experience.

Weber's definition of *Verstehen* and his approach, has had a significant impact on Schütz's positioning regarding phenomenology.

The world of nature as explored by natural scientists does not 'mean' anything to molecules, atoms and electrons. But the observational field of the social scientist – social reality – has a specific meaning and relevance structure for the beings living, acting, and thinking within it. By a series of common sense constructs they have pre-selected and pre-interpreted this world which they experience as the reality of their daily lives. It is these thought objects of theirs which determine their behaviour by motivating it. The thought objects constructed by the social scientist, in order to grasp this social reality, have to be founded upon the thought objects constructed by the common-sense thinking of men (and women), living their daily life within the social world (Schütz 1962, p.59).

Schütz focuses on two key concepts. First, that there is a distinctive difference between natural science and the objectives of social science, and second, that an epistemology will be the

perfect tool to reflect on that difference and identify the meaningful point of social and human action in the social world. The second concept refers to the *obligation* of the social scientist to focus on the first. It is this observation that enhances the feelings of commitment to interpreting and understanding the phenomenological meanings of social reality (Burr 1995; Bryman 2004). Bryman (2004) suggests that interpretivism is a clash 'between positivism and hermeneutics' (p.13). The latter term was drawn from theology to refer to the theory and method of the interpretation of human behaviour. The famous French philosopher Paul Ricoeur drew from phenomenology and hermeneutics in order to depict the way people perceive their world. In this complexity of concepts, Ricoeur defines hermeneutics as the act of interpreting and understanding the world.

Ricoeur's famous phrase 'the symbol gives rise to thought' expresses the basic premise of hermeneutics: that the symbols of myth, religion, art and ideology all carry messages which may be uncovered by philosophical interpretation. Hermeneutics is defined accordingly as a method for deciphering indirect meaning, a reflective practice of unmasking hidden meanings beneath apparent ones (Kearney 1991, p.277).

Positivism for the social sciences, as opposed to interpretivism, seeks to explain human behaviour through observation and report (Robson 2002; Silverman 2011). For example, market research is looking to explain why people act the way they do, based on causalities; how behaviour A initiated the behaviour B.

Interpretivism is somewhere in the middle. With this perspective, the objectives become less tangible, nonetheless of critical significance. This study not only seeks to explain the relationships between secularisation, DDB, religious plurality and professional practice, its core scope is to provide a hands-on interpretation of the explanations made with regard to these relationships, and, to that extent, have a full understanding of the behaviours of professional practice in a secular context for a religiously plural service user population.

The theoretical perspective of interpretivism will assist the process of understanding interpretations of HCPs. With that knowledge in mind, a guide for evidence-based planning in professional practice can be developed, with the aim to enhance its efficiency.

Methodology

Research over the decades has surfaced an intense argument between methodological approaches. The main one remains the distinction between quantitative and qualitative methodologies. Despite the legitimacy of the arguments, both hold strong and justified qualities on different occasions. There is little evidence that shadows the effect of each methodology on research outcomes (Denzin & Lincoln 2011; Robson 2002). However, research on both approaches (Silverman 2011; Bryman 2012; Berg 2009) shows evidence that supports the importance of the distinctive characteristics of both. Simply put, quantitative research quantifies the data, whereas qualitative approaches seek to explain the data and make sense of it.

Social research focuses primarily on qualitative methods so as to interpret the social reality of human beings and social action. Moreover, sensitive research, which refers to the delicate content of the study, methods, consequences, the situation, and all the potential harms involved in it, suggests that qualitative methodologies may be preferable in the process of understanding threats and harms prior to the outcomes (Dickson-Swift, James & Liamputtong 2008). With that in mind, it is natural to use this methodology in the current project with the epistemological and ontological orientations that were discussed earlier. Interpretivism will elucidate the distinctive data that will explain social reality within its context and interrelations (Crotty 1998; Silverman 2011), and constructionism focuses on the interpretations of the social constructions from human beings' points of view (Burr 2015; Robson 2002; Bryman 2012).

This project follows a qualitative approach while it also integrates different methods. Qualitative research has mainly been introduced as the approach that emphasises in words as opposed to numbers, in the process of collecting, analysing and interpreting the data. As Bryman (2004) says, however, ‘there is...considerably more to the quantitative/qualitative distinction than this contrast’ (p.20). The present project does not reflect the contradictions made by writers concerning the opposing ideas toward the positivist epistemologies of quantitative approaches. However, it highlights the importance of interpretivism for the purposes of the study and its outcomes.

Rationale for qualitative methodology

Since the 1970s the qualitative research methodology has thrived (Bryman & Burgess 1999). Its distinct character is yet to be established though (Bryman 2004). Often, writers suggest that distinguishing the nature of a qualitative research strategy is not straightforward (Gubrium & Holstein 1997; Blaikie 2010). Consequently, it becomes a critical part of the methodology process to rationalise the selection of this strategy.

According to Gubrium and Holstein (1997) qualitative methodology has four traditions; naturalism, ethnomethodology, emotionalism, and postmodernism. Naturalism suggests observations that provide an understanding of the social reality in its natural context and interaction. Ethnomethodology has a naturalistic orientation as well, as it aims to create concepts of social order through real-time interactions. Emotionalism is a tradition that seeks to surface the *inner reality* of human beings, associated with social reality. The latter connotes an objective characteristic as well. The last tradition, postmodernism, reflects the ways in which social reality is being constructed prior to gaining understandings of it.

Based on these four traditions derives the rationale for having selected a qualitative methodology for the current project. The proposed methodology had put the cornerstones for

an in-depth explanation and meaning of real-time social reality in relation to religious and/or non-religious matters alongside professional practice in hospices.

The current study had fallen under a qualitative research design, a claim that sits outside of what Edson (1986) asserted: ‘there is no qualitative method per se, only methods to gather information with which we construct our qualitative understanding’ (p.13). Merriam (1998) defines qualitative research as ‘an umbrella concept covering several forms of inquiry that help us understand and explain the meaning of social phenomena with a little disruption of the natural setting as possible’ (p.5). Religious literacy, described and explored by Dinham and Francis (2015), in relation to EOL care can only be captured from a constructionist point of view. A qualitative analysis is required to depict the meaning-making process and carry out reflective research (Silverman 2011; Berg 2009; also see Woodthorpe 2009). As the research methods that had been employed are explained later in the chapter, more links will be made between the choice of methodology and the current study.

Case study

Blaikie (2010) argues that *case studies* ‘have been regarded in a variety of ways’ (p.186). Those include case study as a research design and methodology, as a method of data analysis, and a method for data collection. In this project, case study is perceived as part of its methodology and overall design. Drawing from sociology of religion and religious literacy, I have set out to explore the implications in professional practice. To narrow it down even more, I have chosen to focus on a particular setting of institutional care: hospices. This decision was based on the critical analysis provided in chapter 1; namely hospice care having its roots in religion, notably Christianity, and religious motives being essential for professionals at least until the beginning of the 2000s (also see Clark 2002). In order to support the choice of case study in the research

design, the remainder of this subsection will examine the nature and advantages of the methodology.

Case study has various definitions, all of them aiming toward the same thing; elaborate and in-depth understanding of knowledge (Yin 2013). Bogdan and Biklen (2003, p.54) suggest that case study is ‘a detailed examination of one setting, or a single object, a single repository of documents, or one particular event.’ Berg (2009) explored a number of various definitions before concluding that:

...case study is an approach capable of examining simple or complex phenomenon, with units of analysis varying from single individuals to large corporations and businesses; it entails using a variety of lines of action in its data-gathering segments and can meaningfully make use of and contribute to the application of theory (ibid., pp.317-318).

Given the definitions aforementioned, the current study is a case study of hospice care that set out to explore religious literacy and test its hypotheses. Drawing from Blaikie’s (2010) and Berg’s (2009) claims, the methodology of case study provides the opportunity for a systematic gathering of information about a specific organisation or setting, with the use of multiple methods, which results into extensive and comprehensive understanding of the particular situation (also see Bogdan & Biklen 2003). It would, however, be unreasonable not to look at the criticism that case study methodology has received, to examine the possibility of raising limitations with this choice.

Case study methodology has been criticised as being weak and ineffective at times (Swanson & Holton 2005). However, most of the criticism is rooted in the perception of case study as a method for data collection. As a methodology ‘it has sometimes been considered less rigorous and less systematic than other forms of research’ (Berg 2009, p.317). Yin (2003), in particular, has identified the three main criticisms of this methodology; the risk for sloppy research with

biased findings (objectivity of the researcher), generalisability, and that case studies are time-consuming and generate large amounts of data that is hard to manage. Research scholars (Blaikie 2010; Bogdan & Biklen 1992), however, argue that case study as a methodology is benefiting the overall scope of the project; it allows the researcher to use multiple different methods to systematically construct understanding of a particular individual, or organisation, subject, or event. The main three criticisms can only function as informers when the researcher is examining the limitations of the study.

In order to examine religious literacy in hospice care, three different methods were employed and those are introduced in the following sections.

Methods

Triangulation: A multi-method approach

Originally conceptualized by Webb et al. (1966), *triangulation* was a term that suggested the use of more than one source of data and methods for collecting the data. It was essential to enhance the option of one method alone but reflect on multiple strategies. *Triangulation* has mainly focused on increasing ‘the confidence of the findings’ (Bryman 2004, p.275). ‘As such, triangulation was very much associated with a quantitative research strategy. However triangulation can also take place within a qualitative research strategy’ (ibid., p.275). For example, Zambrano and Barton (2011) report on their findings with professionals who work with the dying, by supporting the data with two methods: observations and interviews.

The current research project took a course of triangulation. Even though what Webb et al. (1966) meant by sources of data, was merely different participants, the term *triangulation* has an extended meaning for the purposes of this project. The sources of data will not be changing per se, nevertheless, as supported by the methodology so far social reality has a unique character that can only be understood in its context and via naturalism. The same source of data

becomes a different one when the contextual concepts change and the interactions of the participant with the environment and/or the researcher change as well.

Participant Observation

This project used participant observation as one of the methods. The researcher spent an extended amount of time in a hospice setting conducting participant observation. The researcher adopted the rota system of the staff and spent approximately eleven months in the field. This is recognised as a long-term participant observation fieldwork (Bernard 2013, p.315).

Participant observation is a method that involves fieldwork. However, ‘not all fieldwork is participant observation’ (ibid., p310). Interviewing participants while in the field would hardly account for participant observation, for example. Bernard (2013) further suggests that participant observation is not the same as ethnography. In his words, ‘ethnography is...the *process* of collecting descriptive data about a culture and...the *product* of all that work’ (ibid., p310). Participant observation goes beyond the *process* described by Bernard; it entails a mix of data collected that may not fit the purposes of ethnography.

Participant observation involves active participation in the context where the data is generated (Bernard 2013). Being in that position, the researcher has the option to collect any kind of data; e.g. narratives, photographs, or field notes. ‘It is about immersing yourself in a culture and learning to remove yourself every day from that immersion so that you can intellectualize what you have learnt and heard, put it into perspective, and write about it convincingly’ (ibid., pp.310-311). Nevertheless, different scholars of research have identified different roles that the researcher may play when using participant observation as a research method.

Marshall and Rossman (1999) explicitly identify the two different primary methods of research, *participation* and *observation*, yet recognise their close relation. *Participation* is

described in the same terms as participant observation has been noted by Bernard (2013) and Bryman (2004), while considerable attention is placed on the personal reflections of the researcher. It is an essential method in qualitative studies that allows the researcher to 'experience reality as participants do' (Marshall & Rossman 1999, p.106). Observation on the other hand, is described as the process that entails pure note-taking and recording of events, and artefacts, in the environment where the study is taking place. I am drawing from Bryman (2004) and Bernard (2013) in identifying the field notes generated through observation as part of participant observation. This is better described by further exploring the roles of the researcher with this method. I will be addressing the roles that the researcher in this project adopted, based on Bernard's (2013) identification of the fieldwork roles.

Three main roles have been identified when engaging with this type of fieldwork; complete participant, participant observer, and complete observer (ibid. 2013). The first role involves covert research, as the identity of the researcher is not revealed (Silverman 2011). The last one is described as direct observation, as the researcher follows participants around, making notes, with little interaction, if any at all. The researcher's role in this project was the second type: participant observer. The observer not only has the privilege to gain *first-line* knowledge that will answer the research question but also has the benefit of interacting with the human subjects of the observation. Also, in this role the researcher can either be an insider, in which case he/she 'observe and record some aspects of life around them (...they are observing participants); or they can be outsiders who participate in some aspects of life around them and record what they can (...they are participating observers)' (Bernard 2013, p.313).

During participant observation I participated in the hospice life as an *outsider*. I shared conversations with the staff members in the nurse stations; participated in team meetings and multidisciplinary team meetings; I walked around in the different wards with staff and also unescorted, but I did not actively engage in the delivery of hospice care. My role was primarily

understood as a researcher who shadows different staff members and records their interactions with other people, whether staff or patients, to gain in-depth understanding of how religion, belief, and spiritual identities have been integrated in professional practice. This process also involved gaining in-depth understanding of the context in which spiritual care is delivered. An example that materialises the nature of this role is Bernard and Killworth (1973). In their study of oceanographic research vessels, they were participating observers, but with no active engagement in the research process being carried out on board the vessels.

In this study, the researcher was openly identified with his role in the setting where the observations were taking place. Most critiques of overt observation support that an openly recognised identity of the researcher potentially deforms the data and therefore potentially the conclusions. This is mainly because human subject participants consciously make an effort to prove the best of their abilities while they are observed (Robson 2002). There are a few reasons why the identity of the researcher was open. To start with, a covert participant observation in a hospice setting should have the researcher register either as a patient or as an HCP. The former should eliminate the research project, as the abilities of the researcher to deliver the project would not be at their best performance due to sickness. The option for being employed in that hospice and conduct covert observations, breaches ethics and values of professionalism, as well as research ethics in auto-ethnography.

Interviewing

The second method employed to collect data was *interviewing*, or otherwise known as in-depth interviewing (Bryman 2004; Bernard 2013). As Jordan (2000) argues, this method shifts the interest toward the interviewee, a method that enriches the data and the intentions of the researcher (also see Robson 2002). Added to that, according to the values of interviewing by Bryman (2004) ‘going off at tangents is often encouraged’ (p.320). Qualitative research is

primarily focused on the interviewee's point of view, so allowing some *rambling* to take place during the interviews, commonly provides some insight into areas of interest for the interviewee, always related to the research subject.

Conducting a hospice study has a very sensitive character in itself. Regardless the sampling (discussed later) the areas of DDB are very “touchy” and emotional subjects. Using interviews also provides the flexibility to reschedule some questions (e.g. their order) or add some comments at the very time that the interview takes place. The only type of interviewing that should not see the above changes is structured interviewing (Bryman 2004). The method of interviewing gives the flexibility to the researcher to direct the conversation where it needs to go and collect rich data via detailed and additional answers. An additional plus of using interviews is that a participant can be interviewed more than one time, according to the needs of the research and the researcher (*ibid.*).

Semi-structured interviews

A semi-structured approach has been employed for this project. This interviewing method not only supports flexibility and detailed answers but also allows the researcher to frame the questions (or key concepts that will be discussed during the interview) based on the interviewee's responses in the moment. However, due to the flexibility of the latter technique, the credibility of the research outcomes might be affected (Robson 2002). With the semi-structured interviews, an interview guide (Appendix D) has been included for the researcher to have a list of questions or at least key themes to be covered during the interview, although not necessarily in strict order or exclusive to any other potential themes that may arise. In addition, the interviewees have more space to extend their answers and provide the most enriched data possible.

Participant observation combined with interviewing

In sequence, participant observation was employed prior to interviewing individuals from the same group of participants. The reasoning behind that is the enhancement of valid (internally) data but primarily for the researcher to affirm the information that has been observed. Moreover, participant observation lacks the potential for in-depth analysis of a subject area (Marshall & Rossman 1999), and this is where interviewing supports and supplements the data collection.

It is also important to tilt away from a structured choice of interviewing for the following reason. It would contravene the research method of participant observation. This would perhaps cause tension during data collection with two differently oriented methods, as well as during data analyses and interpretation.

Based on Bryman's (2004) suggestions, Tables 5 and 6 follow. The former depicts the advantages of participant observation in comparison to interviewing, whereas Table 6 depicts vice versa information.

Employing both methods, participant observation and interviews, for this project, the advantages were enhanced regarding ethical considerations, understandings, making sense of the data, as well as following thematic analysis at a later stage of the study.

Table 5: Advantages of participant observation in comparison to interviews

Advantages	
Focusing on the participants' point of view	Qualitative research is aiming to understand the social world as it is and as it happens. With participant observation, the researcher is spending prolonged time in a setting, which offers the ability to conceptualize the observations a lot more through observatory practice.
Familiarize with indigenous organizational cultures	The observer, in order to fully understand his/her observations, needs to familiarize with the concepts used in that setting, where observation takes place in. Religious literacy may be hard to conceptualize, and HCPs might have a particular slang language that connotes the intentions for becoming more literate, which can be gained through observation.
Observation of implicit features	As opposed to interviewing, participant observation allows the researcher to collect data based on non-verbal communication while professional practice is conducted.
Covert actions	Following up with implicit features in participant observation, covert actions are also significant data that can answer a research question. Such data might not be available via interviewing, as the interviewee is cognitively structuring his/her thoughts.
Mapping behaviours in context	With participant observation, a whole set of behaviours within the setting can be mapped.
Unravelling unexpected topics	Putting together an interview guide is by nature structured, as it is themed with the key issues expected to be found by the researcher. Participant observation, however, allows the researcher to understand better the areas that are key for research.
Naturalism	Participant observation is by nature more naturalistic in orientation.

Table 6: Advantages of interviewing in comparison to participant observation

Advantages	
Themes that are resilient to observation	In-depth interviewing can reveal subjects and themes that may not be able to be observed. Professionals, for example, may have personal wonders and worries that can only be shared in an interview.
Reconstruction process	With interviewing, participants have the opportunity to reconstruct their experiences and hence provide more detailed answers.
Ethics	There are some areas and issues that can only be known by the researcher if the participant is directly asked. It would raise several ethical considerations if covert techniques for collecting these data via observation were used, such as technological support.
Impact of observer's presence	Participant observation eliminates the data collected due to the effects of the researcher's participation. Therefore, interviews provides a more welcoming context for clearing out thoughts and explaining observations.
Less time-consuming	Participant observation is a longitudinal study per se, as the researcher will spend a prolonged amount of time at the setting. Whereas, interviews is scheduled and fulfilled in shorter periods of time.
External validity	Interviews can enhance the external validity of the study. On the contrary, participant observation will merely focus on the professional practice conducted in a particular setting.
Focus	Interviewing allows the process to be more focused, and, therefore, a lot more detailed.

Focus groups

Focus groups were held as the final method of the research design. This was in order to follow up with the findings of the research and support further the outcomes. During this group interview, a structured list of key themes (Table 7) developed from the participant observation and interviewing stages, were discussed. Two focus groups were carried out, and the participants were recruited from the list of participants that were interviewed. During the focus group method, the participants were asked to discuss the findings from the interviews and observations and reflect on the potential outcomes as a group.

Table 7: Key themes for focus group discussion

- **Role of religion and belief**
- **Religion and spirituality**
- **Religion/Belief and DDB**
- **Performative religion and belief in health care practice**

According to Bryman (2004), a focus group method is a form of group interview. Similarly, Berg (2009) identifies the focused character of group interviews, but further suggests that ‘focus group interviews explicitly use group interactions as part of the data-gathering method’ (p.158). Group interactions are one of the most distinctive characteristics and advantages of focus groups (Morgan 2002). It is important to consider how participants may reflect upon the information gathered during the interviews. This is in order to increase the success rate of applicability of the methodological approach (Silverman 2011; Blaikie 2010) and the deductive and inductive orientations of the study (Boyatzis 1998).

The use of the focus group method gives the participants the opportunity to add more information to their initial thoughts and values. The group discussion model of the method opens up the space for more comments and provides the members with a less intimidating atmosphere rather than the one-to-one interviews (Robson 2002; Berg 2009). With this method, the researcher also has the privilege to collect data based on interactive communication among participants' values, ideas and perspectives (Robson 2002). This method also gives the opportunity for the researcher to understand how the participants will collectively make sense of the subject of the study (also see Stewart & Shamdasani 2014). In other words, it provides the opportunity to collect a community group response that differs from individual interviews in that the dynamics differ and, therefore, the responses are shaped differently. This adds to the validity of the current study.

Criteria of research strategy and design

The criteria of reliability, validity and credibility are essential 'in establishing and assessing the quality of research for the quantitative researcher' (Bryman 2004, p.272). However, there have been many discussions about their importance associated with qualitative research as well (Silverman 2011). These criteria need to be taken into consideration, prior to applying the research strategy and design, so as to support their valid implication as guiding tools in the process of gaining knowledge and testing theories.

There have been numerous arguments whether the names of the criteria (e.g. validity, credibility) should remain the same regarding qualitative research. Bryman (2004) writes about alternative named criteria, such as credibility, transferability, dependability, and confirmability). Those names are meant to divert from implying measurement processes and numbers per se, which are mainly methods and tools of quantitative research.

For the purposes of the current project, the research strategy and its design; the names reliability, validity and credibility are used. Each criterion is supported in relation to qualitative research.

Dependability (reliability)

The criterion of reliability refers to the consistency of the research strategy and design (Robson 2002; Bryman 2004). It is fundamental that the elements of this study are such that can be repeated. In qualitative research, Guba and Lincoln (1994) suggest that the study should be trustworthy and be characterised by dependability. Their argument outlines an, 'auditing' process that can ensure dependability for the process.

From the very beginning of designing the research strategy to the delivery point and data analyses and interpretations, both the strategy and design were monitored, reported and assessed by the researcher and two external research associates. The main goal for external auditing during the process and at the end of it is dual. Initially, the theoretical inferences of the research were justified. Secondly, the suggested process increases the levels of reliability of the study, which means that the stability and repeatability of the study is enhanced.

Transferability (external validity)

External validity is a criterion that refers to the generalization of the outcomes of the research. This is largely a quantitatively oriented research criterion. However there have been discussions of its formation with qualitative research (Guba & Lincoln 1994; Bryman 2004). As qualitative research tends to study a small number of participants, it is hard to support the generalization values of the findings. This study employed the triangulation method so as to, among others things, increase transferability of the conclusions and outcomes. With a thick understanding of the research area, and a comprehensive reflection on the findings from the

participants' point of view, as well as the researcher's; the external validity of the study is enhanced, and the potential for steadiness of the research strategy and design is also increased.

Credibility (internal validity)

This criterion is a determinant factor for the applicability of the outcomes in the scientific world. It reflects the causal relationships within quantitative research strategies. According to Guba and Lincoln (1994), the credibility of the qualitative study stresses the importance of the evidence-based reality of the social world.

The establishment of the credibility of the findings entails both ensuring that research is carried out according to the canons of good practice and submitting research findings to the members of the social world who were studied for confirmation that the investigator has correctly understood that social world (Bryman 2004, p.275).

With the focus group method, the technique coined 'respondent validation' was practiced. This technique suggests that the participants are called back to reflect on the findings based on their interview answers. In addition, triangulation is acknowledged (Robson 2002; Bryman 2004; Silverman 2011) for it enhances credibility for the study's strategy and design.

Confirmability (objectivity)

Based on the fact that complete objectivity is impossible with social research by a qualitative strategy (also see Bernard 2013), confirmability suggests that the researcher is acting in good faith at all times, and never allows, to the best of his/her abilities, any actions that will amend the objectivity of the study (Bryman 2004).

Confirmability for the present study was ensured with the auditing process in place, as one of the objectives for the external research associates is to establish confirmability. Also, the researcher, myself, has completed training in 'maintaining objective outcomes in research'.

With the latter skills, the research design and planning has been affected as well, as to promote objective strategies, processes, findings and outcomes.

All the criteria above are interconnected, as one may enhance the potentials of the other (Silverman 2011). For example, when objectivity enhances the research design, transferability in the study will increase too, and when credibility increases, the dependability is positively affected as well. Social research is based on epistemologically grounded beliefs that suggest what acceptable knowledge is (Bryman 2004). The criteria above are setting the boundaries for illuminating the path to acceptable knowledge.

Sampling

The use of multiple methods also suggests different ways of sampling, however, interconnected. It is common that convenience and snowball sampling techniques are used with participant observation methods (ibid.). As for the current research design, multiple sampling methods have been employed, which were interrelated and interconnected.

The approach of theoretical sampling has been used for participant observation methods. According to Glaser and Strauss (1967), with this method, the research was collecting data whereby to induce theoretical inferences, informed by the preceding theory (religious literacy). With participant observation, individual professionals, the context in which they practiced, and the interactions between all were observed. Using theoretical sampling the researcher is able to reflect on the collected data, during the process, and discover categories that he/she will be able to focus later on with the other methods (Berg 2009; Bryman 2004). It would be ideal for theoretical saturation to be achieved with participant observation but that would also resemble a utopia, as the social world in its context is an ever-changing social reality, which can only keep providing the researcher with additional data and new information.

The sampling frame (N) and the sample (n)

In the UK, there are in total 220 hospices and palliative care inpatient units and 42 hospice inpatient units for children (Help the Hospices 2011). The same numbers in England remain high, approximately 120 hospices in total. According to NHS statistics about England, as of September 2014 there are 168 NHS hospitals, out of which, according to the Department of Health, approximately 143 provide some DDB related services while a small number focuses on EOL care.

With regard to the sampling frame (N) of HCPs in England, and according to the current statistics from the Health and Care Professions Council (HCPC), as of 1st February 2014 there are 396,031 professionals registered. It is, unfortunately, unclear as to what the figures are for professionals who work with the dying and the bereaved. However, also noted by Gunaratnam and Oliviere (2009), it is not easy to monitor the number of professionals in distinct areas, especially when that refers to hospitals, where several different conditions are treated in a ward.

Participant observation

Participant observation took place in one hospice in London, and across three different wards and one respite care unit. Eight (8) HCPs were included in this part of the study. Four (4) were nurses, two (2) doctors and two (2) more were physiotherapists. These three professions were mostly involved with the day-to-day care of the patients in all three wards of the hospice. The observation lasted for an extended period of eleven months – started in September 2013 until July 2014. Further, the researcher collected field notes from the above hospice. The two hospices involved with this study, beyond participant observation, shared specific characteristics that supported and enhanced the internal validity of the study. For the purposes of this section, the characteristics are listed in a most generic way to safeguard anonymity and confidentiality. In detail, both hospices:

- Find their developmental roots in religious beliefs and the Church,
- Currently provide palliative and hospice care to people of all faiths and none,
- Maintain their focus on improving quality of life till the end,
- Provide holistic care, and support both patients, and families and carers,
- Have a multi-faith chaplaincy and underscore spiritual care in their services,
- Provide services to in-patients, out-patients, and in the community,
- Promote education and research.

Having knowledge of these characteristics helps us identify how these two settings may vary from others. In other words, even though hospice ideology is universal and the principles of hospice care are applied across the NHS hospice trusts in the UK, hospices are diverse in their history and development, as well as their services. Having said that, both hospices in this study value spiritual care highly, and accommodate the provision of care to people of any or none faith. It is important to reiterate that both support education and research, which indicates that there is the tendency and willingness to innovate in the field and contribute to the overall development of the NHS. Finally, both hospices are located on urban grounds; the services are directed to a wide and diverse section of the population.

Interviewing

Based on the philosophy of purposive sampling, as described by Silverman (2011), participants for interviewing were recruited from the hospices described earlier. Only HCPs were included for interviews, as the study focuses on professionals who are registered with the Health & Care Professions Council (HCPC). On that note, HCPs, during participant observation, were notified

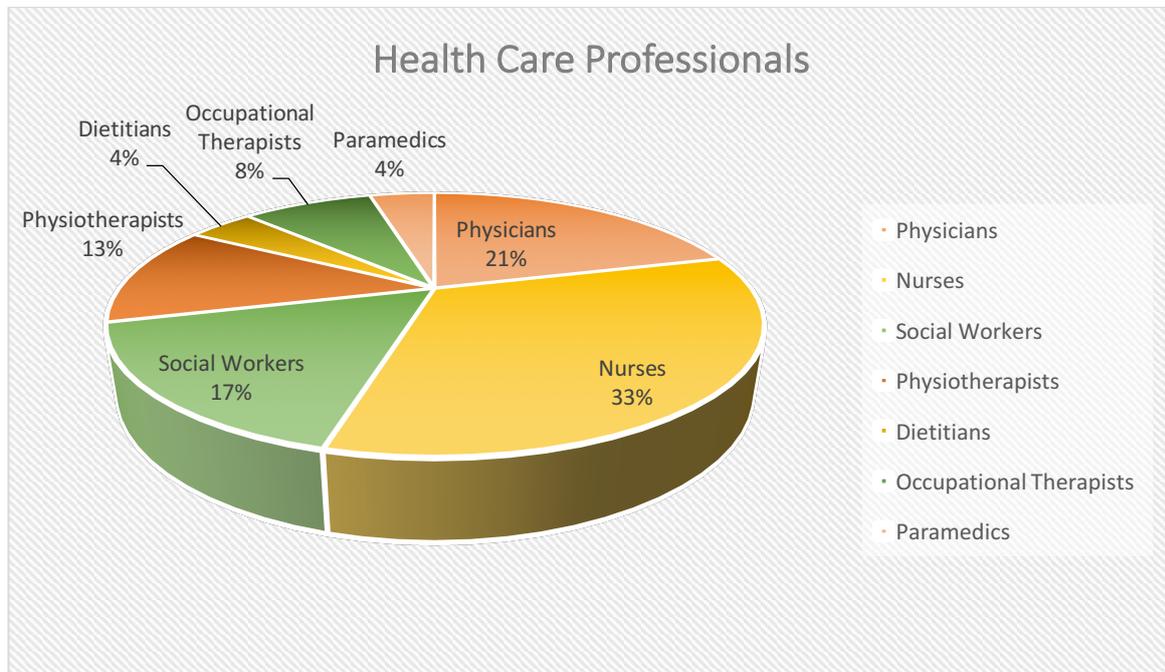
of the process and were given all the necessary information to decide whether they would like to also take part in the interviewing process.

In more detail, meetings were held with the research administrator of one setting and the spiritual care manager of the other. In those meetings, the post holders above had the opportunity to pose all the questions raised by the introduction of the research project. Although cover letter emails were sent to everyone in the hospice, presentations were also delivered in multi-disciplinary team (MDT) meetings, nurses' meetings, and doctors' meetings. Those presentations were used both to present the research that would be on-going for the next few months in the hospice, but also to recruit research participants. Ward managers introduced the cover letter to their teams and offered every employee the option to contact the researcher and clarify the nature of the study prior to making a decision to participate. HCPs interested to take part in the study contacted me and we had a 30-minute meeting. In that meeting, potential participants had the opportunity to ask any additional questions and affirmed full understanding of their participation. Moreover, during that meeting the researcher and the participant reviewed the consent form for participation, which upon a decision to engage with the study, the HCP signed off.

Twenty-four (24) HCPs were interviewed (Figure 1). Out of the whole, fourteen (14) have worked in hospice and palliative care within NHS in particular for over thirty years. Consequently, these professionals have been subject to further education in the recent years, as per complying with current health policies and NHS requirements for qualification. Six have been in the sector for over ten years, and four were newly-qualified HCPC professionals. Participants for the study worked in two different hospices in London, covering two different geographical areas. The latter is important as per investigating how religion and belief have

been integrated into practice and about the needs of the public, based on the composition of the community served by the organization.

Figure 1: Interviewees by Profession



Focus groups

For the focused group interviews, the individual interviewees had all been asked to participate. The purpose of the focus groups was, alongside theoretical reflections on the data, to reflect on the findings and use interactive communications among participants to support the outcomes of research.

Two (2) focus groups were carried out. After the interviews had been complete, eight (8) research participants were recruited to participate in the focus groups. Each group consisted of four participants excluding the researcher.

Figure 2: Composition of focus group 1

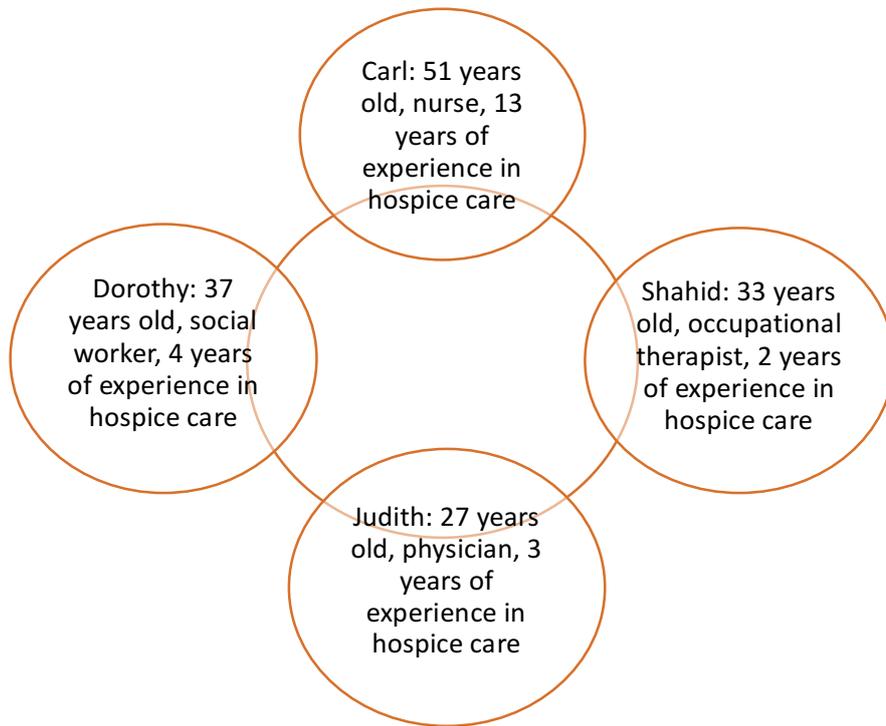
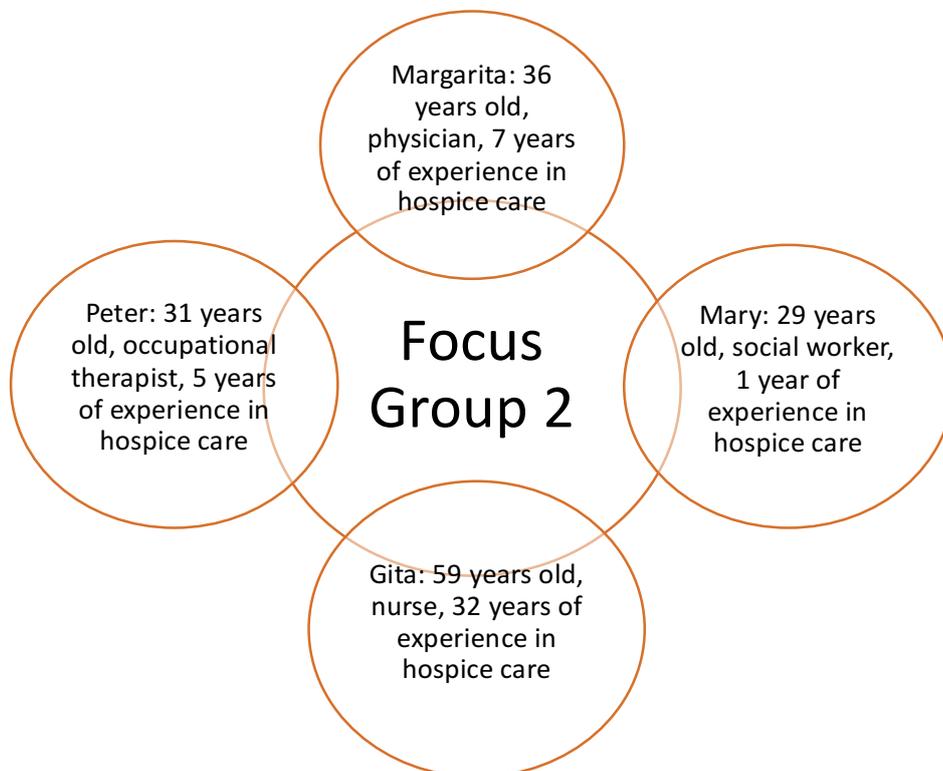


Figure 3: Composition of focus group 2



The diagrams above (Figure 2 & Figure 3; pseudonyms are used to maintain confidentiality) depict the composition of both focus groups. It is important to have knowledge of this, due to different dynamics based on different disciplines. It is worth noting that participants already knew each other before the focus groups were carried out, and therefore already-formed relationships might have impacted on the group dynamics.

Thematic Analysis

Thematic analysis is a process ‘for encoding qualitative information’ (Boyatzis 1998, p.4). According to Boyatzis (1998), this is a process of quantifying qualitative research data. It allows the researcher to interpret and translate thematic research into measurable values. This process aims to organize the data into themes. Patterns of practice or behaviour, observed in the social reality; these themes are classified into categories that can dictate generalizability. Categorisation and classification can be generated via three different ways: theory-driven, prior to research driven, and data-driven or raw information-driven (ibid.). I am only elaborating on data-driven thematic analysis here, as it is the one used for encoding the data of this study. The thematic analysis also allows the collection of information for a wider readership. It facilitates the ‘communication’ of the data ‘with a broad audience of other scholars or researchers’ (ibid., p.5).

Silverman (2011) and Boyatzis (1998) are both referring to the stages of using thematic analysis, even though the latter introduces the steps in order to enable the researcher to ‘develop the ability’ for using thematic analysis (p.11). These stages are four and are as follows: sensing themes in real life, being reliable during encoding, develop codes, and interpreting in the context of a theory.

Inductive/ Data-driven Coding

Data-driven coding is the process of collecting data first, identifying patterns systemically during data collection, classifying them, and inducing them into theoretical perspectives and themes. This overlaps with what has already been discussed in this chapter, regarding the inductive approach that suggests data-driven coding.

Boyatzis (1998, p.30) suggests that ‘data-driven codes are constructed inductively from the raw information. They appear with the words and syntax of the raw information’. He goes on saying that with data-driven coding ‘the result is a higher interrater reliability. Because a data-driven code is highly sensitive to the context of the raw information, one is more likely to obtain validity against criteria and construct variables’ (p.30). In summary, this process enhances the validity of the study, and especially organises transferable information to have a wider audience and implications.

Data coding

During participant observation mental, jotted and full field notes were generated and collected. According to Bryman (2004), *mental notes* are the most useful ones, as it is intimidating to take notes in front of service users and encounters between service users and professional practitioners. The *jotted notes*, which are also known as *scratch notes*, are brief and concise code notes, as to jog one’s memory. *Full field notes* are comprehensive and detailed notes based on the previous ones. Using the full field notes, particular coding is drawn in terms of specific behaviours, responses and their relation to professional practice and service delivery in death and dying settings; e.g. hospices. This coding further assisted with the interviewing method. Drawn by inferences from the observation data, interviews were pre-coded in those terms, but with the probability of re-coding based on new material that might have been collected. In more

detail, the interview guide is divided into three different sections, with questions that are focusing on the following areas:

- The meaning of religious and/or non-religious matters in professional practice with dying and/or bereaved people,
- Past experiences and gained knowledge,
- Professional values and beliefs in relation to being religious literate in the current context of professional practice,
- Suggestions for professional development,
- Identified areas for development of professional practice.

Shortly after data collection had commenced, the coding process started as well. Based on the data certain phenomena and/or ideas were observed and identified, which were then labelled; these were the concepts that were formed. After a concept had been comprehensively considered as a real-world phenomenon, it then became a category (in quantitative research this might have been understood as the operationalisation process). Each category has properties, which refer to particular characteristics of the category. The latter initiates the hypotheses, which are tested with the on-going data collection and coding processes (Bryman 2004).

Developing Codes in detail

In the process of data analysis, particular stages of code development were followed as well. Following Boyatzis' suggestions (1998), the first step was to locate a subsample and identify issues that arose in the raw information drawn from that subsample. The second stage included the differentiation of the subsamples by developing themes that could distinguish their characteristics. This phase follows some steps, including comparisons of themes among

different samples, and the determination of the reliability of the code. Finally, the last stage included validation of reliable codes onto the rest of the sample.

Prior to the last stage in the process of developing codes, descriptive elements of the suggested code had been included in the analysis (ibid.). Those are a name for the code, a description, indicators, an example, and information on any particular exclusion criteria. These elements were also used in examining the reliability of the codes.

Data analysis: the process of analytic induction

Data analysis in qualitative research differs from its counterpart, quantitative research. With the latter, data are analysed after the data collection is fully complete. On the contrary, with qualitative research, an ‘iterative’ process (Bryman 2004) is followed.

Qualitative research strategies commonly follow a framework where data are collected and in the meantime analysis takes place in a fashion that it also guides the following process (ibid.). In other words, data collection and data analysis in qualitative research is an interconnected relationship, and both happen at the same time, with the collection starting the process and analysis finishing it.

The present project followed one general strategy of data analysis; that is focusing on qualitative research. According to Bryman (2004, p.399), analytic induction is the ‘framework that is meant to guide the analysis of data’.

Analytic induction is a framework for data analysis, which has been commonly used in the 1940s and 1950s, but not so much these days (ibid.). This framework follows specific steps; it starts by defining the research question, then placing a hypothesis and examining the cases. When the data is collected, it is examined for whether it is deviant or negative to the hypothesis cases that have been spotted, and if the answer is yes the hypothesis is reformulated or its explanation is redefined. This means that with the analytic induction process ‘the researcher

seeks...the collection of data until no cases that are inconsistent with a hypothetical explanation' occur (ibid., p.400).

Computer – Assisted Qualitative Data Analysis (CAQDA): NVivo

NVivo was used for data collection, coding and analysis. NVivo is a Qualitative Data Analysis (QDA) computer software, which is produced by Qualitative Social Research (QSR) International. It operationalises qualitative data and supports the researcher in making concepts and codes out of the data that have been collected. Furthermore, this software provides space for collating responses together, to create groups and categories of the data, which are then hypothesized. The researcher has undertaken training on coding, analysing and reporting on data with this software, which alongside his previous knowledge, worked effectively to the best of the research outcomes. After all the data had been coded and collated, a final revision and review took place to reflect on all the categories of the operationalised structure of the research methods and coding scheme.

In overall, usage of the software can enhance the research process by allowing it to be completed faster and more efficiently. It is also shown (Mangabeira 1995) that CAQDA may provide developed explanations of the data. Concerning research criteria, as discussed earlier in this chapter, the use of CAQDA enhances transparency, and hence we conclude with more explicit and reflective outcomes. Also, this software has increased the possibilities for intersected analyses within the initial data analysis.

Pilot Study

A pilot study preceded the main study. This was designed for the following four reasons. To test the interview guide generated for the main study, to examine accuracy and reliability of the pre-research themed work, to allow the researcher to familiarize with the hospice settings chosen for the main study, and to enhance understanding of organisational foundations prior to

data collection. The outcomes of the pilot study informed appropriate amendments to the research process and interview guide. These worked effectively toward reliable and valid data collection and analysis in the main study (Silverman 2011).

The Process

Four HCPs were recruited equally from both hospices. A cover letter and an email went out to all professionals at the hospices and from the ones returned, the researcher had a meeting with and signed off consent prior to their participation. The pilot study focused on the interview guide and the way that the research interest of the current project was communicated to participants, in terms of clarity and significance.

The interview guide consisted of twelve questions covering areas of general inquiries, attitudes, knowledge and understanding around religion and belief. The interviews took place in a quiet and private room in the hospices. They lasted for forty to fifty minutes approximately, and interviewees had the chance to discuss further comments with the researcher by the end of the interview, all concerning the clarity of the research tool.

The interviews were transcribed verbatim. Through that process, I have been able to understand the flow of the questionnaire and reflect on it as I amended it accordingly for the main study. The data, however, have not been used in the main study, nor have the participants of the pilot study taken part in the main one.

Assessing the Interview Guide

The topic areas covered by the questions were clarified as follows:

- Religion/Non-religion and DDB
- Religious Literacy
- Religious Patients and religious-sensitive PP

- Religious Patients and secular PP

It was clarified that the average amount of time needed for each interview was forty-five minutes, although the number of questions remained the same. Two of them were paraphrased so as to convey the message more clearly. Additionally, the order of the questions was changed. Last, the content of the answers showed that particular questions should be asked earlier in the process, rather than later.

Reflections

The pilot study was completed within two months – during July and August 2013. In that time, the interviews were spread out due to the availability of the participants. This showed that I had to be mindful about this when it comes to time management of the main study, and be cautious about potential delays due to that. Also, the transcriptions took one month to complete and analyse in a reflective manner.

As the process of recruitment started, certain resistance by the organisations was experienced. This is extensively elaborated and expanded at the end of this thesis. However it is important to include a commentary on it here, as reflective research practice. There had been a constant worry on an organisational level against the potential findings of this study. Even though it had been clearly communicated that this was a completely anonymised study, professionals in managerial posts were cautious about their staff being involved in it. This could be interpreted in different ways. Having knowledge of this, I engaged with a process of building rapport with the management teams; a process that preceded the main study. I have done so by means of presentations, meetings, and informal discussions with the managers.

The staff showed an incredible interest in the thesis of this study, and the research question. After the cover letter for recruitment had gone out, nineteen HCPs emailed me within three days, with an interest in participating. During the initial meetings with the four randomly

chosen staff members, but with precaution to a variety of professions, the discussions were very engaging and participants showed empathy with the intention of the research. This freedom of choice to participate in the study resulted in clarifying one more consideration; whether only religious people would choose to take part or whether research participants would be mixed. Half of the individuals who have shown interest declared to be secular or spiritual but not religious, or nonreligious. This enhances the transferability of the findings overall.

Practical considerations

According to Bryman (2004) ‘...social research is influenced by a variety of factors’ (p.21). Different factors that include theory, epistemology, ontology, values and practical considerations have an impact on the ideal and feasibility of the social research that is carried out.

Nor should we neglect the importance and significance of practical issues in decisions about how social research should be carried out’ ‘...choices of research strategy, design, or method have to be dovetailed with the specific research question being investigated (Bryman 2004, p.23).

The research question of the current project stimulates the ‘need’ for in-depth information and detailed approaches that can answer the qualitative character of the expected outcomes. The aim is to explain and understand the worldviews of HCPs who practice in hospices, in relation to religious or non-religious matters (religion & belief). On that note, the qualitative strategy and qualitative methods entail an exploratory stance that serves the needs of the research question.

Furthermore, practical considerations should be taken into account in terms of the participants of the project and the attempt of the researcher to gain in-depth knowledge. For the purposes of the methods employed in this research project, rapport between the human subject participants and the researcher was critical (Robson 2002; Bryman 2004) in order to achieve

the necessary trust and relationship during the interview. This resulted in genuine, honest and clear answers. The same ideal is mirrored within the focus groups; an established relationship between the participants and the researcher led to effective outcomes.

Research (or social research for this matter) consists of different determinant factors and values that influence each other. A considerate and insightful organizing and planning need to be in place in order to achieve a comprehensive illuminating of the research question and research design. 'All social research is a coming together of the ideal and the feasible' (Bryman 2004, p.23). Practical considerations are of great importance, along with other dimensions of the project. The nature of the current topic and the research question required critical considerations of all aspects, in order to attain efficient and validating results and outcomes.

Ethical considerations

Social science is broad and varied, but often involves human beings. Other ethical frameworks for research on human subjects, such as that which addresses biomedical research, may not be appropriate, which is why a framework specific to social science is necessary. In some areas of social science ethical issues are limited, but in others they raise significant challenges that need to be addressed at an appropriate point or points. The ESRC expects that the research it supports will be designed and conducted in such a way that it meets key ethical principles, and is subject to proper institutional and professional oversight in terms of ethical research governance to ensure that these principles are met. These principles are intended to ensure that unethical research is prevented from the outset.

[Economic & Social Research Council (ESRC), Research Ethics Framework (REF)].

Social research ethics is a topic of long-standing debate (Bryman 2004). There are fundamental issues in research design and methodology, especially when the project includes human subject participants, which need be addressed early on in the process. The key areas that are covered

in this section and which go over all ethical considerations about the proposed project are listed below (ibid. 2004):

- Is there any harm caused to the participants?
- Informed consent for participation.
- Privacy and confidentiality issues.
- Is there any deception involved in the proposed project?

All four of the above areas cover any potential harm or discomfort to the participants, as well as depicting the *ethically concerned research design* that a sensitive subject such as death and religion requires.

Harm to Participants

It is unacceptable to carry out research that is likely to harm its participants (Robson 2002; Bryman 2004; Silverman 2011). However, prior to replying to the question of whether potential harm to participants has been observed through the design, it is necessary to first answer what harm is or looks like. Harm can take several different forms; physical harm, emotional harm, psychological, loss of self-esteem, distress, and discomfort to name a few. Most of the facets above do not relate to the research design and methodology of this study.

The participants of the study were HCPs alone, which according to the National Research Ethics Service (NRES) did not require ethical approval by the NHS Research Committee. This is justified by the fact that research that involves professionals is limited to potential harm and/or discomfort for the human subject participants. Nevertheless, ethical considerations are still important to be taken into account, in order to achieve a transparent, coherent and principled project.

The *Statement of Ethical Practice* of the British Sociological Association (BSA) suggests that researchers should ‘anticipate, and to guard against, consequences for research participants which can be predicted to be harmful’. On the same note, the Social Research Association (SRA), within its *Ethical Guidelines*, states that the ‘researcher should try to minimize disturbance’ in any form that might be likely to appear during the research study. The question then becomes; *what are the consequences for the research participants?*

This study did not entail any harm to its participants, no more than the possibility of having felt uncomfortable if and when sharing personal ideas and opinions with the researcher. The latter was addressed with informal conversations with the line managers of the hospice settings in which the participants practice. Relevant arrangements between the researcher and the line managers of the participants were made prior to commencing the actual study.

Participant observation took place upon participants’ consent, as well knowledge and understanding of both the aims of the study and the role of the researcher. Interviews were carried out in a private space, with only the researcher present. Once again the participants consented to their participation in the process, and they have had the opportunity to express all their queries to the researcher prior to the interviews. As soon as they had a developed understanding of the research, the two parties proceeded to the interviews. Lastly, concerning the focus groups the same ethical procedures have been followed.

The potential harms to participants can be limited drastically with consent forms. It is now also the policy of all professional bodies [i.e. American Sociological Association (ASA)], that the *Codes of Ethics* entail the fact that all involvement of human subjects to professional or research practice should be following informed consent.

Informed consent

Triangulation methodology that is employed in this study, suggests the use of informed consent forms. All methods in this multi-method approach – participant observation, in-depth interviewing, and focus groups – require the consent of the participants.

At an early stage, participants were fully informed regarding the project, the process and what was expected of their participation in the study. Also, they had been given the opportunity to ask any questions they had and to clarify all the information prior to signing of a consent form.

The principle of informed consent means that ‘prospective research participants should be given as much information as might be needed to make an informed decision’ (Bryman 2004, p.511), whether they want to partake in the study or not. Also, this principle underlines, as suggested by the *Ethical Guidelines* of the SRA, that the participants ‘should be aware of their entitlement to refuse at any stage’ and ‘to withdraw data just supplied’. This information was also communicated in the study proposal; participation in the study was completely voluntary, and participants had the right to withdraw at any time.

Privacy and Confidentiality

Invasion of privacy refers to transgressions of the right to remain private or maintain personal information as private and confidential. The latter is inadmissible in social research (Silverman 2011). This principle area overlaps with the previous two, as with an informed consent form, participants already have a full understanding of their participation, and they are willingly and voluntarily deciding to take part in the study. Both informed consent and privacy considerations limited the potential harms or consequences that the study might have had on participants.

A full description of the participant observation method was given to the HCPs that took part in the study. Hence, they had been fully aware of the fact that they will be identified as *observees* in the process, while at the same time the data collected would be kept strictly

confidential and their use would only serve the purposes of the research project's academic aims, as well as being included in academic publications.

Confidentiality of private and sensitive information was maintained at all times and all stages of the process. No invasions of the privacy of the participants have been enacted during the research study. The participation was completely voluntary and participants have had the right to withdraw at any time and for any reason.

Involvement of deception

Deceptions may only be present, either as possibilities or realities, when the researcher presents misleading information to the participants, which breaches informed consent and increases the possibilities for harm (Bryman 2004). None of the above was the case in this study.

The participants received a full description of the study and its purpose, and were given the opportunity to ask clarifying questions prior to signing their consent form, and their decision to take part in the study. No deceptions or possibilities for deception were involved in the current study. Lastly, privacy and confidentiality, and informed consent can only enhance the lack of deception for the project, as explained above.

Ethical issues abstract

The ethical guidelines of ESRC and SRA have both been read and understood by the researcher prior to designing the research project and proposing its implementation. Additionally, consultation was sought with the NRES. As mentioned above, no ethical approval was required by the NHS Research Ethical Committee. However, ethical approval was sought from the *Ethical Committee* of Goldsmiths, University of London and the Social, Therapeutic and Community Studies (STaCS) Department; ethical approval was confirmed in July 2013.

The researcher remained completely confident that no invasions of privacy occurred, as all the data and information shared were kept locked in the safe space of the Research Centre in the STaCS department. Only the researcher had access to the consent forms of the participants. Regarding the data, the only individual other than the researcher who had access to the data collected and research files was the researcher's principal supervisor at the time of the study.

Ethical considerations were taken into serious and transparent account by the researcher who designed the project. The researcher holds a certification and qualification on '*Protecting Human Research Participants*' by the Extramural Centre of Research of the NIH in the USA. In addition to that qualification, the researcher has completed various qualitative methods courses, including one at Goldsmiths, University of London in January 2013; this course stressed ethical issues and considerations when undertaking social research.

Undertaking Challenging Research

Until now, in this chapter, I have explored the research design, and examined ethical and practical concerns as they link to this study, its nature and aims. This section will focus on the researcher's reflections when undertaking this project; an introduction of what made it challenging to collect data, as well as a demonstration of reflective research (also see Blaikie 2010).

There was remarkable ambivalence on the part of both hospices – on both an individual and organisational level – toward participation in this project. After the initial contact with the correspondents of research and spiritual care respectively. Although the project was well accepted and welcomed on a day-to-day basis by the organisations, oppositional feelings started to emerge from individuals in leadership and management teams.

Both hospices had requested that the research proposal, despite the NHS Research Ethics approval and the Goldsmiths, STaCS Department Ethical Approval, be scrutinised and that

further ethical approval be sought from within the hospices themselves. Both, hospice A and hospice B (due to anonymity hospices are identified in this way) delayed the process of the application for two and three months respectively. According to written explanations given to the researcher, the reasons behind this were twofold. Prior to listing them, however, it is worth setting out the context with the following information; ethical approval in both hospices did not come from the research team, but from a medical team composed of 90% physicians and nurses, all of whom occupy leadership roles in the institutions.

First and foremost leadership teams felt 'uncomfortable' with the method of participant observation. After four meetings and presentations of the project, in both cases, the researcher was asked to state officially that he would not be collecting any data in relation to patients alone. However, approval was given for the collection of information arising from the relationship between HCPs and patients, and/or their family members and friends.

Secondly, there were large arguments about what the researcher would be observing during the participant observation. Individuals in leadership roles, as well as ward managers in both hospices, expressed their concerns with regard to the HCPs being exposed with regard to their knowledge and understanding of religion and belief. In particular, managers stated during informal conversations and meetings that HCPs under their management are very well prepared to be working comfortably with religion and belief as social aspects of individuals, however this particular research project might not be in a position to accurately depict this reality. It was suggested that the data collected might reveal a cohort of professionals who lack in skills and abilities to engage with patients who were not Christian.

In addition to the aforementioned, and upon completion of the ethical approval process with both institutions, individual HCPs who decided to participate, also expressed their concerns that the tools of this research project might be capable of capturing realistic aspects of their

religious literacy. Hospice B brought no more practical challenges to the fore but only provocations communicated through individual staff members who expressed similar concerns. The leadership team in hospice A on the other hand, upon completion of the participant observation, decided to pause the project on the grounds of ethics. Notably this coincided with a change of leadership and a restructuring and reforming of the leadership/management team in the setting. The project was paused for two months before interviews and focus groups were carried out. In this interim period, two additional presentations were given to the committee in relation to the aims of the project and why it is important to look at religion and belief, and one meeting was held with the deputy executive. The deputy executive suggested that I should clarify in my project that I am researching religious literacy in relation to non-Christian religions, ‘as everyone knows about Christianity’ (M.L.C. 2013, pers. comm., 27 November). It is apparent from my research question that I am interested in how professionals are prepared, equipped and comfortable to engage with religion, belief, and spiritual identities of service users. However, I am not exploring this through a specifically Christian or non-Christian point of view.

Researching religion and belief is a challenging task. It may incite provocation of individual conscience and challenge intra-relationships and personal perspectives on life (Pentaris 2015a). Religion and belief are touchy subjects to explore nowadays, at least in Western societies, while policy language often responds to research questions. For example, respondents found it easier to respond to religion and belief related questions if using the UK Census to express whether they agree that religious practice is in decline or not.

Challenges that derive from the above factors might feed into limitations of the research project, or might raise proposals for future studies, a topic we will revisit in the conclusions.

Limitations of the study

Although this research study has been carefully prepared, there are certain constraints and shortcomings of which the researcher is aware. First of all, overt participant observation took place in only one hospice. According to the Person in Environment (PIE) theory (Karls & Wandrei 1994) and the method itself (Silverman 2011), participant observation results in data that are collected from behaviours that are observed in the particular context and interactions between the observee and the environment. The current study is limited to two specific environments, which might create limits in terms of generalisability (transferability) of the outcomes. Moreover, this study was undertaken in a secular context and utilised that context as a framework to analyse and interpret the data. The results of the current study may not apply to different nations with different policies, for example. This is because secular beliefs may be presented differently and hospice care in those contexts may be influenced differently by those beliefs, than they are in the UK.

Chapter 4

Hospice care under observation

Three chapters report on the findings of the study; chapters 4, 5 and 6. This chapter reports on the findings of participant observation. I am doing so always bearing in mind that social policy governs professional practice. The findings often mirror recommendations made by policies: whether fuzzy or crystal clear. The findings involve all areas of the hospice, as well as various different practices, and stances and attitudes about religion, belief, and spirituality. Last, this report is inclusive of a discussion.

Participant observation and ethnographic notes

The findings of this part of the study led to eight themes, and those are as follows in the diagram (Figure 4). These are themes that constitute the context in which professionalism is practiced. Also, these themes are overlapping and key indicators that represent the degree to which religion and belief have been integrated in professional hospice care.

Figure 4: Religious Literacy in Hospices



Images and *spaces* are directly linked together. This is because images and crosses are adornments in the space. Regardless, it has been necessary to separate them as ethnographic notes suggest an independent addressing of the two; images in association with the adornments in the space, and spaces in relation to prayer rooms, wards, and chapels. Further, distinct themes were necessary in addressing how HCPs include religious accessories in their outfit, or not

(*dress*), as well as in examining what *language* HCPs use when delivering services, or what *practices* they perform regarding similar needs. These themes emerged due to the repeatedly used religious language by health care professionals during participant observation, however without conscious awareness of it.

Another theme that emerged was *public vs. private talk*. This theme was reached from the following. HCPs were found to be ambivalent toward discussing religion and belief, especially when they thought that they might cause distress. However, findings showed that HCPs consider religion related conversations to be highly private and not a concern of the HCPs. This relates to societal attitudes toward religion and belief, reminiscing Bruce (2011) and the notion of privatised religion.

Last, the themes *attitudes* and *stances* emerged from the data. The former is concerned with the HCPs' attitudes toward religion and belief, as well as religious diversity within hospice care. The latter refers to the overall opinion about other religions based on own religion or other belief. This theme highlights *how* and *why* HCPs are working in hospice care, which often relates to Christianity and Christian-centred perspectives.

All these themes are explored in the following subheadings.

Images

When participant observation commences in the hospice in October 2013, religious icons, crucifixes, crosses and representations of religious texts in frames decorating the walls of the corridors, offices, patient rooms, quiet rooms, the garden and the entrance of the hospice are all present in different numbers and density. More than twenty icons of Jesus Christ or Virgin Mary and baby Jesus adorned the corridors of the hospice, on all floors. Two large crucifixes in the lobby areas at the bottom of the staircases and four small crosses were carefully placed in small dents in the wall when walking upstairs to the floors. Every prayer/quiet room was

equipped with at least one crucifix and two (one big and one smaller) icons with either Jesus Christ or Virgin Mary and baby Jesus on it.

Toward the end of this part of the study, which was no later than July 2014, a significant number of religious icons, crosses and crucifixes are removed. The intention was not to put them back up (M.E. 2014, pers. comm., 23 May). The April 2013 NHS Mandate recognises the importance of EOL care and suggests that inviting spaces, neutral of personal characteristics and preferences should be a priority (see <http://www.ncpc.org.uk/news/nhs-mandate-amended-include-end-life-care>). Suggestions include the need to develop a physical environment in EOL care, which can be inviting to all cultures and religions. Therefore, the intent of the mandate is that the internal and external of the hospices should remain neutral in terms of decorations and representations of particular cultures and/or religions. The opposite is considered to work toward excluding people from other religious groups or denominations, whereas the hope is to be inclusive. This speaks to what Camila, a 52 year old nurse assistant said in an informal interview during participant observation: “We had a lady who is very reluctant to come here because there are nuns, and you know, crucifixes and rosaries and other stuff about Christianity...”

The extract from Camila above, indeed, shows justification for taking measures. Nonetheless it questions the liability and truthfulness of the measures. Might people be reluctant due to an obviously open environment on religion and belief, or might it be due to a Christian-centred presentation of the institution? Are people of other than Christian faiths reluctant or everyone? What are people reluctant of? Dearth of data does not allow us the answer to these questions yet, which raises another issue; how is the decision for neutral spaces made when there is no evidence to support that the opposite is what enhances ambivalence and inequality?

Moreover, and without evidence that suggests otherwise, the removing of the icons and crucifixes seems a tactic responsive to what is believed of the service users. Beresford (2000), for example, examines service users' knowledge and social policy in relation to whether the two collaborate or there is opposition which leads to further tensions.

Similar to Beresford's analysis, the spatial changes might as well indicate forthcoming changes in professional behaviour and organisation (Bissell 2012). This is paramount when striving to enhance quality of care while maintaining professional satisfaction. The interplay of these changes with professionalism and organisations raise the following questions. How is this affecting HCPs? What is the impact of this on professional practice? These are things that are yet to be considered in the decision-making process.

Vignette 1

Walking in the hospice for the first time, the reception desk being on the right hand side, next to it there is a donation box with the inscription 'The Order of the Nuns' across the front side of it. On the left-hand side of the entrance, there is a human-like size Virgin Maria statue and next to it a large crucifix. For the next few months, and as I kept mental notes while entering and exiting the hospice, people, either professionals or not, would either look at the crucifix or the statue, they would sign a cross on their chest, or even hold up a cross that is hanging around their neck and kiss it as they walk by. Eleven (11) months later, the statue is no longer there, and the donation box is replaced with one without an inscription on it, but a laminated sign on top that reads "To the Needy".

Dress

Religious jewellery

During the eleven months of participant observation, there have only been nine people noted with a religious jewel on them. All of these adornments were discreetly worn by the staff, and gently covered with a part of the cloth, e.g. sleeve, when entering a patient's room, especially if the patient was known to be of different than the professional's faith. This is shown in the

following vignette. On this note, it is also worth mentioning the lack of evidence in the area of professional practice and in relation to whether HCPs have a different stance when working with people other than their own faith, or people of different faith in general.

Religious jewellery and how, when and why those are worn and shown or hidden in the workplace, is also a subject impacted by the European Court cases on the grounds of religion and belief. An example of this is the case of Nadia Eweida, a Christian employee, who finally won the case against British Airways; she advocated for her wearing a cross about her neck and over her uniform. Such instances in history influence professional behaviour, not only in a hospice but generally (Ashford & LeCroy 2010).

Some scholars have considered, especially in nursing (Stephenson et al. 2003), that spiritual care has been largely neglected in hospice care. The fine line between neglect and illiteracy is gaunt and easily crossed. The hiding of religious jewellery before entering a patient's room merely indicates that HCPs find it at least challenging to provide services to individuals with different faith from theirs. The irritation for hiding the jewel is also evident, as the HCPs would reveal the jewel as soon as they have left the patient's sight. With the current evidence in mind, I argue that spiritual care has not been neglected. On the contrary, social policies, education, and organisational contexts, may have neglected to equip professionals fully to be able to deliver it. This is where the concept of religious literacy, despite its unsteady definition as we will see in the conclusions, becomes relevant; lack of religious literacy results in HCPs unable to address religion, belief, and spiritual identities of their patients and thus come across as neglectful. It is reminisced with Sue and Sue (2008) too. Cultural competence has become paramount in professional practice, since the beginning of the new millennium. Literature on cultural competence argues that lack of it may present itself as neglect in professional practice (Johnson et al. 2004).

Vignette 2

It is afternoon, and I have just started my participant observation in the respite ward. The nurse that I am observing, and I are in the nurse station, and she is briefing me for the patient we will be visiting in his room afterwards. That patient I am told does not believe in God a lot, so she does not want to upset him in any way when it comes to religious belief. Being a little opaque about it, she invited me to follow her to the patient's room. The nurse is wearing a cross around her neck, which while entering the room she gently tucks into her shirt, in a rather natural way. On our way out of the room, and back to the nurse station, she is untucking the cross from her shirt and gently rubs it for a second with her fingertips. I then ask her if there was a particular reason for this sort of practice. Her reply was straightforward and spoke to her earlier comment; staff in the ward are advised to come across neutral in their attire so that no one feels excluded from care. Staff are expected to make everyone feel welcome.

The nurse in the above vignette is sharing more than what I enquired for. She is explaining to me that organisationally there is advice that keeping a neutral stance, in connection with one's beliefs, will enhance the patient experience, and promote an open and inclusive environment. It is appropriate to now return to my earlier questions concerning the faiths of HCP; are such practices undertaken at the expense of the HCPs? Debates about ideas of the secular are directly linked with the neutral stance that professionals are keeping. Sue and Sue (2008) explored the oppressive feelings of people with different characteristics in order to highlight, on the one hand, the importance of cultural competence (including religion), but on the other, they also wanted to underline that cultural competence involves self-understanding and self-awareness of the professional which is embraced not by hiding one's true characteristics but by remaining true to the service user and, therefore, have rapport and an honest and open communication.

Religion and belief in the space

Similar to images, when I first started taking notes concerning the space, and how religion and belief are both present or absent from it, I had noted small religious icons of Christian belief (i.e. small wooden crosses, small laminated icons of Jesus Christ) in the prayer/quiet rooms of

the hospice. At the end of the study, none of the quiet rooms had any icons as such. Imperative is the following. Two of the rooms, when the study started, were named *prayer room*, but that was renamed to *quiet room* within a few months.

Religion and belief are either present or absent in various ways in hospices. In the following sub-headings, each hospice space is addressed separately, and findings are reported about each.

Prayer/Quiet Rooms

In October 2013, the hospice had two rooms called *prayer rooms*. Those are designated space for people's prayers, as well as find themselves in a peaceful place (Wright 2001). The interior of the prayer room appeared religious, but also as a temple of spirituality (Hollins 2006). There was a crucifix on the wall, a few CDs with prayers, the Bible, the Quran, and some teachings of Hinduism in typed form.

In summer 2014 those two rooms were renamed to *quiet room*, which made up three quiet rooms. All three quiet rooms were, at the end of the study, neutrally set up, and according to the clinical manager of the hospice, appropriate for all religious beliefs and none. Walking in a quiet room, someone will now find a TV, DVD player, a large number of DVDs and Books, none of them relevant to religion and belief. Reminiscing Saunders words (1988) that hospice care should provide the individual with all the necessary resources for them to die peacefully, it seems that current politics and policy of end of life care find peaceful death in the above. Further, the Bible was, in one of the wards, intentionally removed as "it would have favoured Christians only and not being inclusive" (P.M. 2014, pers. comm., 13 June). In addition to the DVDs and books, large boxes filled up with board games are placed by the side of the couch in each room, with a hardly visible sign that reads 'family connections'.

In other words, quiet rooms resemble the neutral spaces in society, where religion and belief were, up until recently (also see Davie 2013), not discussed or properly approached. Wilson

(1966) argued that society secularises as it modernises. Similarly, one can argue that hospices are not primarily in the process of secularising. On the contrary, they are modernising and secularism comes hand-in-hand.

To my observations, quiet rooms have now turned into a space that staff have acquired usage of as well. Over the last few months, every time, but once, I have been in a quiet room a healthcare professional is either having a nap, or HCPs are having a meeting or a discussion regarding their well-being or the progress of a patient's condition. Three of the interviewees of this study suggested that they have 'booked' a room for the interview. It turned out later that the room that was booked was one of the quiet rooms. This demonstrates the various ways in which these rooms are used nowadays. On a similar note, the rooms appear to be available for booking. Does that also suggest that patients and/or family or friends who wish to make use of the space shall first book it?

It is interesting to witness change in real time; from 'prayer room', a space provided for prayers and religious practice or practices associated with an individual's faith, to a 'quiet room', a room for personal insight and spiritual growth (K..F. 2014, pers. comm., 17 April), and finally, even though it is still called 'quiet room,' to what seems to be a 'recreation room'. These rooms are now equipped with all the appropriate material to amount in a recreation hall, which offers activities (e.g. watching a film) that are far from keeping the space quiet in any way. I will return to this point later in this chapter again in order to link it with the use of hospice chapels and the gardens.

The transformation of the rooms, however, has preceded the realisation that they have transformed. If a quiet room is where an individual will go to find peace and explore their spiritual dimensions (Wright 2001), it is unsunny to suggest that a set of DVDs, a TV, and a set of group games are defeating that purpose. On the contrary, the current neutrality from

religion and belief increases the distance between the individual and their religious or non-identity; their need for spiritual care is sought to be met in a different space where particular identification of the person's religion and belief exists, or the individual has the freedom to initiate it.

Vignette 3

It is 6 pm and I have decided to stay a little longer after participant observation and collect some extra ethnographic notes on the prayer rooms. I left the ward I had spent the last four hours in and went to a different one, downstairs. The prayer room is outside of the ward on that floor so I would not need access to it by the ward manager.

As I opened the door, I heard a light snoring coming through. I walked in, and a nurse was taking a nap halfway her shift (my presumption). I said 'hello' in a very low voice, just to see whether she was indeed asleep at the moment. She was. I walked out and sat at the bench by the door scribbling notes on my pad. After a while, a young girl approached me, in her twenties, looking rather exhausted, while her eyes looked as if she had been crying. She came up to me and asked if the nurse is still asleep in that room. Instantly I thought that she needed a nurse, so I directed her to the nurse station, as more staff were available, and it would be that the nurse in the prayer room was on a break. The young girl thanked me and told me that she does not need a nurse, she just thought of finding some peace in the room as she was feeling overwhelmed with the news her family had received that day concerning her mother's further prognosis.

Finally, as this appears to be a space for multiple uses nowadays, what are the ethics for making use of it? This question is illustrated in the following vignette as well. However, it is worth noting here that different users of the space have different purposes; it is no more a place of universal aim. On this note, different purposes interact and often these might have adverse effects on each one. A concluding thought on this is that there is complete lack of data which can inform us as to why and how prayer/quiet rooms are used. Research to date merely praises the good use of prayer/quiet rooms in association with spiritual care and well-being of the

individual (e.g. Nolan 2012 in his examination of the relationship between patient and chaplain).

Chapel

The first nine months during which participant observation was taking place, the chapel of the hospice had been closed due to renovations. For nine months, someone could follow the signs toward the chapel, and get to a large sign reading that renovations are under work. Hence the public should start revisiting after June 2014, and so I did. Representations of the Bible were decorating the walls of the chapel, with a large crucifix right in the middle and numerous prayer benches around the room. When entering, on the right-hand side, there was a bench with bibles for the public to use while at the Mass, whereas on the left-hand side there was space for artists with an interest in Christianity, who can exhibit and sell their work there.

The chapel was located in the building where all the business components of the hospice were and it took good physical health in order to get there, as there was, for example, no lift but only stairs. On a different note, the usage of the chapel has widened up, and it became not only space for worship, prayers and religious practice. It reopened offering an additional opportunity for merchandise and product exchange, as well as provided fundraising opportunities. The ‘showing’ and ‘selling’ of art projects in the chapel suggests two more aspects. First, it is presented as a touristic attraction, one that people would visit and buy a souvenir on their way out. Additionally, hospices are institutions that promote well-being and provide EOL care, and, therefore, offer the opportunity for people to express their beliefs, fears and hopes in the chapel. Nonetheless, the exchange of products defeats the purpose while it contradicts with the practice of neutral spaces. If someone buys a religious icon he or she are likely to display that in his or her room or relative’s room, however, they are not encouraged to do so as the space, according

to Tina – a nurse assistant, shall be neutral and welcoming to all (T.M. 2014, pers. comm., 7 June).

Last, outside of the chapel there is a timetable with the working hours. The chapel is not open any time of the day. Individuals have to know the schedule if they wish to visit, either for prayer or to talk to someone, or to find peace for themselves. Reminiscing Cadge's (2013) argument for on-call spiritual carers, the chapel here is not an on-call service. People who wish to make use of space in the chapel, or talk to a chaplain need be aware of the opening hours and schedule their visit accordingly. This depicts a comforting situation when one has no urgency to pray or seek any other form of spiritual support (Cadge 2013), and, therefore, may schedule their visit.

Vignette 4

A gentleman is speaking to the cleaning lady in the chapel, a middle-aged lady is sitting on a bench quietly, staring at the crucifix in front of her, lost in her thoughts, while another gentleman by the entrance is setting up a booth with rosaries with a tiny price sign next to them reading '£7 each, two for £10.'

Vignette 5

It is Saturday afternoon, and the ward that I am spending the shift in is rather quiet. Very few people are moving in the corridor, and most of the staff are occupied with several occupational obligations, i.e. administration of medicine. Thus, I am spending some time in the lobby, taking notes. I did not stay by myself in the lobby for a long time. Ten minutes later an old lady approached the lounge and sat down on the couch. She was particularly short, had a walking stick with her and spoke with a very slow pace. We started chatting, and I then found out that her husband has been coming to the hospice for over three years, for respite care. He is now in for good, as she said. His condition had worsened and he was admitted for pain control and symptom management to make the process less painful. The lady shared with me that the news they had received after his latest tests were not very good. He had fallen asleep that afternoon, and she had decided to go to the chapel and pray. However, the chapel was closed as Saturday afternoon was not listed in the working hours of the chapel.

Nonetheless, a hospice is not merely a unit for respite care. Respite care is embedded in the services since only recently (Nolan 2012). Hospices are there to accommodate the needs of people who are dying; the latter being an event that one has no control of. That said, dying may happen in the evening, the morning, weekend, or weekday. There is no schedule for it, and therefore sometimes it does not coincide with the opening hours of the chapel. In a religious literate environment, the chapel shall be available for use, regardless of whether a priest or a chaplain is on duty. A different argument, discussed later, however, comes to answer to this, according to hospice organisational culture and professionalism. The different argument refers to religious leaders connected with the hospice, and who act as sources of support, whether out of hours or not.

Garden

The garden has become a place for prayers and peacefulness. Icons and small statues of Jesus Christ, as well as Virgin Maria are situated in, commonly, hidden places. I walked around all paths in the garden, looking for signs of religious icons or crosses or any signs that have been absent from the quiet rooms or the wards. I was given the impression that I should be examining the garden, by patients and family members who have talked about the garden as the “quiet place to be”.

Looking into the flower bushes and the pots with flowers I spotted seven icons and four crucifixes. In detail, icons are placed inside the pots with the flowers (Photo 1), in places where a visitor would not know that they are there. A couple of crucifixes are hanging from a thin string off the gazebo, and a rosary is hanging from a tree branch. All these items seemed to be carefully placed there while people would use the garden to pray and find their way in their experiences in the hospice.



Photo 1: Icon in the pot
Source: Photo by the author

It is evident that the gardens have transformed conceptually into what Wright (2001) is describing to be the functional role of a prayer room. Prayer rooms shall provide a peaceful place with the possibilities for religious practice, where the individual will enjoy spiritual comfort. Regardless its politics, and the way it is produced, as well as for whom (Gilliat-Ray 2005), the findings of this study shed some light on the way that prayer rooms are used or not used (see *chapel* sub-section). Gilliat-Ray (2005) suggests a transformation of sacred spaces in public institutions and her suggestions primarily include chapels and prayer rooms. What is found here is that the sacred space keeps transforming, and it does not always regard the same physical space. From chapel to prayer room (ibid.), from prayer room to quiet room, and from quiet room to the garden (Figure 5).

Figure 5: Transformation of the ‘sacred space’ in Hospices



Conceptually the *sacred space* is something very personal and well detached from institutionalised approaches. It is the space where an individual, regardless religious or not belief, seeks to acquire as personal and express belief or disbelief about his/her experiences. However the identified need for spiritual care provision in EOL care, and in addition to the ongoing change of the name or title of the space used for related purposes, individuals seem to

have felt needs (Bradshaw 1972), which are yet to be met. The current arrangements in hospices (i.e. quiet rooms) appear not address these needs, and therefore, individuals are using different spaces such as the garden, where they have more freedom in action, in order to seek spiritual comforting.

This is worrying to an extent. If service users in hospices have felt that their needs are not met, and seek alternative resources, even though policy has identified spiritual needs (DoH 2009), there must be a gap between the communication of the two. Social policy (also see Chapter 1) seems to legislate guidelines that lack practice-based information, which makes for a challenging situation for all parties involved.

Vignette 6

I walked out in the garden on a sunny morning, in order to sit down and write down my jotted notes before leaving, when I saw a middle-aged lady, on her knees, eyes shut, and praying to God as she was murmuring. After ten minutes of being quiet and in the same position, she stood up and walked inside. Another example is when I was having a walk and a chat with a doctor in the garden, when two ladies, a mother and a daughter, sat close to each other on a bench and holding a cross in their hands they hugged each other and sat there for more than fifteen minutes. I could hear a whisper coming out of the older woman's mouth saying 'Oh God, please...'

Corridors

Similar to the quiet rooms, corridors were, according to staff members of the hospice, once adorned with icons and symbols. Some of those (at least nine to my account) representations (i.e. icons, crucifixes) has been taken down during participant observation.

A week prior to completing this part of the study, one small size crucifix was hanging by a flower on a shelf on the main corridor wall. Also, four icons, based on my observations, are placed in four different areas of the hospice, none of them in the wards, where patients are.

Vignette 7

As I am walking past the main corridor of the hospice that will take me to the exit, I walk past a large pot with a plant at least six feet tall. Its leaves were also vast, so much that you could hide your face if you covered it with two of them. Having a slight interest in gardening, my attention was drawn to the plant, and I leaned forward touching one of the leaves, trying to guess what it was (which I failed in doing). As I did so, I noticed a small wooden cross, crafted on hand, hanging from one of the leaves. What a strange place to have a cross hanging, I thought.

Similar to previous discussions, spaces in hospices appear to become neutral over time. The experiences of secularisation that the public sphere has witnessed since 60 years ago are now becoming evident in hospice care. The secularisation of EOL care might have started a lot more years before that (also see Walter 2015), Nevertheless lack of social policy in the area, since ten years ago, as well as lack of dialogue and communication between research, professional practice and social policy have led to the inability to identify how, what and why religion and belief are treated. The case of the corridors is one of the examples that illustrates the above.

Wards

There are three wards in the hospice, and each has one manager. Each ward manager has said that there is no religious icon or symbol representing any religious belief in their ward, unless it is very discrete and small. The rationale behind that is that the policy of the hospice, according to staff members, suggests that no one should be made upset due to other people's beliefs. 'Things should be neutral and inclusive around here' said a staff nurse when asked during her night shift (J.O. 2014, pers. comm., 14 February). Once again, this is evidence related to the debates around ideas of the secular (e.g. Wilson 1966; Davie 2015).

Religious icons and symbols are not necessarily absent from the nurse station in the hospice wards, when those are coming in small sizes. In other words, and as a shift manager suggests, we can accommodate religious icons as to respect someone's belief but, at the same time, this

cannot be large in size. Otherwise it would show disrespect to people of other beliefs or none. Similar to what is communicated to the patients. This is not merely problematic but impossible. For example, what if the conversation was covering multi-ethnic environments and the intention was to be neutral and not show characteristics of HCPs', in order to avoid exclusivity in hospice care. What if my ethnic background from Nigeria cannot be *hidden* when I am working with a white Irish service user? Would this indicate lack of inclusivity? Would I be showing disrespect to the service user because our skin complexion is different due to ethnic origin?

There is an uncanny belief that resides within professional practice, and often HCPs' mentality; that acceptance of one person's religion will result in biases against another's. Also illustrated in the following vignette, an inner argument seems to be dominating the decision-making of HCPs. There is the willingness of acceptance of people's social identities associated with religion and belief. However there is seeming ambivalence toward acceptance.

Greer and Mor (1986) discuss how hospices, from social movement, became an institutionalised care for the dying, which later on transformed into an institutionalised cure for the dying and the bereaved (Pentaris 2014). The ambivalence for displaying a larger icon of Christ in a hospice ward, for example, may be interpreted in a few different ways, not necessarily independent from each other. There is lack of religious literacy in relation to how space can be used by professionals when it has a religious character (i.e. there might be a need for integrating that reality into professional practice). Secondly, this is an additional sign for how professional practice in hospices responds to the Equality Act 2010, and especially the newly added strand of religion and belief. There is an ill understanding of hospice care, which stems from the organisational foundations and the core principles of the leadership teams, something that should be included in later studies. Last, but not least, EOL care secularises as we speak; HCPs have received secular education, and to that extent deliver secular services

(also see Corr, Nabe & Corr 2009). This makes for a further challenge that requires the attention of not only policy-makers, but educators as well.

Vignette 8

Having spent approximately five hours observing an associate nurse in one of the wards, and having assumed that not much information concerning how religion and belief are addressed in the hospice setting by HCPs is apparent, I happened to witness the following. The associate nurse and the manager nurse walk in a six-bed room. Four patients are occupying that room at the time, and one of them is a devout Christian. She has a large icon of Virgin Maria by her bed, along with an A4-like size cross and the Bible. The manager nurse walked up to her, asked how she is doing today and whether there is anything she might be needing. Afterwards, with a kind, warm and soft voice, like a whisper, she asked the patient why she needed these icons. The patient murmured something and used the word, Christian. Then the manager nurse, with a louder but still warm and kind voice said that the patient would have to replace those with something smaller as these might be upsetting other patients in the same room.

Practices

The 'exit' of the nuns

The role of nuns in the hospice before, during and after the undertaking of the current research project is of interest. Located in Parkes's work (1972), as well as elaborated with the Sisters of Charity in Ireland, nuns have a longstanding contribution to the development and building of hospices in England. The hospice's history is at large rooted in the support and voluntary work by the nuns (otherwise sisters). Without repeating information already mentioned at the beginning of this chapter, the following descriptive observation illustrates what has been communicated to me through informal interviews with staff members. That is, two nuns would go around in the wards at night or early evening, they would go to all patients and they would pray for them, for the improvement of their health. When participant observation began, the nuns were still visiting patients at their beds and would pray to God for them and their health.

Irrespective of the person's faith, the nuns would still stand by the principle that Christian prayers may save all.

During the period that I spent in the hospice, I saw the nuns a few times in the beginning, but then these became rare, up to a point where I asked the manager of spiritual services the reason I did not see the nuns anymore. When the new CEO was in position many changes occurred. Some included the *exit of the nuns* as their role contradicted, according to informal interviews and data collected during participant observation, with the neutral character of the hospice and the inclusive attitude toward a diverse population. For clarification, the nuns were not asked to leave but were asked to remain available at the request of the patient and not regardless of their [patients'] volition.

Vignette 9

It is after 9 pm, just an hour in the night shift, and I am shadowing a nurse down the corridor as she is visiting patients to make sure they have everything they need before they go to bed. Right before we walked in a room, I spot with the corner of my eye a nun, who is just entering the ward. On the way out of the room and walking toward the nurse station I saw the nun in a patient's room while the patient was asleep, and she is standing near the door, with the door open, and it is clear, as she is holding her prayer and having her eyes shut, that she is praying. Later on I received more information saying that the patient has not asked for her to do so, but that it was her 'job' to do that.

The above is another proof of the secular character of hospice care, not only in terms of practice but also with regards to organisational foundations and internal policies. The changes in the management and leadership teams were only effective since 2013, and yet these have rapidly influenced all different layers of policies and practices in hospice care, up to the writing of this thesis.

Language

Religious language and secular practice

Despite the attitudes and levels of engagement noted in this part of the study, HCPs, and more specifically nurses, have addressed patients as ‘angels’.

‘He is an angel’

‘How are you today my angel?’

‘You are an angel’

‘An angel like you should always be smiling’

‘They are all angels’

‘She has an angelic face’

‘I know you will, you are an angel; that is why’

All the above are examples of all four nurses that participated in this part of the study. Either used when in a patient’s room or when referring to a patient in a meeting or to a colleague, or when talking about a patient to me, as a researcher, this is the most prominent way in which patients were addressed; as angels, a term that derived from religious texts, affiliated to religious belief and connoting belief. Nonetheless, contradicting to the majority of the findings in this thesis. Perhaps this is another area of research that needs attention in the future. Namely, how traditional belief (drawing from Day’s work on performance and religious practice, 2011) of HCPs influence professional practice.

Public vs. private talk

Ambivalence toward religion

Ambivalence to publicly talk about or engage with religiously related conversations or beliefs is observed across healthcare disciplines in hospice care. There seems to be a gap in the communication between patients and HCPs. The former seek to publicly discuss a very unique dimension of their social identity, one that influences their experiences of dying and grieving,

whereas the latter decide to keep the conversations private, not to engage and divert from openly acknowledging the different faith groups and beliefs. The above is also illustrated in the following observation. A patient receives some non-promising for their health news by the doctor, and during their next appointment the patient asks how long it would be until they are with God. Doctor nods his head and says that he does not know whether they will be with God or not and that he is not the right person to talk to about that. The doctor in question not only diverts from the conversation about God but also makes a statement that seems to oppose the patient's belief. This observation leads to outcomes beyond religious illiteracy as similar reactions by HCPs may have a significant impact on a person's psychosocial and emotional well-being. Nonetheless, this is not the primary concern of this study.

Further ahead, as spirituality and levels of devoutness in a particular denomination have been explored in scientific discourse, HCPs appear to be translating religion into spirituality and making measurements that are necessary due to policy procedures. A doctor asks a Muslim patient what they would like to eat. The patient said that they were Muslim with the indication for halal meat. Doctor then asked, but are you spiritual or not. Moreover, added later on that if he is spiritual he should also be aware of the services of the chaplain in the hospice, and make use of them.

A different situation regards a nurse who showed more courage in addressing a patient's request to have a conversation about religion and his beliefs in relation to his health deterioration. More specifically, the nurse explains to the patient that she would welcome the conversation on this subject. However she would not be the right person to expand on talking about Islam as that would imply that she has further knowledge of this particular religion, whereas she does not. Although she is responding to the patient's request, she is still making certain assumptions on whether she can engage in conversations with a particular denomination based on whether she has any knowledge about that religious creed. Equivalent to a nurse

assistant's comment about the Bible and its teachings. The nurse replies 'that is to do with personal stuff and I would not know anything about it' (J.O. 2013, pers. comm., 14 February).

Ambivalence toward religion is also observed in and throughout multi-disciplinary team (MDT) meetings. I have sat in fourteen (14) MDT meetings throughout the period I was carrying out participant observation. All meetings, without exceptions, have been bio-medically driven. Doctors and nurses were dominating the conversation with medicine, med doses and change of treatment plan notes. On the other hand, physiotherapists occasionally had a say concerning whether a patient is in the appropriate physical condition to receive support. In one of the meetings, a social worker was involved with little to say about a patient's psychosocial status and needs, which included lack of social support. Moreover, in a different than that MDT meeting a nurse has mentioned that the patient is a devout Christian and maybe calling the chaplain would be something to have in the plan. This is relevant to the vicarious religion thesis (Davie 2007). All HCPs agree to the support that a chaplain will provide and embrace this kind of support, but they are not the ones contributing to it in other than the above ways.

As far as my observations go, HCPs have presented themselves with limited involvement with religion and belief when perceived as a personal trait. This matter is what is nowadays 'treated' by the chaplains (Harper & Rudnick 2009). A great deal of ambivalence toward religion has been shown. However these are comments to expand on in the findings of the interviews and the focus groups in the following chapters. What is evident here is that HCPs are on the one hand willing to engage, but on the other, unable to do so. Controversially, the study shows that there are signs of ambivalence to engage in public talks about religion and belief, and demonstrate attitudes that religion and belief are private matters, which shall remain as such. The latter may be a form of coping mechanism in light of the challenges associated with religion, belief, and spiritual identities.

Vignette 10

A nurse assistant is sitting down in the lobby of the ward with another four patients. All four patients start talking to the nurse about beautiful churches around England. Then attempt to engage the nurse in a conversation about going to Church or praying. The nurse says ‘this is nice’ and walks away, and later on she shares with me that quite often people feel religious or spiritual but it should not be for us [HCPs] to question or intervene with that.

Vignette 11

At 1:30 in the morning, only two nurses are at the station. One goes to a patient’s room as a patient feels uneasy and calls her in. When she comes out of the room there is a sighing and she is [nurse] saying ‘dear God’. Another nurse asks her what the situation was, and she replies that the patient feels like time is approaching and that he will be with God soon. When she is back at the station, she makes a note to call the chaplain in the morning and tell them that someone is feeling ‘religious.’

Attitudes*Understanding religion and belief*

The vignette below supports my whole argument about the challenges of HCPs regarding religion, belief, and spiritual identities in EOL care, as well as the ill understanding of social policy about how religion and belief are addressed in hospice care.

After having introduced my research project to the HCPs in the hospice wards, the commentary included that such research that looks at “all those different religions”, but Christianity, is an important one. In other words, there is a suggestion or expectation or understanding that what I do is to do with other than Christianity religions. To further illustrate this I am referring to the following example from my observations. In our first meeting with the ward managers, when I was presenting and elaborating on my research project prior to commencing participant observation, one of the three said “we know fascinating stories of religious people here. What do you want? Sikhs, Muslims, Buddhists?”

Findings show that HCPs are comfortable with Christian-centred elements but find it hard to accommodate the differences between Christianity and other religious denominations or non-religious beliefs. There are verbal agreement and acceptance of different faiths and how people shall hold their personal belief system and be respected for those. However, in practice, HCPs prove to be lacking skills and abilities in order to integrate those differences and their acceptance of those differences in professional practice. This is one of the core suggestions in Dinham and Francis (2015); professionals need to reconsider new language and skills in order to properly and adequately respond to religious diversity, and this is in accordance to the religious literacy thesis.

Vignette 12

It is late afternoon. Two doctors, three nurses, two healthcare assistants, a nurse manager, and I (researcher) are all in the nurse station. There is some conversation initiated due to my research interest; religion and belief in EOL care. All HCPs in the room are very passionate when they are saying that it is critical to look at that side of things when caring for people in a hospice, and that they are all at a very competent level of confidence in order to provide such care. All agree that chaplains are employed, who are always called in when patients feel like talking about their spiritual health and care, and so on. Ten minutes later, the nurse manager pulled out a patient file, a thick and loaded with paperwork file. She asks everyone in the room to point where in the file are religious and/or spiritual beliefs/preferences mentioned. All HCPs in the room spent the next twenty minutes looking for this piece of information, talking over each other and legitimizing why it is hard to locate it. Finally, the nurse manager steps in and looks at the forms and admits that it is not exactly where she thought it would have been. After a few minutes, she says: ‘It is on the second page of the form, but we have not filled out this one. Probably the patient did not answer the question’.

Stances

Matching characteristics

Data shows that there are HCPs that state strong relations with their religiosity. Also shown is that HCPs's beliefs and values of their religious heritage have led them to this job, as well as informed their choice to be working in a hospice. Examples to illustrate this will be provided in the following chapter. However, there are a few observations worth mentioning here.

Findings show that HCPs view the embrace of their beliefs and the imposition of prayers to be paramount toward the aims of hospice care. The latter is also highlighted by the presence of the nuns earlier in this part of the study. Some HCPs appear to hold strong personal faith and that shapes or guides sometimes their attitudes toward religion and belief in the public; with patients and family or friends in this instance.

Complementing to the previous finding is the following. A doctor and a nurse suggested providing spiritual care in the hospice is contradicting to the fact that all the crucifixes and other Christian icons have been taken down from most spaces in the hospice. Spiritual is to be Christian, and, therefore, a Christian-centred approach on care should be applied. This finding goes to highlight what was aforementioned.

Vignette 13

The nurse manager of the night shift is on her computer looking at images of Roman Catholic churches on google.com. I am making mental notes while a ward assistant is putting a pocket-size prayer book in her pocket. The manager caught my attention when she randomly addressed the following to me. 'We need religious patients, you know. I am, and others are, very religious people and if patients are religious, you know, Catholics, then we can help them a lot more'. I have to admit that during my time in the hospice I have come across evidence suggesting that HCPs believe the following. When HCPs share values and beliefs with the patients that can only benefit patients and their families/friends. However, sometimes that has been challenged in the interviews and focus groups as to whether the personal is separated by the professional

at those times. The same nurse manager and I went on for about thirty (30) minutes in this conversation. She finally concluded that what HCPs can do for patients in a hospice is pray for them, even if they (patients) do not believe in God; ‘pray to God that they will get better, and if they do not believe, then still pray for them as they do not know how God can save them’.

From observing to talking

Participant observation has enriched this study with data that have broadly shown that hospices are a space that are currently undergoing a process of secularisation. This research method has allowed the researcher to witness and explore not only practices, rather the interconnections and interrelationships between HCPs, service users and family and friends, and organisational culture and foundations; i.e. context. Even though this study is not concerned with the latter, it is yet inevitable not to consider professional practice in relation to the organisational synthesis and culture.

Drawing from Hughes and Wearing (2013), and their taxonomy of organisational theories, the hospice here may be considered either a cultural lens toward understanding further end of life care, or a living organism that sketches out the behavioural patterns within multi-professional environments. The findings reported on in this chapter also reflect on the cultural dimensions of the hospice as an organisation. The way in which space is used is reflective of behavioural patterns within the system. That is an observed example of the functionality of the hospice in relation to how religion, belief, and spirituality have been embedded in professional practice.

Nonetheless, participant observation in itself is not sufficient to make the above claims, or to understand the challenges, in-depth, of HCPs in connection with religion, belief, and spirituality in professional practice. The next findings chapter will report on data from the interviews and focus groups, which further cultivate my thesis.

Exploring religion and belief in hospice care

This chapter reports on findings collected from interviews and focus groups. Twenty-two HCPs were interviewed, and two groups were carried out successfully; four HCPs participated in each. Both, interviews and the groups, played an important role in the study. The former provided opportunities to explore HCPs' perceptions in-depth, and gain a sound understanding of the information. Focus groups offered the chance to collect community group responses from within the hospices. Group dynamics played a principal role in the process of data collection for the focus groups. As opposed to individual interviews, members of the groups explored the themes under discussion in relation to the ideas and views of others in the room. That led to a collective effort to reach points of agreement in the discussion. In a sense, it could be said that the groups simulated a team environment where professionals would be compelled to voice their opinions in front of each other, and could be influenced or inhibited by the presence of others and their views. The individual interviews, however, allowed HCPs to express their views candidly. In summary, focus groups assisted in conceptualising team-based challenges and controversies in hospice care while individual interviews gathered information pertinent to the individual professional's attitudes and opinions. The chapter reports on the findings from interviews and focus groups together, occasionally highlighting the differences in the findings between the two.

The chapter begins with reporting on the definitional issues of religion and spirituality. It moves on to thematic analysis, reporting and discussing the main categories that derived from data analysis, and, last, reports on data referring to religion and belief in relation to DDB.

Separating religion from spirituality

Spirituality is a new emerging area of research, which lacks serious scientific history when it is addressed independently from religion (Egan et al. 2014). Nonetheless, when religion is researched spirituality is embedded as a new religion or form of worship. Similarly, exploring HCPs' attitudes, skills and literacy around religion and belief, it is necessary to identify how religion intersects with spirituality in the professionals' perceptions.

Participants were asked to define both religion and spirituality. Consequently, these answers can lead to a better understanding of the levels of religious literacy examined in this project, inclusive of the challenges and controversies on the subject. Table 8 lists the categories that emerged about defining religion.

In overall, HCPs view religion as a constitution – a particular set of values that when adapted they can shape and put a value on an individual's experiences. There is an element of religion being presented as something that cannot be changed; religious beliefs are thought to be knowledge that purely derives from teachings and religious texts, and thus not subjectively perceived; on the contrary, measurable principles.

Despite the universal definition of religion, as a set of values and beliefs that acts as a guide in the believer's life, when intersected with spirituality its definition takes a radical shift and more intimate concepts (i.e. personal meaning) emerge. Of note, data here shows that religion has a stiff and unchangeable character, which may be mended when discussed alongside the concept of spirituality. In addition, and similar to Day's (2011) *believing in belonging* thesis and the dialogue around *cultural Christianity*, HCPs consider religion being a form of culture or tradition. It is something inherited to people down from older generations and it is traditionally followed or practiced.

Table 8: ‘How do you define Religion?’

Inductive categories	Participant’s responses
Guided lifestyle	<ul style="list-style-type: none"> - Religion is a particular practice and recognition of a being who created the world. And following that up in day to day life. - Religion is an expression of someone’s beliefs. - Religion is the book, whatever the book might be, and you follow it.
Set of beliefs	<ul style="list-style-type: none"> - Religion is a specific set of beliefs...it involves rituals {to} practice those beliefs and it usually has a title to it as well. - A religion is something that is more organised and structured, a framework that brings together particular beliefs, rituals, rights and sort of a definition for a group of behavioural beliefs and values, but particularly rituals, and externally looking at that you may understand that definition. - I think it is a set of beliefs that somebody is taught as a child. Somebody converted to it, it is an organised system itself. - Just some set of values or beliefs that seems to be organised.
Community	<ul style="list-style-type: none"> - Religion has communities that come together and practice. - It is like the centre of the town. We come together as a community because of religion. - I guess if you go to other places you might see people acting as a community by going to Church altogether.
Cultural system	<ul style="list-style-type: none"> - Religion is...cultural...a historical cultural system. Even with political anthropological parts in it...that is it... - I guess...I mean...you can say that it is culture...or maybe a cultural sort of system that...
Source of knowledge	<ul style="list-style-type: none"> - It {religion} is attempting to deal with...existential questions...those from the part of life that is beyond a known. - You learn from it. It is knowledge and enlightenment, no?

Table 9: ‘How do you define Spirituality?’

Inductive categories	Participant’s responses
Personal identity	<ul style="list-style-type: none"> - Spirituality is much more about what makes you YOU, what is important to you,...and the life that you have lived, your value systems, etc.
Meaning of life	<ul style="list-style-type: none"> - It says what gives you meaning in life and how you make meaning of life. - That is your sort of spirituality, as to where you have fit in such a world and your life and what is important to you. - Spirituality is just...a human’s quest for meaning...and becoming more...finding a place in the universe and you can express yourself. - That is an individual’s perception of meaning and life and what is important to that person, physically and psychologically; the meaning of life and what is important. - Spirituality is something about life. What is important in life, what is quality, what is value, what is the meaning, what is the purpose, what drives you, what gives you hope, what gives you happiness? It is just making sense of your place in the world, and the bigger picture, something like that. - I suppose you can define that as the individual’s beliefs. Some specific form of rationalisation of their existence if you like, which is not a formal religion but something more than that or outside of that... - Spirituality is about the person’s essence of life, the person’s being, and it is one of the most difficult terms to define. But it can be based on the religion one might follows.

On the other hand, spirituality is presented as a subjective experience. HPCs refer to spirituality with the descriptions of meaning, identity and personal interpretations, all reminiscing Ricoeur’s (1976) interpretation theory.

Spirituality is a complicated term that lacks definition, mainly due to disagreement among researchers and theorists. The need to define this term, or at least address it in this way in the current thesis, is because we come across it in social policy and health regulations regarding holistic approaches and person-centred perspectives of EOL care. What HCPs offer (Table 9)

is a clear understanding that spirituality is merely something personal and that it purely refers to the meaning an individual makes in life. These two approaches to the definition of spirituality are critical to how religious and non-religious beliefs of service users are perceived, interpreted and integrated into professional practice.

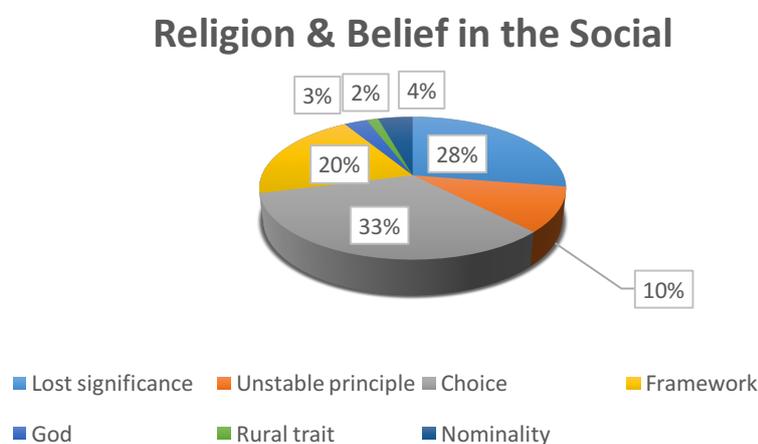
Being aware of how HCPs in this study perceive and understand religion, belief, and spirituality will enhance the understanding of the findings reported on in the following subsections.

Religion and Belief in Society: HCPs’ perceptions

HCPs were asked about their perceptions of the place and the role of religion and belief in society. This is largely linked to how the research participants are addressing religion and belief in hospice care, as well as indicates the level of religious literacy currently evident.

There are three general perceptions. The first refers to the loss of significance of religion as a structure and as an identity. The second clusters religion and belief as primarily private areas, which shall be untouched by professionals. The last is a significant lack of religious literacy about how religion and belief as social identities are understood and how HCPs engage or feel comfortable to engage with those. Figure 6 below depicts all the categories that emerged from this set of questions.

Figure 6: HCPs’ perceptions of religion and belief in society



Lost significance

19 HCPs have suggested that religion has lost its social significance. It is apparent by the responses of the participants that religion is perceived as something that is not important to individuals. Such stance may suggest however that, similarly, religion and belief are not well regarded in professional practice.

‘I mean...you hear the statistics, which you do not know, and they quote like two-thirds of the population are unsure of their religion, or are agnostic or atheist and only a third are actually practicing some form of religion; somewhat fifty thousand are... This is us; Jedi minds or whatever. So, I mean you get the impression that in society in general religion seems to be having less of an importance’ (John, 53).

‘Well, you know, people are not really religious are they? I guess it is not that important and... well it depends I guess...’ (Janice, 47).

‘...not very important, is it? I mean, everybody says that religion is declining and all, you know. Even the chaplain here says so, so I guess...well, it does not seem that people think that it is important anymore...?’ (Nick, 41).

Judith, a 27-year-old physician, says that ‘religion is no longer something important. Other things seem to bother patients now, and it is not that necessary to be asking about religion I guess. Belief is what matters’. A newly qualified physiotherapist said ‘I do not know. I guess some people have religion...or not...I do not know. We did not talk about this much I guess in class, but I mean, is it any important when it comes to the hospice?’ (Jenny, 24).

Religion is considered an insignificant matter in society, and thus HCPs show less interest in engaging in the conversation. For example, the debates from early sociologists (e.g. Wilson 1966) suggest that religion has been losing its social significance in society. Nonetheless, numerous scholars, including Dinham (2015), Davie (1994; 2007), and Hervieu-Léger (2000),

argue that religion, religious belief and religious practice have not been lost from the public sphere, rather changed. Having said that, HCPs are not unwilling to engage with this strand of social identity. However, lack of public recognition and conversation about religion and belief leads to lack of courage in doing so within hospice care.

Despite the above, belief in a concept draws the attention, and HCPs share more in-depth thoughts about belief and what people believe. It is interesting that when religion is mentioned, the conversation naturally shifts toward creeds, whereas when ‘belief’ is specified, the conversation flows in a different direction; becomes more ‘spiritual’ as we saw earlier in the findings. This further evidence supports the claim that HCPs stray from talking about religion while spirituality, belief and meaning-making makes for a more comfortable conversation. However, it is yet not evident, due to dearth of data, whether the HCPs’ perceptions of what is important and what not about professional practice is informed by service user worldviews as well (see Beresford 2000).

One of the participants responds to the lost significance of religion in society, due to secularity. Thus, they suggest that religious behaviour changed after secularity took hold.

‘I think it has much less of a role than it has done in say the earlier part of the twentieth century to what we [people] have experienced to the end of it. So...to the twenty-first century. I think our society in this country has become quite secular, whereas religion used to be very much the centre of people’s world; that has changed throughout the 20th century and into the 21st century’ (Peter 31).

Similarly, the notion of lost significance is illustrated in the following extract from a focus group. Individuals present their perceptions in an explicit manner, whether they hold personal or not beliefs. A distinguishing factor of the focus group’s response is that there is a tendency

to form opinions based on previously stated views. Nevertheless, in both occasions, interviewees and focus group members shared this suggestion.

Focus Group 2

Margarita (36): it [religion] is not at all important nowadays. People might go to Church, but is that enough?

Mary (29): yes, yes,... I mean it is all about going to Church...

Researcher: What comments are there in the room when you hear that religion is not important anymore?

Mary (29): it was different before, people cared about it more and did a lot more than just going to the Church.

Carlita (46): I would agree actually...because...- religion or spirituality or whatever you want to call it, is not so important now. I mean, go out and ask ten people if they believe in God and they will say 'yeah..' 'my own..'

Margarita (36): Maybe spirituality is what people lie upon nowadays, not religion.

Perceptions of lost significance, or the following categories, become important indicators of how religion, belief, and spiritual identities are perceived and integrated in HCPs' appreciation of an individual's experiences, which later on influences professional practice; also illustrated by the following. Parkes et al. (1997; 2015) reviewed different religious groups and their response to the experiences of DDB. They did this based on the principle that religious belief is a significant aspect of an individual's understanding of their experiences, and this project adds that this has an impact on professional practice in hospices.

Unstable and unnecessary principle

Four of the respondents expressed thoughts regarding religion as a constitution that has ‘fallen apart’. Besides particular guidance and teachings by religious leaders, the core principles and values are seen as unstable and even unorthodox at times. Jeremiah, a 58-year-old physician strongly suggests that ‘religion used to have to offer something, hope. ...it is unfortunate...it does not anymore...it feels like something unstable these days and it is sad...people find it unstable’. John, 53, also adds that ‘It feels like something that has let loose, and it feels very unstable and those are things that are falling apart [in society]’.

Two participants went beyond ‘unstable’ characterisations and talked about religion as an unnecessary social identity. ‘It has turned into something very unstable. You believe and you do not believe, it is the same thing, so religion is not necessary’ (Alex, 44). Mirna, 48, is readjusting a small icon of Jesus Christ on the nurses’ station desk, so that it is better visible while she is telling me that ‘religion is not really necessary...I mean...people might believe in something, or whatever. There is no stability I guess’.

The latter, the acknowledging of an unnecessary principle, while a religious icon is ‘religiously’ adjusted on the desk at the same time, is a contradicting finding. On the one hand it could be suggested that religion is important. However people do not feel comfortable with that reality. On the other hand, though, this act of adjusting the religious icon might as well have nothing to do with core beliefs and significant values. Day’s (2009; 2011) thesis on ‘performative religion’ is another way of looking at it. It might merely be an act culturally bound; someone is brought as a Catholic and alongside how to treat icons or crosses.

Similar to the comments earlier, if HCPs consider religion and belief not as necessary as they are deemed to be by dying and/or bereaved individuals (Pentaris 2011; De Hennezel 2007; Reming & Dickinson 2005; Parkes et al. 1997; 2015), a large gap between service user’s needs,

service provision, and service delivery arises. Lack of acknowledgement or lack of the right language to address needs related to religion and belief may lead to inadequate services. Therefore, hospice care that poses challenges in social policy and professional development. Last, if religion is considered an unnecessary and unstable principle, this is coupled with how religion and belief are absent from the space (also see findings in chapter 4). The removal of religious reminders in the spaces of a hospice can alternatively be witnessed by the discarding position of HCPs against its stability.

Religion as choice

Most of the interviewees (21) suggested that religion is merely a choice. People either choose to believe or not. This was found to be a rather strong statement among the respondents.

‘...historically religion was more like a thing...it was not a choice. Now it is more of a choice’ (Carol, 42).

‘You are raised with values. Whether you frame them with religious beliefs that is a choice you have in life’ (Nick, 41).

‘It is less of an issue and less of something, which dictates the way people behave. But people can also choose how they want to behave’ (Michael, 43).

‘Well it is not something that people have to do. You can choose not to believe, can you not?’ (Jenny, 24).

‘Religion is just something that we choose to do. I guess there is no one to tell you when and how. You know, you will decide if you want to go to Sunday Church or not. Like, I grew up going to Church, and my family wanted me to go with them, but did not force it to me. It was more of a family thing to do. And then you choose your own path...it is definitely something that people choose’ (Shahid, 33).

‘...religion might have been important in the past, but now...well how to put it...it is a little hard...it is just a choice. There is nothing else to it, is there?’ (Margarita, 36).

‘It is not really something that interests me anyways, but I just say that it is one of the choices in life’ (Raul, 26).

‘People should ask what do you choose, instead of what you are? Like...you know, when someone comes here for palliative care, they ask them what religion they have, and...you know, well, I am not sure, but you know, you do not have to ask that. You just say, what do you choose and put it in’ (Johannes, 39).

Moreover, in both focus groups, when this issue was raised, the participants all agreed that religious belief is indeed a choice, however sometimes mandatorily embedded in an individual’s lifestyle. The latter was discussed in terms of cultural expectations, familial desires, and expectations by the educational system.

Focus Group 1

Carl (51): I believe that it is a choice. Nobody believes because they have to.

Shahid (33): yes...but there is something to do with culture as well. I mean, for example, we had a patient that practiced their religion because their culture wants them to. So that would not be a choice.

Carl (51): yeah, I guess. We had a patient with lung cancer and he just said – well I will believe now as this might save me. And he chose to believe, but there was no question of what to believe in...or...

Dorothy (37): I agree, this is all a choice by the end of the day. No one is forced to. So I am thinking that when they {patients} that they have a particular religion, it means that they have chosen to believe in that.

Shahid (33): unless when there are times when someone has inherited their own beliefs. I have seen it with patients that have said, well my family was Jewish so I am Jewish.

Judith (27): I agree with you. Also, what about schools? There are religious activities for the whole school, like a prayer or something, and that is really not the same for everyone.

Dorothy (37): Indeed, but then you can still choose, so I guess it is a choice. No one will force you, will they?

Religion as a choice is a theme that emerged widely from the findings. Given this finding, further insight is offered about professional practice. Professional attitudes toward understanding and perceiving religion and belief are paramount to professional practice. If it is indeed a choice, what religion is, should this not be the individual's decision (i.e. service user's)? In other words, data shows that HCPs perceive that dying and/or bereaved people consider religion and belief to be a choice. Nonetheless, also shown in Chan et al. (2005) with their study of the experiences of Chinese dying individuals, people experience DDB through a lens of belief, whether that concerns a particular religion or not, regardless their mixed background.

Further, this finding also links with Day's 'performative religion' thesis (2011). Professionals drew their conclusions about individuals often having a religion not as a result of their volition but because of cultural traditions and expectations.

Religion as framework

Religion has been described as a framework; a particular guide, which dictates or points out the path on which religious people experience their lives. Interestingly, participants approached this description in two different ways. Two of the respondents say that religion is of incredible

importance in society as it provides a framework that people will use to guide their lives. Gita (59) points out:

‘I think there is a huge role of religion in society and I think it can be really valuable, and I see it to be a wonderful thing for many people. Like a hugely safe supportive framework emerged in their lives’.

On the flip side of this, twelve participants suggest that religion is merely a set of guidelines and a framework that can direct an individual’s life if the individual chooses so. This number of participants strongly collated their responses about religion as insignificant, a choice and a framework.

‘Well, we all need some sort of guidance in life. This is just that. People who might be lost or whatever, can find guidance there. Maybe that is why people need to believe I guess’ (Cirik, 46).

‘not very important I think...you know...some people might choose to believe because religion will guide them in life. Maybe that is one reason’ (Margarita, 36).

This theme also emerges in policy documents (e.g. EOL care strategy) (also see the end of Chapter 1). How religion and belief are addressed in hospice care truly reflects how religion has been conceptualised as a framework with particular guidelines and specificities that direct a person’s experiences. For example, the latest brief on NHS Improving Quality document (DoH 2013) suggests that it is important to have prayer mats in institutions, on the occasion that a Muslim patient is admitted.

This example also raises a challenge and a question that will be addressed later in this chapter. Do HCPs pan out professional practice based on the assumption of religious belief, and all according to religious affiliation? Further, if religion and belief are a set of rules that create the path for people to walk on, then this should be where the dying person or bereaved individual

are met at by HCPs, in order to demonstrate empathetic and person-centred approaches in EOL care. The discussion becomes more complicated if we draw from the debates about secularity and secular professional practice (see Pentaris 2014).

Religion as realisation of the divine

Almost half of the respondents (9) suggested that the role of religion in society is to enable the individual to come to terms with the knowledge of a God, any God. Religion here has been described as the proof of realisation of the divine; a proof that the individual is aware of something larger than themselves.

‘It is people having an awareness, any awareness, that religion, any religion, that there is a God that we are not the most important things and it is having respect for being above us who puts us here’ (Gita 59).

‘Whether you go to the Synagogue, the Mosque, or wherever you go, make sure you take time out and go and thank that God and show respect to somebody that is bigger and better than me that I do not fully understand, and be thankful for what we have’ (Janice, 47).

‘Some people believe in depth, and believe in a God’ is what Margarita (36) says when she is asked to elaborate on the above point. As the conversation progresses, she adds ‘we are made by God, of course, he is above and beyond all of us’.

The realisation of the Divine is not merely an idea of what God is, but a stance: a personal attitude toward religion and belief. This may have a twofold implication to how HCPs blend the realisation of the divine in their professional practice. On the one hand, acknowledging the importance that someone might feel concerning his or her belief system and religious identity shows respect and comprehension. Nonetheless, this stance raises expectations to service users.

In other words, this stance works fairly exclusively regarding non-religious people, or people that are of a particular religion by tradition and not by belief.

Additionally, views about religion and belief in society might as well indicate personal beliefs. Some HCPs identify God as the authority and see prayer and attendance to believe an obligation of the believer or follower. Nevertheless, and if people who do so are the ones who are aware of the reality of a higher power, how are people who do not meet these criteria identified? Does this stance create more barriers to the communication between HCPs and service users, than bridges? Religious literacy after all is also about having the language to communicate openly religion and belief, and not believing strongly in one thing over the other.

Religion as nominal statement

Other participants have considered religion to be something insignificant, nonetheless important to include in the description of themselves. Once again, reminiscent of Day's suggestions (2011) on performative religion, participants here express thoughts of a culturally-bound response to the question 'what is your religion'.

‘or someone can say I am Church of England as a nominal statement’ (Raul (26).

‘I think religion is not well understood in its actual clear definition. I think religion is a statement of what you believe, but in order to have a truth you must have a faith in that belief. And there is the difference. Faith is a way of life, religion is a statement of what you believe’ (Peter, 31).

‘...also, sometimes you say Christian because that is what your family is... or even say I guess I am Jewish Orthodox, because that is how you have grown up’ (Margarita, 36).

Day (2009) in her ethnography of young people argues that religion is identified in connection with power and authority and that it suggests links with socially constructed religious belief.

Later, Day and Lynch (2013) propose different ways in which religion and belief are experienced, as cultural performances. It is a nominal statement to perform belief due to cultural background. Similarly, HCPs' attitudes toward religion and belief resemble a performance, or otherwise a performative experience (Day 2011).

With this in mind, there is a higher risk of false assumption in professional practice. If religious identity of service users is understood as cultural identity with no significant aspects of belief and meaning making in life, then HCPs may oversee how the individual perceives his/her aspect of religion and belief. If so, the risk of unmet needs of service users in hospice care is higher while the quality of care is in question.

Lived religion in rural areas

One of the research participants lived, at the time of the study, in a rural area. Her perception of religion in society is of a different kind than the rest of the participants. In particular, Mirna, a 48-year-old nurse, lives further out of London, in a rural area of Hertfordshire. As she is talking about religion and the importance of belief in someone's life, she is directing her thoughts toward the area where she lives. Having taken a few seconds to think about it, she says that:

‘You can still find it [religion] in different areas or in communities in rural areas. The Church still has a role there’ and she goes on saying ‘I actually live outside of London, in a rural area, where the Church...it is still the centre of the village; everything goes on there’.

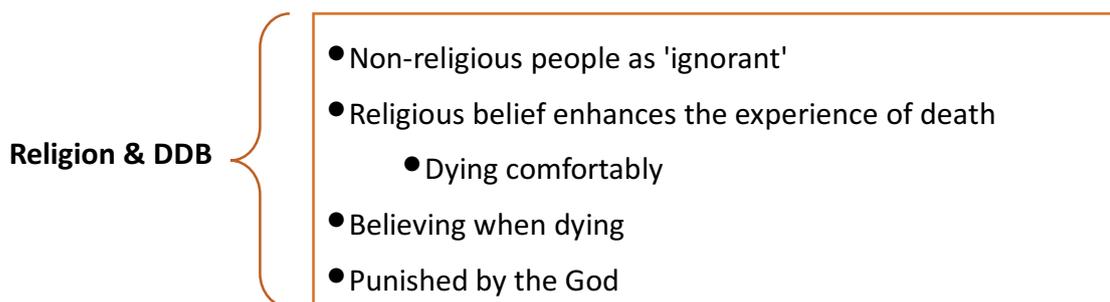
For this to be a strong argument, there would need be further evidence to support it. Nonetheless, it is worth noting that only one of the participants in this study lived in a rural area, and that participant had a significantly different stance than the rest. However, this

different stance might as well be an indicator of less religious practice decline in rural areas. To answer this question, further research is necessary.

Religion in relation to Death, Dying, and Bereavement

In this question, HCPs were asked to show their understanding of the links between religion and DDB; whether there is any and if so how is this perceived. This is important in this study due to its relevance in the area of professional practice, which is examined via the lens of religious literacy.

A general understanding is evident in the findings that religion acts as a facilitator toward gaining better familiarity with an imminent death or a recent loss by death. The following categories are induced:



Non-religious people as 'ignorant'

The first theme in this category implies that religion or religious belief is rather significant when making sense of the experiences of DDB. Data show that lack of belief results in ignorance when approaching these experiences in life. In particular, ten (10) research participants suggested that if an individual is dying but has no religion, then it is likely that they are ignorant of their death and the meaning of it.

‘...again, they come to my mind, all those patients that are...they just seem so...they are not afraid of dying. Those are some people that I cannot see that they have a strong spiritual {or religious} connection but they still...sort of still not afraid of dying. They

are very pragmatic about it. I wonder if they are ignorant sometimes, you know, . . . even when they are actually imminently dying they are still not engaging with what is actually happening; religion or spirituality might be the only way to do this' (Janice, 47).

'In this particular hospice there is a drive to try and accommodate if you like whichever expression of faith or religion is given by an individual encounter with the family. And you know, even for people who are a bit more lost and have no means to make sense of what is going on, you know like people with no faith or agnostics, we do the same' (Margarita,36).

One respondent implied that ignorance toward death, which stems from non-religion, enhances happy feelings within the individual and lifts fears: 'People without faith are probably happier when they are dying, as they are ignorant about the afterlife and have no fear of . . . judgement' (Johannes, 39).

Borrowing from Feifel's work (1977, p.6), it is important to be reminded here that ' . . . death is for all seasons'. If belief is a season, then death is for all beliefs. Belief is not always religious while death is not always direct. All these factors are notable to whether non-religious individuals are ignorant or not.

Nonetheless, we are still in an era of EOL care, in which 'dying and death are now the province of the "professional"' (Feifel 1977, p.5). Hence significant to address professional practice and/or social policy deficiencies and/or adequacies.

'I just feel jealous sometimes. They probably die and they feel nothing about it, no fear and the like. It is annoying some other times because you want them to react and realise what is going on. Some patients will say that God is not for them, but if they appreciated that the end is near, they would be less ignorant' (Johannes, 39).

It appears that HCPs have the tendency to use *ignorance* and *non-religion* as interchangeable and interconnected terms. This raises many challenges and questions concerning professional practice, and how current thinking of non-belief in society plays out in this sector. Becker (1973) suggests that there is always belief in something, which is precisely what motivates people. Researched in philosophy extensively (Ricoeur 2008), ignorance may be the guide of lacking something about something else. What is argued in this thesis is that lack of religious literacy may lead HCPs in ill perceptions of the ways in which religion and belief are perceived and lived by service users (i.e. ignorance).

On the contrary, what else comes out from this finding is the assumption that HCPs receive benefit from the service user's religious belief toward the end. To explain further, religious teachings give answers. There are answers in relation to dying, death, the afterlife, and judgment or purification. These are answers far from the scientific, clinical and biomedical approaches of hospice care, and therefore not handled by physicians or nurses. In the occasion that a dying individual does not have a religious belief, there is also the possibility that the answers about what happens next have not been given. What if the individual then turns to the HCPs for answers? Do HCPs feel uncomfortable due to lack of non-scientific status in order to address these issues, which leads to perceiving non-religion as ignorance in dying? Of course, this is merely a speculation, but with legitimate grounds for further research in the area.

Religious belief enhances the experience of death

It is evident from the responses that HCPs perceive religion and belief in overall as significant elements of how service users are experiencing DDB. Beyond this point, findings here suggest that religious and/or spiritual belief may enhance the experience of death by providing meaning in life. Jeremiah (58) said that '...for people that are dying and for people that are bereaved, [religion or spirituality] seems to...give the basics and meaning of what the essence of life is'.

‘...I feel death is like...it is like something...everybody has to relate to it and in a way they – If we can relate to death in a meaningful way, that would be religion and spirituality, then that could be like a spiritual...sort of have to involve our spirituality I think, to be able to...deal with death or accept death, you know, sort of healthy way’ (Shahid, 33).

Also apparent is that respondents agreed on ‘judgment’ by God being a major element in how religious belief may influence the experiences of dying and grieving respectfully:

‘I think the link between the two is when people are looking for meaning for their life. So, if people are religious, it means that they have a God, they hope that they have done their best for their God in this earth in life, and then they will go onto Heaven, or where Allah is taking them, or where Jewish believe they will go’ (Mirna, 48).

‘...when you are religious...the idea of religion helps...supports you through life. You have a relationship with your God. So, at the time of death you still have that relationship with your God but you are dealing with different things with your God. So, it does not change your relationship with God, you need your God there in different ways and you need help and support in different ways’ (Mary, 29).

Two HCPs supported that the enhanced experience of death through religion and belief is mainly based on the importance of religious icons and symbols:

‘...very religious people they tend to hang on to icons, they like their prayers, they like to see religious leaders. I mean, Greek Orthodox have beautiful icons and crosses on their bed, Roman Catholics have their holy water. So, I think religious people and their families find symbols very important’ (Dorothy, 37).

‘...it is also...people like symbols. When they come in here and they unpack their bags you see them. I think that...well such symbols, like in Christianity, are important; they help people with their experiences’ (Carol, 42).

Overall evidence suggests that HCPs hold general perceptions about religion and belief intersecting with the meaning of life and enhanced experiences regarding DDB:

Focus Group 2

Gita (59): It is vital. Religion will give people meaning in their lives. And then...

Mary (29): Not always though. I do not disagree completely, well... Just saying that there are people with no religion, who...well still have a meaning of life.

Gita (59): I am not saying the opposite, but religion is different. You have...it is...this is something pure and welcoming. Believing in God is...purifying, that is it.

Mary (29): I am not quite sure about that yet. So people with...you know with no religion or if they do not believe in God...how does it work then?

Margarita (36): I am guessing that Gita also means that with religion you have some sort of knowledge there waiting for you. All these texts sort of tell you how and why things will happen, so in that way purifying. I am just very confident that no matter what people who have a religion usually experience their circumstances in the hospice in a better manner.

Complementary to the above part of a transcript is what Carl (51) has said: “People might say ‘I am going to a better life’, so religion helps experience this”. Further ahead, religion is seen as a mean toward spiritual evolvment:

‘I think the relationship with death, dying and bereavement...I think, if you had somebody who was allowed or enabled to follow the expected process of what happens

with somebody who dies in that culture, I think that would lead to a karma, more feelings that do not work and non-complicated grief; many people with religious belief have a better experience of dying' (Raul, 26).

The theme of 'enhancement', coupled with 'ignorance', introduces an at-large argument about the levels of religious literacy of HCPs in hospice care. In all, HCPs suggest that 'non-religion' equals ignorance while 'religion' equals enhancement. In other words, people with non-religious beliefs would not be subjected to enhanced experiences of dying and bereavement. Alike, individuals with religious beliefs would not be likely to be ignorant of their own dying and/or grief.

Apart from the above challenge and controversy in the data, HCPs see religion as the mean that the individual uses to make meaning of his/her lived experiences of DDB. Religious teachings help individuals construct and structure their experiences according to an afterlife scenario (also see Garces-Foley 2006).

Dying comfortably

It is conspicuous in both occasions, interviews and focus groups, that HCPs appreciate that religious beliefs, as well as spiritual, become the mean toward comfort and a peaceful death for the individual. 'Patients get comfort...from a religious belief that they have had all the way through their lives. Religion gives comfort, meaning and purpose', says Cirik (46). Added to that, Felicia, a 32-year-old community nurse, who also works with inpatients, says that '...they [patients] can get comfort from that [religion] and support from their religious community'. Dying is a crisis in itself; the idea of a deteriorating body and numerous future losses might be hard to cope with; 'religion makes people feel comfortable. It is that simple' (Jenny, 24).

It has also been mentioned that religious beliefs may provide comfort to the bereaved – family members and friends, who are seeking to understand and accept the event of death:

‘I do feel that death is usually generating some great emotions and that at that point those emotions are incredibly fragile, and if you have something that is really and uniquely important to you or your family and your faith or religion that you follow, you can tip someone either way and that is a very delicate balance. This will give comfort to the family and especially the griever will feel better, I feel’ (Michel, 43).

Reming and Dickinson (2005) review the ways in which people find comfort and peace in their dying or other people’s dying. The dying process has been described as a lonely process (DeHennezel 2007; Elias 1985). Levine (1989) stresses that the individual can experience a conscious death toward the end. This is the result of a conscious life, which precedes. If the latter is missing, dying becomes an uncomfortable experience; similar to a lived discomfort looking into the unknown. Religion and belief are important aspects of the enhancement of the experience, and the alleviation of some of the anxieties accompanying death, as well as the means toward a conscious life and death. A recent source of literature that reflects on this is Parkes et al. (2015).

Believing when dying

This category is, not exclusively, based on Elias’ (1985) thoughts on *the loneliness of the dying*. It is suggested that individuals experience their own dying in a lonely environment even if they are not alone. Toward dying, people show more openness in the religious/spiritual aspects of their identity. Thus, signs of belief are stronger. 19 of the respondents suggested that patients are prone to believing, whether that refers to a particular religion or any belief, when they are imminently dying; when the inevitability of it is ascertained.

‘...if they are facing the fact that they are dying, their life comes toward an end, that can sometimes make them focus on their spirituality or religion in a way that they might not have done previously’ (Alex, 44).

Often, dying calls for self-reflection in past experiences and the relationships that the dying person has cherished or not in life, suggested by Carlita (46):

‘My experience suggests that religious beliefs are intimately linked to death and dying. When someone is going toward the end, it is very rare [for that person] not to stop and reflect. And for some people do it within a religious context, you know, {God why is this happening to me?}, {How could you let this happen to me?}...Trying to make sense of how they have lived a good life. So, I think they are intimately linked, whether you call it religion, faith, non-faith, spirituality. There is something that happens for the vast majority of people. They do something about making sense of themselves within a bigger picture’.

Toward the end of life, patients have the tendency to become more religious, and this is acknowledged by HCPs:

‘For some people, it [dying] can be a returning to a religion that they might have experienced earlier on in their lives that they might have lapsed from’ (Mirna, 48)

‘It comes to the forth in the dying phase. And I mean, even for someone who has not been a practicing religious person during their life, as the end of their life approaches they begin thinking about...questioning their beliefs, their afterlife, wondering what is to come...so, again it is an added importance I think, in the final stages of life’ (Peter, 31).

‘I think as people get closer to death, in many cases, they look at their own mortality, and perhaps speak an expression of a kind of religion. They [dying persons] may start seeking what they have not before, like meaning and life after death’ (Dorothy, 37).

‘...very often, toward the end of life it becomes more focused through fear, or that they come closer to the maker, or whatever. That feels at ease with different expressions of

religion, because religion I think is a very personal thing. Especially toward death, people find new ways to express their religious beliefs, and even gain new ones' (Carl, 51).

According to Saunders (2005), patients who are closer to the end of their life, tend to experience a spiritual quest (also see McSherry & Ross 2010), and find themselves challenged by the irreversible and inevitable reality of no more opportunities for future experiences, reflections, and/or doing right or wrong. Life as they know it comes to an end (Feifel 1959). What patients at that stage are left with, according to Field (2002), is the uncertainty of the when, how, and why. Findings of this study show that HCPs consider religion and belief to be the answer to these questions.

Kellehear (2000) describes three sources of meaning making that amount to a theoretical model of spiritual needs. He is identifying three blocks of spiritual building in palliative care; the situational, the moral and biographical, and the religious. The situational here refers to the dying state and the context within which dying is taking place. The ethical and biographical highlights the moral history of the individual, what principles and values that have been passed on to the person by tradition or culture contribute to his spirituality in dying. Last, the religious refers to religion and belief. Similar to Kamath's (1978) philosophy of dying, religion is of the most ancient medicines for the dying and the bereaved. Religious practice and death rituals are what linked the deceased's departure with the grief of the living.

This finding may appear to contradict previous research findings indicating that the older people are the more religious they are (also see Blazer & Palmore 1976; Levin 1998). However, the following is important to note. The current study does not contest the relationship between ageing and religion. On the contrary, it often places this relationship within the context of a hospice.

Davie and Vincent (1998) explored what surveys indicated regarding older people and religion and belief. 'Older people...have always been more religious than the young' (ibid., p.101). Research literature (Levin 1998) and sociological explorations (Phillips et al. 2010) largely support so. Simultaneously, studies never rejected the idea that death interrelates with religion (Garces-Foley 2014). In this study, HCPs share views that want religious needs to increase as service users' lives get nearer to the end. However, the findings do not show from what experiences, in particular, HCPs draw.

According to the findings, HCPs identify the connection between DDB and religion being created at the time of dying at least, if not earlier. At large, there seems not be an expectation that religion and belief may precede. They are either generated at that stage of life, or magnified. The question for both social policy and professional practice, therefore, is: During initial admission, should service users be asked, if religious, how much their belief has magnified since the change of their health circumstances? This is additional suggestion for future research, in relation to policy and guidelines in EOL care.

Punished by God

Often, also noted by De Hennezel (2007), HCPs perceived that religion or religious teachings and beliefs dictate judgment and eventually punishment on the individual. Jeremiah, the 58-year-old physician, says that 'sometimes it can be...they [family members or friends] can feel that religion has let them down, because ...the patient is not cured'. It is discernible from the data that HCPs, alongside the perception that dying individuals become more religious or become religious, appreciate an adverse perspective of religion when it comes to linking it with illness and DDB experiences.

“You have people who are very devout, and sometimes they see it as a form of punishment. Or ‘Why is this happening to me?’, ‘Have I done anything wrong?’, ‘Do I deserve this?’” (Janice, 47).

‘They [patients] are actually going to die from this illness, and how can that be right?’ (Shahid, 33).

‘People feel anger and disappointment toward God. Fair enough people have the right to feel distressed and angry, particularly if they are young and they are losing young children; it is dreadful, is it not?’ (Anna, 59).

Six (6) of the participants suggest that people who find such negative aspects of their religion and belief identity tend to lose their faith in their death:

‘People lose their faith toward the end...You cannot believe in a God that allows terrible things to happen to people in Rwanda, terrible things to happen to..., terrible things to happen to you. There is no God anymore’ (Mark, 61).

‘For some people...there is not a loving God because if He is a loving God then He would not do this to me’ (Alex, 44).

This is quite contradicting in relation to the previous theme; i.e. believing when dying. Nevertheless, it is worth noting that HCPs, regardless to whether they believe that a terminal illness might highlight religion and belief within the individual consciousness, also consider that dying patients are losing their faith too. Curren (2001) responds to the needs of DDB helping situations with belief. Similar to this theme, religion and God are described as elements that either punish or reinforce.

HCPs' perceptions of how religion and belief are viewed by service users

There is a general understanding by HCPs, and similar to previous findings, that service users give a significant meaning to their religious beliefs. Even if individuals have not been religious throughout their life course, toward dying they tend to reminisce their religious beliefs and seek comfort with those.

‘The symbols are one thing that is important to patients. Also, I think they always find it very important to see the priest or whoever their religious leader is at the time. So it almost becomes intense {if a patient cannot attend i.e. the Church}. It is really important that that can come to them’ (Anna, 59).

‘I think there are probably times in people’s lives where although they might hold a religion, it does not have a huge amount...it is not on the top for them, they just carry on with their lives and their lives are busy and it carries on. But I think when people are unwell, that comes more to the surface, it becomes more important’ (Dorothy, 37).

Nonetheless, HCPs show a lack of understanding concerning why religion and belief are important. Janice, 47 years old dietician says: ‘For the majority of patients, I think it is quite important. But I do not know why’. Moreover, this is one of the least times that HCPs (6/22) suggested that even if someone is of no religious belief, belief in general and faith are still quite important. The following quote is representative to illustrate this:

‘I think it is very important. For a lot of people. Even people with non-religious identities, it is still important to them’ (Raul, 26).

Further ahead, five categories of how HCPs appreciate the significance of religious and non-religious identities of service users emerge (Table 10).

Table 10: The role of religion and belief for service users: HCPs' perceptions

Category	Description	Example
Meaning-making	Religion and belief assist in making meaning in life events such as DDB.	'...because a lot of the patients look for meaning and their religion always helps.'
Cultural beliefs	Religion and belief are mere traditions of the family or society/country of origin of the individual.	'They ask to be buried here and there for example, not because they might be Orthodox, but that is what they know from their own home.'
Universal Spirituality	HCPs believe that there is no individual without spirituality or religion.	'If someone says that they believe in nothing, then that is not true. Everyone has a spirituality.'
Unique understanding of religion and belief	Religion and belief are individually understood concepts.	'...well, if they do not explain to you what and when and how, how would you know? It is very unique.'
Decision-making	Religion and belief assist in making significant decisions in life.	'...if they...well with religion people make their decisions easier.'

Meaning-making

Despite the different opinions regarding what the role of religion and belief is, as well as the disparities between what is considered religion and what spirituality, 21 of the participants

stated that religion and belief assist in meaning making. There is a considerable acceptance of personal perceptions and subjectivity in EOL care (Pentaris 2013).

‘A lot of them [patients] talk about – even if they have got no particular religion – many of them talk about what gives them meaning to life; what their life has been about; what is important to them’ (Shahid, 33).

Johannes, the 39-year-old physiotherapist, takes a few moments to think prior to replying to the question – Do you find religion and belief being important for patients, family members and friends? ‘When people have a religion, they have stronger feelings of making meaning in life and of their experiences’. Evidently, all HCPs in this study agree that spirituality, whether religious or not, meets inner and existential purposes. Individuals seek making sense of their experiences, and this is an important way in which they do so.

‘...for a lot of people it has been something that it has been there from...throughout their entire lives. And it is part of how they make sense of the world, and have done since they have been very young’ (Michael, 43).

‘I think for some people their religious part of their lives is phenomenally important and they want that to be recognised and it is quite...to their identity and to their meaning, how they make sense’ (Cirik, 46).

‘People have to make sense of what is happening to them in the context of their understanding of the world, and their understanding of religion. It is a big part from what I have seen...from what I have witnessed. For a lot of people it seems to be part of them, making sense of what is happening, and understand why they are making the choice that they are making’ (Margarita, 36).

In addition to meaning-making, HCPs consider religion and belief to assisting toward reflective meaning making. In other words, the findings demonstrate that service users employ their

beliefs for two main reasons. To reflect on what their accomplishments in life have been and how their life events have led them to the point where they are at the time of dying or grieving, respectively.

Judith (27) says that religion helps individuals ‘making meaning of what their life has been, and the death process’. Similarly, Carl (51) says that ‘religion can help people make sense of their experience’. Another illustration of this is John’s (53) words: ‘Toward the end people want to make better sense of their lives and what they have accomplished. Religion helps them with that task’.

The current theme, alongside the rest of the categories in this set of questions, support the current thesis and rationale of why the religious literacy of HCPs is important in hospice care. If service users find such immense comfort and meaning in religion and belief, then HCPs, as well as social policy and the politics of hospice care, hold vast responsibilities to be meeting these needs.

Cultural beliefs

Often requests or wishes expressed by service users are interpreted as beliefs that purely stem from tradition and not within the individual’s consciousness. After a long pause Johannes (39) says that:

‘Sometimes it is tradition, but sometimes people really use their cultural background to invest to treatments or investigations or the type of management. And you will see it often in the Jewish community, and the request is usually based on *oh this is part of our tradition or this is part of our belief*’.

Twenty (20) of the respondents suggest the same. This directly links to Day’s (2011) thesis of performative religion and cultural Christians. Similarly, HCPs are here discussing *cultural Jews, cultural Muslims*, and others.

Further, HCPs, and especially nurses, have been noticing religious practices seen as cultural practices as well. Nonetheless, these are said to be respected and well received in terms of advance directives and within the context of holistic hospice care.

‘If there was a religion...there are specific events or specific things like a purification ritual or something as they were dying...that will signify the grief as well. Like in Irish culture there is a wake. That is a cultural belief, is it not?’ (Janice, 47).

‘Like culture, you know. For example, I had a Muslim lady, whose husband I looked after, it was a great privilege, and she rang me up to say - -. She would like to come up and see me. And I said that is alright. That is great. ‘Would you like to come to the hospital?’ And she said ‘no, I am not allowed out of the house for a hundred days’, which I had no idea. So, these rituals need to be observed, need to be respected’ (Carol, 42).

In the face of future changes in EOL care (DoH 2013), explicit policy seems to be lacking. Policy that addresses not only conceptual needs on a mainly theoretical basis, but finds the right language to communicate them to professional practice, and which shows thorough understanding of the difference between accommodation of request and integration of faith, belief or values, and principles.

Universal Spirituality

Four (4) of the research participants responded to the question including non-religious people that there is not one person that has no spirituality.

‘...I think people are not necessarily aware...you know, of their spirituality. It {spirituality} is there and it is alive but they {people} are not aware of it, sort of still living through them but not be able to explain it or they might not think that they are

spiritual. People....even if they are not religious for instance, they might pray as well...’
(Mary, 29).

‘There is, though, another element, which is spirituality, and in my experience, everybody has a spiritual identity....I think it is incredibly rare not to have a spiritual identity’ (Shahid, 33).

‘I do not think I have met a person who is not at least spiritual’ (Michael, 43).

‘Spirituality is very important. People, no matter what their religion is or not or whatever, they are spiritual’ (Alex, 44).

Service users are seen as spiritual beings, often tantamount to religious. The challenge with this is twofold. Firstly, the statements contradict the previous findings by some participants. Those showed that spirituality is a very personal matter and that it can be defined only as such, whereas with this in mind the category *universal spirituality* seems provocative. Second, spiritual care has been embedded in hospices as the means to respond to religious needs. Therefore, there is a question whether non-religious people are seen as such, or if HCPs are describing their views in this way, which will serve for their comfort.

Unique understanding of religion and belief

Along the same lines, of considering religion and belief as important aspects of an individual’s identity, HCPs, at large, suggested that the level or type of importance that the individual takes on it is completely down to their personal association with it:

‘I think it boils down to the individual. I find there are some patients who are atheists; they are agnostic, have no faith at all, and they have - - they go through the death process very peacefully, and think ‘I have had a nice life on earth, I am sad, but I am not worried about stopping breathing and going to nothing.’ Some people are traumatised by that.

There are other people, who are deeply religious, who have deeply traumatic spiritual and psychological dying process and thus they do not understand why - -” (Peter, 31).

In her interview, Mary (29) was asked about the concept of individuality in relation to religion and belief. She responds: ‘Everybody is different, so I think people’s faith or no faith, people respond to reacting in various ways. If that makes sense’.

More HCPs referred to the individualistic interpretation of their faith, often linked to cultural beliefs (also see, Day 2011), as well as contextual meaning-making through experiences of DDB.

‘I think it is very very complicated. Religion and spirituality on an individual level. But I think it is not just that. It is remembering to have some context of these particular religions and their frameworks so that you have some understanding, but I think you need to look at it at each time on an individual context and figure out what does that mean for that individual’ (Judith, 24).

‘A lot of people question ‘Why me?’ they question their faith and actually when...then again when a younger person who has been struck before their time and their terminal illness will question their belief and their faith, and sometimes that is enough to shake someone’s faith. A lot of guilt sometimes. It varies from one individual to another’ (Carl, 51).

Once again, this finding proves the core argument of this thesis; HCPs shall be religious literate in order to meet needs of the service users, in connection with religion, belief, and spiritual identities.

Decision-making

Only two HCPs interpret religion and belief as important aspects of service users' lives, yet due to assisting in making important decisions in life:

‘It [religion] influences all the values that are important and affects the decisions and choices people are making throughout their lives. And to my experience, when people are poorly, that is magnified even more so’ (Alex, 44).

‘Whatever belief they [patients] have, it is important because that is how they will make their decisions. When we ask family to let us know about how they want things done, this is how we know. Often they [family] will say that they will cremate or bury or whatever, and it is because their belief says so’ (Mirna, 48).

Even though only two participants suggest this, it is still an important category given the limited number of inpatients in a hospice, as well as the small account of HCPs interviewed (22 in total) and participated in group discussions (8 in total). In relation to this category, lack of religious literacy may lead to lack of understanding of the decisions of the service users. Such decisions may be affecting the treatment, pain management or other decisions, such as advance directives. This is a significant challenge that appears to contribute to how religion and belief are or are not integrated with professional practice, as we will see in the next chapter.

Religious Literacy: controversies and challenges

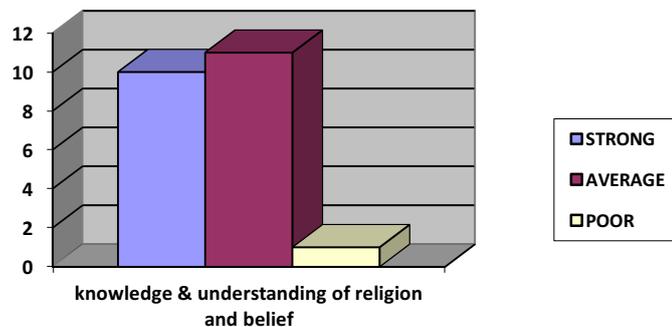
This chapter reports on findings directly linked to HCPs' perceptions of their knowledge and understanding of religion and belief, as well as skills and abilities to engage with them.

Knowledge and Understanding of religion and belief

Religious literacy in this thesis also refers to acquired knowledge about religion and belief, understanding of the knowledge, and willingness to expand it. Prior to introducing this topic in the interviews, research participants were asked to provide the researcher with a rate of their level of knowledge and understanding of religion and belief. This self-assessment assists in analysing the information collected via the interviews, but also acts as a counter fact that is used to contrast and analyse data against.

All participants were asked to rate their knowledge and understanding of religion and belief on a scale between poor, average, and strong. The results are shown in Figure 7. Ten (10) of the respondents suggest that their knowledge related skills concerning religion and belief are STRONG, another eleven (11) support to be on an AVERAGE level of knowledge, while one respondent assessed themselves with POOR in this question.

Figure 7: Self-rating knowledge and understanding of religion and belief



Nineteen (19) of the research participants approached this question, along with many others, from a Christian-centred perspective. There was an element in the responses suggesting that the questions were concerned with other than Christianity religions and beliefs, rather than identities of any faith and none, as introduced in the induction session of the study.

This finding supports London's (2008) reviewing comments that Anglican churchmen relied on their pre-existing Christian-centred worldview, to address new issues. Alike, HCPs appear to evaluate their level of engagement with religion, belief, and spiritual identity, based on their Christian-centred knowledge and understanding. If we look at this finding in comparison to the findings presented in Chapter 4 (*Attitudes*), there is ample evidence to support that HCPs are driven by Christian-centred attitudes, which in relation to this thesis enhances religious illiteracy.

Eight themes have emerged from this category: knowledge and understanding of religion and belief (Figure 8); six regarding knowledge about religion and belief, and two about how HCPs understand religion and belief. HCPs, in general, suggest that they are knowledgeable and that there is considerably good understanding of religion, belief, and spiritual identities. Nonetheless, when asked to elaborate, suggestions shift toward assuming knowledge and most participants further avoid to claim proper understanding of religion, belief, and spiritual identities. The following subsections expand on the findings.

Figure 8: HCPs' Knowledge & Understanding of Religion and Belief



Knowledge by assumption

A large number of the sample (21) assume their knowledge and understanding of religion and belief, as well as the factors that will get them engaged with such identities of the service users. It has been apparent throughout the interview process, but also later on with the focus groups, that professionals on the one hand they take ownership of their comfort and set of skills in order to engage with religion, belief, and spiritual identities. However, when asked directly there is hesitancy in responding to it clearly, but feel at best comfort to assume their own awareness on the matter.

‘From a religious point of view, there are some things that are incredibly important, and you probably know and are respectful for that, and have some insight I think’ (Jeremiah, 58).

‘You probably have lots of awareness. And this is sort of...your knowledge’ (Jenny, 24).

‘I would assume that you have knowledge and probably have awareness of it’ (John, 53).

‘I am sure that you know and hopefully you are aware of these things’ (Janice, 47).

‘I mean...I probably have lots of awareness, and you know...I am aware of things like that’ (Michael, 43).

‘I think that I have a lot of knowledge about these things. I might be Christian but I still know so much about other religions, I am sure I do’ (Mirna, 48).

In all answers, in response to the question regarding knowledge and understanding of religion and belief and how professional practice integrates such identities, HCPs used vocabulary such as ‘think’ ‘probably’ ‘might’ ‘guess’ ‘would suggest’ ‘possibly know’ and ‘assume’. The choice of words indicates uncertainty of one’s knowledge. It points that the interviewee might have not been challenged on answering these questions before, and therefore an indicator of not having had thorough analysis of how, when and why such social aspects of individuals’ identities can be integrated into practice. Also, uncertainty on this matter by HCPs is contradicted by health and death policies that suggest holistic and spiritual care as results of high expertise and professionalism by the NHS staff (DoH 2008).

An additional element in this category adds to the Christian-centred approaches. It is taken as an ability toward having an understanding of different beliefs and faith in general; similar to a requirement.

‘And I do not need to be a Muslim to know what Muslims want or why. I probably know a lot of things as a Christian...and, you know, I can respond to all these’ (Janice, 47).

‘I mean...yes is the answer. It is my belief, my religion that has taught me to be sensitive about different faiths. As a Christian I,... I am confident that being a Christian really helps me do my job much better and understand all other faiths’ (Gita, 59).

‘My Christian beliefs have definitely helped me be more understanding, and...I understand things...’ (Anna, 59).

It is unavoidable to link the above with the origins of the hospice movement (Saunders 2005; also see Walter 1994). The care of the dying and the bereaved, in the West, was driven by Christians and in a Christian-centred context. Inevitably the principles and values of hospice care developed around Christianity, and thus similar principles became centric to the HCPs’ education. Nonetheless, the ongoing changes in the composition of the population, cultural diversity, including religious, demand further competency building and training. This has generally been taken into consideration. However, how such emerging needs in education and training have been looked at reflects on a Christian lens and a secular-minded approach (Also see Davie’s 2015 review *Religion in Britain*).

Regarding non-religious beliefs, only one HCP addressed the matter by saying that:

‘All religions, I feel they offer something really good, really great; really sacred, and I think for people who do not have religions that is their right that is fine. They can often be much nicer people than religious people. So, I am just open about it. Not casual, but open about it’ (John, 53).

Once again, there is an element of assuming knowledge. An additional and important suggestion, however made with caution, is that there is a notion of clustering religious and non-religious people as nice and not nice people respectively. In his statement, John attempts to come across as open and comfortable with all different forms of faith. Nonetheless, he is succeeding to indicate discomfort on the grounds of suggesting that non-religious people can be nice as well when the question has not been intended to address this matter.

The latter is partly linking to Campbell’s work (2013). In it, Campbell argues that *irreligion* is an important aspect of religion, and which refers to the acts and processes of rejecting religion.

When non-religious service users are perceived as ‘not nice’, the following argument is raised. Are HCPs, who suggest so, religious and this is merely a form of judgmental attitude which jeopardises the service delivery in the long run? Or is this pure coincidence, and when HCPs say that non-religious people are also nice, they just make use of this coping mechanism that invites them to understand something different than what they believe? No matter which one, this study shows that HCPs suggest that they acquire adequate knowledge and understanding about religion and belief.

Basic knowledge

As soon as the conversation went deeper and further, and complementary questions were asked, the majority of the respondents refrained from having the thorough knowledge that was framed in previous responses.

‘I think I have got a sort of like an overview of the different religions. But most of them I do not know in detail’ (Carl, 51).

‘I think I have enough knowledge to adapt but I can definitely do better than just the basics’ (Carol, 42).

‘I have reasonable knowledge about religion and belief in this setting, and that just from my experience and work. ...it is my experience that there are certain cultures that have radically different views to those that I hold myself personally, or that I would suggest palliative care holds’ (Peter, 31).

‘I think I have some knowledge...on some religions, mainly the...if you like the more European English ones, Catholics, bits and pieces like that. I have very little understanding of some of the more African expressions of religion. My knowledge is quite limited I suppose’ (Jenny, 24).

There is a general acceptance of mainstream knowledge attained, mainly through own religious background (i.e. 'Being a Christian I have gained knowledge of other religions' Mirna, 48). There is though a tendency for HCPs to direct responsibility of their limitations to their education or lack of education. Dorothy's (37) response illustrates this in the best way:

'I think you can always learn more, can you not? I mean I have not done a degree in theology, I have not done any courses in theology and have not studied different religions, so I have basic knowledge, I know what to do, to do the right thing and to care; how not to upset people that - - we are always learning, aren't we?'

Questions regarding knowledge and understanding of religion and belief aimed to address how HCPs respond to the diverse faith identities that they come across in professional practice. Scholars on the subject include the following. Daaleman and VandeCreek (2000) have suggested that religion and belief not yet found their right place in EOL care. Hermann (2000) found that dying patients have unmet needs about the spiritual aspect of their identity, whether that includes religion or not. O'Connor (1988), on the other hand, in the late 1980s, suggests that professionals have not yet acquired the full skill set in order to meet spiritual needs of the service users.

It is clear from the findings and extant research that there is conceptual misunderstanding of faith. Research participants indicate that having some basic knowledge of different religions (i.e. times of prayers for Muslims) amounts to proper religious literacy and effective professional practice in hospice care. However, these indications have similarities with O'Connor's (1988) group of professionals, as the latter also claimed basic knowledge of religion. The extract above shows how potential lack of knowledge and/or understanding are justified by professionals.

This is also enhanced with Dinham's and Francis's (2015) work, in which they highlight that religious literacy is not acquired with simply getting to know more about more. It would be utopian to expect that HCPs would be able to hold in-depth knowledge and understanding of every religion and belief system in the world. Religious literacy is concerned with being comfortable about religion and belief, as well as asking the right questions and working with service users' identities.

Strong knowledge

Only a few individuals, beyond the self-assessment scale, support in their interviews that they have a strong set of knowledge and understanding about religion, belief, and spiritual identities. The following is the only quote that refers to this directly.

‘I mean...as I grew up I was exposed to numerous different cultures and numerous different faiths, which for me if you like, was also a journey of discovery. So, I was fascinated by different beliefs and different thought processes, and then again as an individual you always have-you always question things in your own mind’ (Mark, 61).

Strong knowledge is a good start, which needs be coupled with strong understanding of that knowledge, and eventual integration of that understanding in professional practice. Research shows (Crisp 2008) that spirituality is a lived experience, which professionals shall consider as subjective knowledge in their helping professions. That said, current professional status that stems from a secular-minded educational background may clash with Crisp's suggestion as it is taken into consideration for professional development and practice. Despite the contrary, religious literacy, as well as subjective knowledge are context-bound; they can only be appreciated and understood through the context in which they are experienced (also see Dinham & Francis 2015, for religious literacy).

Knowledge exchange among hospice staff

More than half of the respondents (15/22) suggested that even though knowledge is limited within self, there is always an opportunity to learn from one another:

‘I think that the good thing is that we are, most people in the hospice have worked here for a long time, so it is like been developed, so it is quite an experienced...team. ...Your knowledge is constantly pulled, you know. So, in the end there is awareness and knowledge that we will learn from each other’ (Alex, 44).

‘Working here also means that we get to talk to each...it is with peers that we learn. If I do not know something, then someone else does and we learn this way. I guess this is awareness anyhow...’ (Nick, 41).

The experience of knowledge exchange has been identified by Shahid (33) as a support system, which can only benefit service users: ‘I may have the skills to address some of those issues, but I may need support from within the multi-professional team to support better some people with some of these questions’.

Often, research participants considered seeking extra information from colleagues an essential tool in their work. This is a well-established and most times necessary principle in hospice care, however, it primarily refers to *information transactions*. Mere facts of religious practice are hardly enough evidence to present a service user’s understanding and meaning of life and death. Similarly, information based on the past experiences of other hospice staff are narratives of the HCP’s life, and not a pure representation of a service user’s beliefs. This poses questions and ethical dilemmas in what informed-based practice may be or how that should be shaped. It also raises concerns in whether informed-based practice is not necessarily evidence-based but purely subjective knowledge, as described by Crisp (2008).

In other words, information transactions take place but fail by nature to carry out the deep meaning of the data, while the same piece of information is the result of the HCP's experience in relation to, for example, a dying service user's religion. This fails to consider believing as a unique experience within individual consciousness. The latter was also underlined with Berger (1999), when he changed his position against religion and belief in the public sphere, and suggested that his work before that time has been wrong, and that religion and belief have always been present, both, in individual consciousness and the public sphere. Belief has no universal example of practice. It is a unique and individualised experience which would hardly be communicated from one professional to another, unless the professional's post was to dedicate time and space for rapport building and working through sessions for some period with the service user.

Increased knowledge by professional setting

Religion, belief, and spiritual identities were all seen by HCPs as being related to hospice care and end-of-life support. At large, research participants suggested that professional experience within a hospice naturally leads to increased awareness and knowledge of religion and belief.

‘Working within palliative care you are probably more aware of people’s spirituality and that it is not just around religion. Spirituality covers much more than that. I think, maybe if you don’t work within this sort of area, you might not have this sort of awareness’ (Margarita, 36).

‘Hospice we work really helps you know much better about religion and spirituality. I guess if you work here then you are more likely to know better than a nurse in a hospital for instance’ (Carol, 42).

‘Working here helps I guess. I am definitely more aware because of being employed in palliative care’ (Judith, 27).

It is identified as a unique healthcare setting, in which respect and dignity of religion, belief, and spiritual identities are better preserved and promoted, as opposed to other healthcare settings (i.e. hospital).

‘I think that here at the hospice we are better than another healthcare setting. I think we understand the concept of...we use the terms religion and spirituality. I think we are a bit better understanding there might be a particular religious need that needs to be met for a particular family’ (Mirna, 48).

‘I worked in a hospital for two years before here. The difference is that here we talk about spirituality, you know. In the hospital we did not that much. Having these conversations make you more aware...you know more...you know...’ (Cirik, 46).

Johannes (39) made a comment that hospice and conversations about religion go hand in hand. ‘In hospices, due to the setting, you know that people will go in deep conversations about religion because this is what you are supposed to do’. Similarly, Cirik (46) points out that hospice settings allow for your knowledge to develop further and expand when it comes to religion and belief. ‘Working in hospices you become exposed to even more beliefs and even more traditions that you have been exposed previously. So your knowledge expands’.

Worth mentioning is the age gap in the responses, something that will be highlighted in the conclusions, however, necessary to mention here. It is shown in this study that HCPs above their 40s are more contradicting to their statements across their interviews. An example to illustrate this is Jeremiah’s (58), who in the question of whether he feels that religion and belief are well integrated with professional practice, he says ‘...not really. There is so much to do still’. Nonetheless, referring to the current category, during a focus group he suggests that ‘palliative care is as good as it gets for the healthcare setting. Working in the hospice makes you learn so much more about religion and belief’. It is evident by his responses that two

different stances are adopted according to the situation. It is likely that HCPs shifted views when having given answers in a focus group or during the interview.

Again and again HCPs referred to the privilege of the hospices being of a religious background, which automatically placed them in a position of learning more, or having more opportunities to learn.

‘In this institute it is slightly unique, because of the background of religion in this hospice, and because we look after dying people. So again, I mean, if you go in to someone and have their knee replaced they might ask you what religion are you, and they might...and that will be the end of the story... But here, because someone is dying and families are going to do... a priest is available, and they will be offered one. So again, I think it varies from setting to setting. You know, our setting is giving lots of emphasis on this and you know better by working here’ (Gita, 59).

However, one participant, Raul (26), suggests that ‘people here think that because they call it ... that they also know things’. Other participants focused on concepts as non-judgmental care, and tolerance in order to demonstrate their knowledge, as well as that hospice settings and palliative care, are the right places to develop these skills further and better.

‘As I specialised on the palliative care site, so I have become more aware of that aspect of care, and I said I have become more tolerant. Non-judgemental is very-very important even if you do not agree fully with what has been said. In this hospice you learn to respect others’ (Carlita, 46).

A minuscule number of the participants (2) acknowledged that working in the hospice has led them to a deeper understanding of the importance of religion, belief, and spiritual identities.

‘Initially it did not seem to be as important as their emotional, mental and physical well-being. It is only as I have grown older in the profession and in this hospice and my life

experience is showing me that this aspect of life is very important for someone' (Mark, 61).

'Physical and mental health are the most important, and that is what I always remember in my practice. But I guess, since I came to this hospice I have realised that religion is very important to some people as it even affects their physical and mental health' (Peter, 31).

With this in mind, all research participants showed agreement that working with EOL matters puts them in a position to either have more opportunities, with regard to spirituality and religion development, or provides the space for a better understanding of why these aspects of life are important. Indeed, there is a strong link between caring for the dying and/or the bereaved and understanding of religion and belief (Golsworthy & Coyle 2001). Nonetheless, there is no evidence showing that the understanding of religion and belief does not refer to the personal beliefs of HCPs, and not to a general comprehension of belief, or faith (also see Crisp 2008).

Study days and training

There is a general acceptance by HCPs that training in this area has increased throughout the years, and that organisationally, this area has been taken more into consideration that it has been before.

'Spiritual care is actually seen as an important part in the culture of this hospice, and everybody who starts here does spiritual care training level 1, at the time of induction into the hospice. And there are subsequent levels of training in this as well, if you want to do them' (Jeffrey, 39).

'Our knowledge is brought to us through our training. Then if you do specific training, because certainly you can do degree master levels, modules, and sort of spiritual care

for the patients. I think it is much more taught than it was used to be for healthcare professionals' (Carlita, 46).

Nevertheless, Anna (59) indicates that having had the day workshops and study days in the hospice, has really been enough for HCPs to be identified as knowledgeable professionals. 'We all have spiritual care training in the hospice. So we are knowledgeable' (Anna, 59). Alike, Janice (47) says that 'you learn something from your training and you have sort of study days at work, you sort of pick it up and know what is going on'.

Study days and general training of the staff is paramount toward inclusive, competent, and literate professionalism when it comes to religion, belief, and spiritual identities. There is though a notion of misunderstanding of how and why training may act as that. HCPs seem to address attendance to the study day as a preceding factor to knowledge and understanding without any particular work in-between or afterward. As seen later in this chapter, there is an expectation for one-dimensional training, as opposed to learning experiences through interactive training. The training is currently expected to provide HCPs with one person talking to them, giving guidelines of how, when and why, but the lack of critical and reflective knowledge and learning.

Lack of understanding

Conscious responses regarding knowledge of different religions and understanding of that difference in faith systems have come across widely depicting HCPs with a fair amount of it. However, this category is created from capturing elements in the responses that showed the opposite; HCPs show a lack of understanding of different faiths, different religions, and beliefs. Simultaneously, the difference among different religions is found to be *obscured* or *out of the ordinary*.

‘Some times patients have beliefs that do not make sense. We had a request from a patient to come to the hospice here to London to die, from Brighton. He lived all of his life in Brighton, and we just went, ‘well, why?’ And the patient was of the Baha’i faith, and their belief is that after somebody dies, they have to be buried at a distance no further than fifty kilometres from where they died. And, so, they were asking for him to come here, so that he could die here, and then be buried in a Baha’i cemetery, which was within fifty kilometres from here. Again, sometimes you question things, but that is your own personal thing going too. In Baha’i religion, there were no kilometres at the time. So, kilometres came out in the eighteenth century. So, how they managed to measure the distance and bury them in fifty kilometres, I do not know. It is a belief, and we were more than happy to accommodate them, but I do not know why they had to’ (Jeremiah, 58).

Carl (51) admits that he has seen all kinds of faiths that are out of the ordinary, in his career:

‘So many faiths I have seen, strange ones...and...the beliefs and practices are so not normal as we know them’. When asked to specify what the ordinary is, we end up talking about Christianity: ‘Well, we are Christians here [in this country] and so the normal is to practice that, right?’

Additionally, Nick (41) is taking a defensive stance toward Christianity and says that ‘not all religions that people represent are appropriate in the hospice. We have to respect other people too, like Christians’. At this moment Nick is projecting his lack of comfort in engaging with different religions, and he is identifying with Christianity as a personal belief. His statement suggests two things. First, that there are belief systems and faiths that are inappropriate for the hospice setting and against Christianity, and secondly, that having one of those beliefs would naturally mean disrespect toward Christianity.

Over 80% of HCPs state that religious practices and requests when it comes to hospice care are generally *weird* or mere traditions, and therefore not always viewed as personal preferences.

‘Patients and family have all these weird requests, like the bed facing Mecca when someone is dying, or lighting a flame when someone dies, but we have to meet their needs as it is part of holistic care’ (Michael, 43).

‘Practices like Mecca are just traditions. Those are not religious practices, like prayer, so we will accommodate as we can but not to an extreme’ (Nick, 41).

‘There was this particular situation, the person’s...there was a family and the wife had cancer, and it was felt that the husband’s, how to put it, unfaithfulness to her had somehow angered...she had become unwell with black magic. And the husband’s fear was that if she died, and he was hoping that she will not, her father would be very-very angry and would come to England where they were living and would kill him. No matter how many times we have told him that this is never going to happen and that there is no black magic, he kept believing it, you know’ (Carlita, 46).

The above extract from Carlita demonstrates professional reactions beyond the lack of understanding and shows that HCPs sometimes might as well embrace the change of beliefs if those are traditionally different from the ones that are usually addressed in experience. Furthermore, Nick (41) says:

‘Even with Muslims for example that they want to bury their loved ones within twenty four hours, if it is twenty five that is still fine, why would they [family members or friends] get so upset?’

If we examine the current findings in relation to the changes, challenges and controversies of religion in the public space (Dinham 2009; Davie 2015), religion and belief are essential

aspects of lived experiences of the individuals, which have not been well thought in the past decades, when EOL care was planned out. Death and dying settings are currently secularising while religion, belief, and spiritual identities remain essential to the service users (Pentaris 2013). On the other hand, HCPs find themselves before service user needs, which they lack understanding or adequate insight in order to assist.

Religion sets boundaries

Six (6) research participants state that religion and belief are categories that set extra challenges and barriers in healthcare. In more detail, the case of Jehovah's Witnesses is discussed in the quote below, which shows that HCPs might view a particular belief system of the service users as obstacles toward delivering healthcare services.

‘In the healthcare setting I feel that you can have expressions. For example, let us take the ones [religions] that bring up health care issues, and that would be Jehovah's witnesses, so the religion would define the kind of care they would receive or reject. I think swinging toward the other end, certain religions have very set rights after death’ (Judith, 27).

Likewise, HCPs appear to pose critique on patients' preferences on the grounds of their religious and/or spiritual beliefs. Alex (44) says that ‘Often times the case will be that if someone has a religion this will automatically tell us how their treatment must be delivered, which might not always be the right way’. It is also indicated here that treatment, according to HCPs' opinions, is religiously bounded. The latter contradicts with earlier findings, nonetheless important.

This study has shown (Chapter 5) that HCPs perceive religion and belief as a guided lifestyle, which often is enough. HCPs have also indicated that religious people are always in an advantageous position, in terms of how their dying or grieving is experienced. This has also

been examined by Garces-Foyle (2006), who has considered how different religious people experience death and dying, and concludes that religion is an important mean toward peaceful death and acceptance of loss.

Despite the contrary, HCPs find beliefs to carry out barriers to their practice. It may be the nature of the helping profession that HCPs experience failure in the face of accepting the death of a patient (Bern-Klug 2010), or it might, as well, indicate resilience toward different approaches in dying. No matter which one it is, this finding is far from integrating and positively reflecting on the subjective experiences of the service users, whether religious or not.

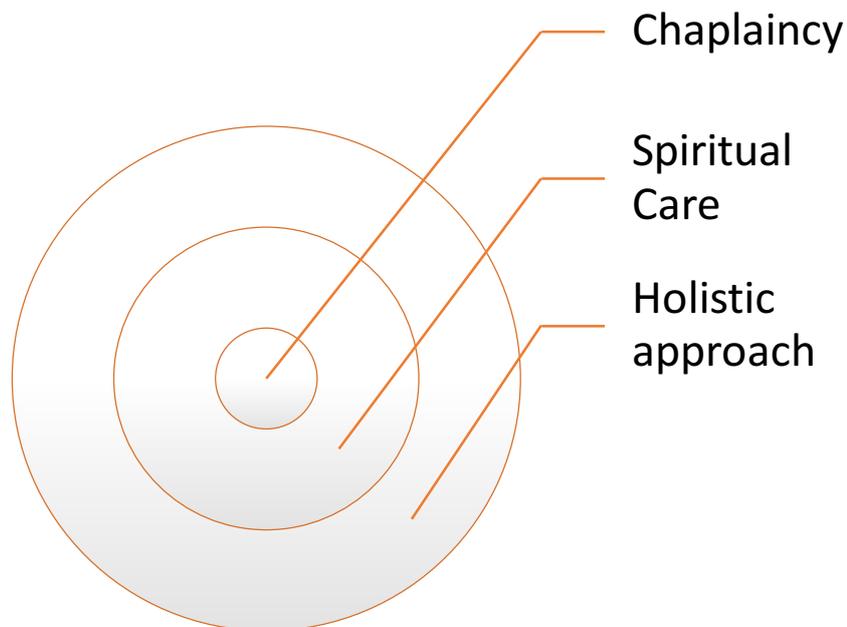
Skills and abilities to engage with religion and belief

HCPs have either demonstrated or were asked to share how they perceive their comfort level when working with people who are either religious or of no religious belief at all but yet experience a form of faith; of spirituality as it has been described by HCPs (also see Chapter 4). In this, HCPs were asked to elaborate in terms of their abilities and skills to respond and address religion, belief, and spirituality in hospice care.

The categories that induce from this part of the interviews, as well as from the focus groups, cluster skills and abilities that concern religion, belief, and spirituality, in chaplaincy, spiritual care, which is undertaken by religious leaders, and holistic approach, which is a social care aspect not always linked with the medicalised model in healthcare and hospice care (Figure 9). Data show that HCPs turn to the chaplaincy team when a service user requests services that relate to their spiritual or religious identity. If support is not available with the chaplaincy team, spiritual leaders from within a community network are available but upon appointment. Last, data show that HCPs consider the above approach to the subject as an element of effective and efficient holistic approach in hospice care. All themes that are explored in the following

subsections, are rooted in holistic care and the role of the chaplaincy team, as HCPs perceive those.

Figure 9: Religion and Belief Integrated in EOL care: Approaches



Asking about religion and belief: resolving the pragmatic, measuring belief, or finding guidance

Indifferent from whether the professional was a clinical one (i.e. physician vs. dietician) or not, HCPs, on a 100% tie, appear to be willing to ask what religion people have, or which religion they (service users) affiliate with, for a number of reasons. Between the most important ones are, initially, asking about religion and belief because legislation requests it and it is indicated in health policies. This reflects organisational theories, and, in particular, bureaucratic and technocratic theories (Hughes & Wearing 2013). Hospices may be seen as machines that run as a business that needs to meet efficient outcomes and be productive in all. That said, HCPs follow on guidelines that have been designed for that purpose.

Religious belief or affiliation becomes an indicator of care and a piece of information for the HCPs, which will answer pragmatic questions surrounding the care of the individual (i.e. food). Lastly, asking about religion and belief is the means of avoiding potential harm in the form of spiritual distress to the service users.

‘...it would always be asked in any transition, any admission, and it is sort of like what their religious beliefs are, you know? That will always be asked. That can have direct affect to their healthcare, for example with blood transfusions, etc.’ (Jeffrey, 39).

‘Jewish people do this and that and you know, obviously I have lots of experience, but I cannot rely on that so much, because it is so different from every individual family; how they express their tradition, so it is just about asking the family and the patient; making clear...things that have implication for their care’ (Carol, 42).

‘We would be very much guided by what the patient is telling us, as to how they – they would like to be treated based on their religion’ (Johannes, 39).

‘I never make assumptions....If I am not sure, I always stop, and think and ask people what they want. So, I do not cause up upset or distress’ (Margarita, 36).

Despite the drive to ask patients, what is common in the findings is that often HCPs will start the conversation after the service users have let them know that they would like to be asked or discuss this matter. The responsibility therefore lies with the patients in the hospice, and not the professional team:

‘You have to always ask a patient, with an open mind I suppose you need to know. What you need to know is that there are things that you need to ask for and know when it is time to ask for those things, so that is more important than all the experience I have’ (Peter, 31).

‘I am very comfortable, because I know...sometimes they are waiting for you to ask, so I have the responsibility to ask. If you ask in the right way it is very rare that there will be people that sort of get upset, or you know, you need to be aware of how far you would go with asking, etc.’ (Dorothy, 37).

‘Of course we will ask them, but also you have to wait till they (patients) tell you that it is the right time to do so. Otherwise you might be upsetting someone. I would definitely ask them if they would like to be asked! (Janice, 47).

Findings here show that HCPs expect that service users are the responsible individuals for whether their belief will be taken into consideration, and if so how, for integrated hospice care. This finding seems to question the skills and abilities of HCPs to engage with religion, belief, and spiritual identities of the service users. Nonetheless, as it has been shown by findings reported in Chapter 5 and earlier in this Chapter, this might relate to an issue of general ambivalence toward difference. Also shown by the conclusions about Christian-centred thought processing in hospice care. Therefore, and in this instance, skills and abilities to engage with other than Christian beliefs may be questioned. However this is a hypothesis that needs further exploration.

Approximately half the participants of the study (10) indicated that religion, belief, and spiritual identities are not the priority to be confirmed when patients are admitted. This has a twofold meaning. First and foremost, it underlines the medical models of EOL care, as well as the bio-medical approaches employed by HCPs and the organisational foundations (also described in my critical analysis, Pentaris 2013). Secondly, itemising the gaining of knowledge relevant to the service users’ faiths and belief systems undermines their dignity as it also indicates lack of respect on someone’s preferences in care. An additional comment on this is the contrast of such conclusions with the intent of holistic care and palliative care. The latter

focuses on the psychosocial and spiritual care of the individual, as well as pain management, but not on treatment.

‘But we do not really sit and ask people about that [religion]. I mean, rightly or wrongly, when people are really feeling ill and tired and drowsy, they are not in the right mind-set or place for those sort of debates really. But we are happy to open to their families and friends if we have the time’ (Anna, 59).

‘Definitely we will ask, but it is not the first thing to ask, and to be honest it might not be touched at all. I mean, it is not the most important thing when someone is admitted. If it is not brought up in the conversation, then there is no need to explore more at that point’ (Michael, 43).

In the extracts above, what is striking is that deliberately the aspects of belief, faith, religion, spirituality, and so forth, all come across as non-prioritised matters. This is largely questionable, however. Hospice care is developed around the psychosocial and emotional care of an individual, for whom treatments and medical interventions are no longer an option (also see Saunders 2005). If the priority in hospice care, according to the findings of this study, is of medical nature and treatment-centred or medication-centred, what we are left with is a failed attempt to define hospice care. WHO’s definition of EOL care has as a core the enhancement of quality of life, and that prolonging life is not the aim. Also, in the definition it adds that spiritual aspects of care shall be integrated. This is one of the examples that illustrate the contradiction and controversies with the findings of this study.

HCPs mention that avoidance of assumption in religious belief is preferable. This is age centred as younger professionals suggest similarly, whereas their older counterparts do not refer to such concepts.

‘Generally I think we are quite good, because I think we are not afraid to ask. And I think that is one of the key things. I think...in religion you want...specifically in religion you do not want to get things wrong and offend people, and saying the wrong thing or making the wrong assumption, and I think the sympathy to do so is not to make any assumption but just simply ask’ (Raul, 26).

‘...and that every patient when they are first admitted if they are able to answer, [then] fine, if not the...their family is asked if they have any particular religious or faith belief’ (Jenny, 24).

‘...all patients are asked what their beliefs are, and whether they would like to see any person from that denomination’ (Mary, 29).

This is an indicator of the education received by different generations, at various times, and in relation to the shifting face of religion in the public space. Nonetheless, older individuals that would not refer to the above stances have had a longstanding experience in hospice care. On the contrary, younger professionals have practiced in hospice care for a very short period, and this might be a variable that influences the above as well.

Even so, there is a general notion from the findings that has HCPs believing that professionals who do not feel comfortable engaging with religion, belief, and spiritual identities should not be practicing in a hospice. That is because, according to HCPs, occupational hospice posts are only for people who are religious themselves to be able to understand the service users’ religions.

‘I mean I have to deal with its...entirely basis, so again, it is part of my job if you like. So yes, if I was uncomfortable with those discussions I should not be doing this job’ (Janice, 47).

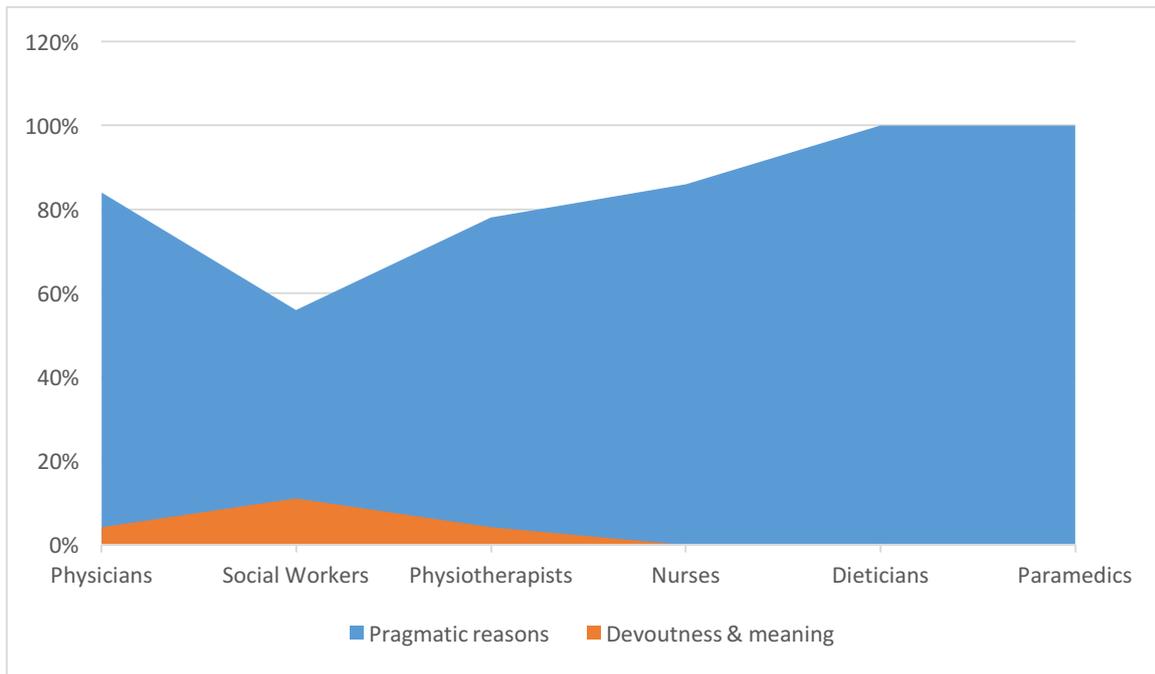
‘If you feel uncomfortable, then maybe you should not be here, right? I mean, if you have your own religion and you are a Christian, then obviously you can understand all this and can connect to it’ (Carlita, 46).

‘You cannot feel uncomfortable if you work in hospice care... I meant,...- caring for these people is spiritual in itself, you have to be religious or spiritual yourself. I would not be able to do it if I were not a Christian...’ (Carl, 51).

Figure 10 depicts the reasons why professionals would seek knowledge of the service users’ religious or non-religious belief and practice, by profession.

Two categories emerge from that: *pragmatic* and *understanding*. HCPs ask individuals what their religion, belief, and spiritual identities are, mainly, as shown in the figure above, due to pragmatic reasons. Examples of that are food preferences, gender match (i.e. female professional with female patient), funeral preparations, visitation style (i.e. how many people and for how long). On the contrary, only a small number of professionals, mostly social workers followed by physicians and physiotherapists, ask religious or belief related questions on the purpose of understanding how the individual is experiencing their dying, imminent death, and/or grief and bereavement.

Figure 10: Reasons for asking about Religion & Belief by Health Profession



It is clear from the same Figure (10) that nurses, dieticians, and paramedics have only addressed this set of questions due to pragmatic reasons, the first category. Social workers, physicians, and physiotherapists have an additional agenda for gaining insight of the person's experience.

'I cannot know whether we log their devoutness. Because I have - - I know of them [people who are devout Christians or Muslims] but I have never witnessed that element of it. In the community we talk about that with people, but I have not actually seen this in the ward. But I do know that in our prayer areas...I have seen very regular use of that. So, I think in terms of devoutness the needs are accommodated in respect (Anna, 59).

Devoutness level of belief is in general not an aspect of someone's life that HCPs (including all professionals added to the Figure above) will register, or gain knowledge about in overall. This results in lack of insight into the individual's meaning-making process. In addition, this counteracts with 'spiritual care' in EOL care (also see social policies subheading). Further, this

proves that HCPs are mainly interested in collecting information regarding religious practice and religious-centred traditions of the service users. Albeit important, such practice perhaps defies the principles of holistic care and holistic approaches, as well as the NHS Constitution (launched in March 2013), which presents suggestions with regard to dignity and respect for the individual, compassionate care, and informed choices of the service users.

Lastly, only one research participant finds that religion can act as a facilitator for hospice care:

‘Talking to patients in religious or non-religious terms I think is important because it enables us to have a conversation and explore what does this mean to that person. What are their fears, what are their worries, enables us...it facilitates a dialogue’ (Carl, 51).

Even though only 1 participant suggests the above, it is still worth exploring the following. This finding complements the point made earlier, that service users are asked about religion, belief, and spiritual identities, when that piece of information will solve pragmatic challenges (e.g. how many hours before burial) and that it will facilitate professional practice within EOL care. This is underlined as the main reason HCPs should be asking about this social aspect. ‘We have to. Otherwise, how will we know if we burry them or cremate them or whatever’ (Peter, 31).

Religious/Spiritual Care Toolkit

Over half of the research participants stated that, within the hospice, they have either generated their own or borrowed a *spiritual care tool*. With that tool HCPs respond to questions regarding ‘abilities in relation to religion and belief’ their religious literacy and also that they are well prepared and comfortable to engage with religion, belief, and spiritual identities in EOL care or healthcare in general.

‘We have a spiritual care tool that has been piloted for a year by a couple of nurses, but I think it is just very recently that it started to be used’ (Mirna, 48).

‘All the tools in spiritual care help us talk about religion with patients, or not exactly talk about it, but at least we note it down’ (John, 53).

‘There are definitely forms that religion is included in them. I mean we ask people, but of course only if they are able to answer’ (Dorothy, 37).

References to such tools also relate to the initial assessment; the admission process and the way information is gathered:

‘Simple thing, when we do the initial assessment with all patients, we always ask about physiological stuff like the food they prefer, but then it is the meaning that their choice has to them. The cultural, religious aspects of food. So, that is part of that assessment....’ (Anna, 59).

There is also an element where HCPs acknowledge the release of a tool (i.e. form) that is planned to enhance spiritual care and increase religious knowledge. Nonetheless they are indicating that it is not necessarily used.

‘The group within the hospice that looks at spiritual care has developed an assessment form for people’s spiritual care needs, that has been piloted and is now on our computer system and it is meant to - - it is seamless that form that is available across all the professions that can access the patients spiritual needs and add into that form as appropriate and be able to demonstrate what action has been taken or needs to be taken’ (Janice, 47).

Janice, in the latter quote, is relatively expressing that the assessment form in question has been piloted and therefore in the right place to be used, however, not quite the reality of it, according to her. Also, this form is an open document, in which any and every professional in the team may go on and add or remove information from it. This practice might pose some challenges

for professional practice, as well as for the delegation of roles among practitioners in the team (e.g. the role of chaplain, the role of nurse). One example of this are chaplains.

Chaplaincy is a relatively new role in hospice care. Nolan (2012) suggests that chaplains are there to promote spiritual care, which includes religious sensitive practices. Although there is much critique about the role of chaplains in palliative care (Harper & Rudnick 2009) these roles have been appointed with the responsibilities mentioned above. Therefore, the assessment form would be a document accessible by chaplains, given the descriptions of it by HCPs. However, this is not the case. During participant observation, I have joined nine (9) multi-disciplinary team (MDT) meetings in the hospice. In no meeting was there a chaplain present. Additionally, the spiritual care assessment form was always kept in the nursing station, where chaplains would not have access. The chaplains are not informed about the information added in the form, although they carry the responsibility to care for the spiritual needs of the service users. The following extract from one of the focus groups supports this analysis too.

Focus Group 2

Mary (29): ...yeah, have we had any chaplain in the meetings..? I am not sure to be honest.

Margarita (36): Not really, I mean if the chaplain needs something then he can come ask someone in the ward and we can help with more information. But usually it is the nurses that will call the chaplaincy and will at the same time tell them a bit of information about the patient they are calling for.

Gita (29): That is true. Every time I have called [the chaplain], I have always read them information from the patient's folder.

Researcher: Are there restrictions on information sharing outside of the ward due to confidentiality and privacy? Do patients need to consent to that prior to sharing the information?

Gita (59): Yes, we ask them... you know... I always ask the patients. I mean when they say that they want you to call the chaplain, then it is a given sort of that you will share some information with them.

Researcher: In what other way can the chaplain have access to this information but to have them communicated to him/her by a nurse?

Alex (44): They do not...I mean...they are not healthcareers to have access to medical files. So they have to ask someone else working here.

Individual skills dependent

Fourteen (14) HCPs, mainly nurses and doctors, assert that whether a professional will respond to religious needs and beliefs of service users is dependent on the particular individual's skills and knowledge. Despite the long discussions about training and study days, which would lead thoughts toward universal understanding and appreciation, HCPs are also encouraging the idea that each in the hospice has different skills.

‘...if someone is on the LCP they will explicitly direct you to ask those questions, and then it is up to the nurse how skilful they are to do so, or how much to ask for, etc.’ (Johannes, 39).

‘It depends on the individual [professional] whether they will decide to go deeper in understanding the importance that religious belief might have for patients’ (Jeremiah, 58).

‘If a practitioner approaches the subject of religion, then it might be explored’ (Mary, 29).

A worth mentioning point derives from this category, especially when looking at the focus group input. Individual professionals suggest that skills and abilities are dependent on their unique knowledge. This enlarges the argument that it is not possible to generalise findings of HCPs being religious illiterate or uncomfortable to engage with religion, belief, and spiritual identities.

‘It has to do with every professional individually. Me for example, I would say that as I become older, and learned more about the world and become more involved with the people who are in their terminal stages, I have come to respect the difference. As a younger nurse I did not come across the same amount of content with people who are dying, and so the aspect of religion did not raise this very much at all’ (Cirik, 46).

‘I am not quite sure that many professionals would be at ease with that [engaging with religion and belief]. I only learned it toward the end of my career’ (Mark, 61).

I have hereby found that HCPs rely on their personal judgment during the initial assessment in order to understand how the service users position themselves in relation to religion and belief:

‘Whether patients are devout - - we would couple that again within their spirituality. So, their devoutness would come into it. Quite often, when people give you their religion you usually get some sort of flavour as to how devout they are’ (Raul, 26).

‘When you are doing the assessment, you quite understand whether patients are devout to their religion or not. They give it away at the time of asking them their religious affiliation’ (Jeffrey, 39).

This finding is increasingly worrying and for some reasons. First and foremost, the education received by HCPs across disciplines is questioned in terms of universal content when it comes to religion and belief. This also raises issues of assessment and evaluation of the services, which seem hard to achieve if services are bound by an individual perception or stance. Also, it brings ethical issues on the surface, such as lack of equity in hospice care. According to Coward and Stajduhar (2012), hospice care has always been concerned with ethical issues in relation to how well prepared practitioners have been in order to care for the dying and the bereaved.

Also, I have found from seven (7) HCPs that the professional's perception on whether or not religion and belief are important aspects of life might signify their engagement with service users: 'If patients have the same belief system as me, then it becomes social and I can talk with them' (Gita, 59). 'My experience is that all nurses feel comfortable doing that. However, I think the issue is whether that is important to the particular nurse' (Alex, 44).

'If a nurse does not have a personal belief, then it is not a priority to discuss this with the patients. I think that if it is not important to us, it is a challenge to remember that it is important to somebody else' (Carlita, 46).

Personal beliefs in the professional

A vast proportion of the data shows that HCPs consider personal beliefs and religion key factors toward better understanding the target group of hospice care. The perception that personal beliefs, which are integrated with professional practice, only enhance the chances for more developed skills and abilities in this area, is depicted below.

'I think having a belief system, for me personally, does help with looking after this group of patients, and to be able to face it on a day to day basis and to give the support that is needed to the relatives in particularly' (Mirna, 48).

‘One of our junior doctors was a devout Muslim, and I do not know how... we had a Turkish patient, who had just died, and I do not know why, the patient’s wife ran up to him and said ‘my husband has just died. Can you please come in and say a prayer on his bedside’ (Jeremiah, 58).

‘Being neutral about this myself, actually helps me being open minded to all different cultures and religions that I come across with. I don’t believe in anything, so it is easier to talk about anything’ (Judith, 27).

It is also suggested here that HCPs should have religious belief in order to engage with religion, belief, and spiritual identities of service users. Gita (59) says: ‘If you are not religious, how do you expect to understand other people’s religious beliefs?’ Similarly, Nick (41) says: ‘Personally, I find that having sort of strong awareness of my own spirituality and my religious beliefs, and that gives me support within the job which I am doing’. In this perspective, I have found that individual consciousness appears paramount when it comes to religion and belief, while HCPs declare self-awareness of personal meanings and faith or no faith, in order to engage better with service users.

This study also demonstrates, as analysed in earlier sections but for different themes, that HCPs believe that being a Christian is vital for understanding and working within a religiously diverse environment:

‘I am totally able to engage with religious identities, because I am a Christian by belief. I believe there is a God and a son of God, and I knew before I came to this hospice that it was a multi-faith, no faith, it was everything. And part of my role is to meet people where they are at. So, I have no problem with any of that at all. I am here to meet people where they are at and help them if I can’ (Carol, 42).

‘I am a good Christian, so I know how to respond to other beliefs too’ (John, 53).

Moreover, HCPs consider working in hospice care a *Christian duty*. Findings show that HCPs believe that acting as a palliative care professional supports the prospect of having religious motivation for it, be strongly religious, and in general strongly feel the religious responsibility of helping others; promoting social solidarity.

‘Here you have got people who...come into practice of care looking after the dying, they do it with religious motivation. So, certainly, that is why a lot of nuns used to do it. And quite a lot of colleagues, in particular from the older generations, are motivated by belief. They consider it their Christian duty to look after dying patients. So, we still have a number of very devout Christian persons who are very devout themselves’ (Peter, 31).

‘Many people are driven by religions. Because they lost a loved one here, or they want to pay back to the hospice if you like, they will be volunteers. They feel usually that it is their obligation as Christians to do so’ (Nick, 41).

‘It is my obligation...because...as a Christian you have to do it. You are here to help others. That is what Christians do’ (Mirna, 48).

‘...respecting people’s views...I have done this as a Christian, and because I am a Christian I should be respecting other people’s views, no matter what they are, and try to respond to their needs, even if they come from a religious point of view’ (Anna, 59).

‘I have been a good Christian for a long time, and this job is really proving this. As long as this hospice was led by the nuns, it was a wonderful Christian experience. Now that nuns are not running this place, it is more of a business, but still, being a Christian you should stay and support all these people’ (Gita, 59).

It is also argued from the data collected what the real motivators for working in hospice care are. Carlita (46) closes off her interview by saying: ‘As a Christian I have to keep doing this’.

It is very interesting to see how religious belief drives HCPs toward their professionalism. However this might not match the expectations or desires of a service user.

Effective communication skills – increasing religious literacy

‘Sometimes I will come across somebody who seems distressed in some way, and you try to have a dialogue with him, to try to open that out, to try and figure out how you can help them. And, particularly as a doctor, when I approach people I think it limits what people talk about. Their expectations of a doctor is quite narrow focused. So for me in particular if I want to look at things broader [] talking to them using religious, non-religious, faith, spiritual or non-spiritual language allows me to open that conversation a bit more. So, it is that whole - - when I am with a patient I try not to stop with how is your pain. Because then they will think that we are only talking about the physical. But actually trying to use a much more general, open language sometimes it will ... or enable people to start having conversations that they would perhaps not expect to have with a doctor’ (Mark, 61).

In the preceding quote, I introduce my finding that HCPs are considering open communication beyond the medical or non-medical roles. This is seen as key – effective communication skills – in order to be in a place where HCPs can engage with service users in this manner and feel comfortable to discuss religion and belief as aspects of the individual’s attitude toward an illness, diagnosis or prognosis, but also as a personal characteristic in making sense of the world and their experiences in it.

‘...need to know when and what to ask. It is all about communicating with the patient properly’ (Mary, 29).

‘If communication with the patient is better established, then you would be able to know and understand more about their religious beliefs’ (Raul, 26).

‘How I engage with religious beliefs of patients and their belief system is very much focused to what the patient wants. And that would depend on their particular religious beliefs’ (Margarita, 36).

‘Again,...., I hope that I would be able to listen, maybe not with full understanding but with respect. That is something that has become very important to me here. Because it has been much more concentrated rather other areas that I have worked. It is the need to accept that there are many great different ways of expressing a faith or religion than the ones that I understand, and that should come by listening’ (Janice, 47).

‘...it is deciding what they [patients] want, but then again...it is...talking to them [patients]’ (Cirik, 46).

‘One thing that I hope that I will be able to do is that I will be able to listen with empathy even if it was not with full understanding’ (Jeffrey, 39).

Physicians, in particular, strongly argue for their communication skills and their openness for discussing all aspects of the individual. Jeremiah (58) states that ‘I think that one of the skills we have as doctors is our communication skills to listen, read cues, and a bit like... adapt to the individual in front of us. So we have good skills to read the signs...’ Similarly, Anna (59) suggests that ‘...all these listening skills...doctors are so well equipped with such great communication skills, it is a fact’.

Levinson (1994) argues that there is a large gap between physicians’ perspective of communication skills, and the service users’ satisfaction. He is suggesting that more work on this is necessary on a practical level. More recently, Maguire and Pitceathly (2002) highlight the importance of increasing communication and interviewing skills for HCPs, in order to decrease emotional distress of the patients. Curtis et al. (2013) ran a randomised trial of HCPs who received communication skills training. They had found that large gaps in professional

practice are still to be filled in this matter. However, the findings of this study show that HCPs believe that their skills are ‘great’. Whether this is accurate or not in this instance would require further research, in order to understand it. Even so, literature in the field yet disagrees with it.

Chaplaincy team contacted

Findings in this study are controversial and contradicting at times. Claims are made of knowledgeable and well comprehended in terms of religion and belief professionals, however not always evidenced, or supported via Christian-centred views. Alike, despite the statements of skills and abilities for engagement with individuals’ religion and belief, HCPs are selecting a practical solution on what I like to call *spiritual care emergency kit* (Table 11).

A contrast amongst data is the following. HCPs declare strong religious literacy, whereas it is suggested that there are elements of avoidance and ambivalence toward religion and belief concerning integrating these social aspects of an individual identities in professional practice. On the other hand, chaplains are not considered HCPs, neither are they qualified by the HCPC body. Despite this, HCPs are including the chaplain’s role in their responds regarding effective professional practice that meets expectations of a religious diverse population and clientele.

Whether I have challenged the following in earlier chapters, it is still appropriate to say that spiritual care in hospice care has been developed to be delivered by nurses or social workers or other HCPs, but not by chaplains. McSherry (2001) reclaims that the traditional role of nurses is to be spiritual carers. His suggestion is based on the historical development of nursing from within religious institutions and medieval Christianity. On the contrary, Nolan (2012) challenges McSherry’s views, among others, when he claims that the role of spiritual carer ‘is more suited to that of a suitably qualified spiritual advisor or guide’ (p.118). Even though Nolan’s critique is lacking clarity and evidence in order to be considered in the way the spiritual care emergency kit works, it is, however, the dominant practice observed.

Table 11: Spiritual Care Emergency Kit

	Participants' Responses
Spiritual Care Emergency Kit	<ul style="list-style-type: none">• ‘If someone needs spiritual support or religious support, we can always be available to call the chaplain of the hospice’ (Michael, 43).• ‘I will always contact the chaplaincy team if a patient seems more religious; if they seem to require more support spiritually’ (John, 53).• ‘Patients can always be referred to the chaplain, if they have any particular spiritual needs, like their religion’ (Shahid, 33).• ‘Even if the person is not well, and the relatives have informed us about the patient’s religion, we will bring in a religious leader from their own group’ (Dorothy, 37).• ‘I tell patients that if they want to talk about it [religion] I can find someone to come and talk to them. Possibly from the chaplaincy team’ (Carlita, 46).• ‘There is always a list with the contact numbers of the chaplains in the office, so if needed we can look it up there’ (Mark, 61).• ‘Yes, we are very comfortable with this here [hospice]. We share these information with colleagues during MDT meetings. Like, if someone has spiritual needs, we will say that we need to call, I do not know, the Church of England Minister, or X chaplain’ (Nick, 41).• ‘But equally said, if I had no understanding of a particular person’s request, then I would try and find them the chaplain, an Imam, a rabbi, somebody who perhaps know their faith. To try to support them in any way they need’ (Cirik, 46).• ‘My simple answer with that would be that there is access to specific religious leaders and specific beliefs’ (Alex, 44).• ‘...and efforts are made to facilitate their own pastor, or specific religious leader to come in. alternatively there are many people in the community who are able to be called upon and come in and run last rites and do whatever specific religions do’ (Mirna, 48).• ‘In this hospice, they have a chaplaincy here, and they have a Roman Catholic and they have a Church of England on staff. They also have other people... a list of people that are called in and it is led by one of the nuns... one of the remaining nuns that work here’ (Carl, 51).

HCPs' response to religion, belief, and spiritual identities of service users is to refer them to the chaplain. Such practice requires a set of skills, indeed. Nevertheless, not religious literacy. This would demand resourcefulness and availability, as well as communication skills in terms of passing on information about the subject in reference. It may be the case that what this finding of mine also shows is a lack of ability to address such needs differently, and hence in search for other sources.

Ticking the box

Seventeen (17) HCPs said that asking about religion or religious affiliation or practice when the patient is admitted, counts for being comfortable and welcoming to the engagement with this subject. In spite of the unease of asking the question during the initial assessment, also stated by Carol (42) who says, 'If it is a nice atmosphere and appropriate then we can ask, but usually this evaluation has to happen quickly so that the care starts', HCPs appear to consider the act of ticking the box 'religious or spiritual' an indicator of religious literacy. HCPs believe that ticking the box demonstrates skills and abilities in this area.

'When a patient is admitted, a questionnaire is used for assessment. Part of the questions is sort of asking them their name or address, and also their religion. So, it is put down as to what religion they are, and that is how it is looked at' (Nick,41).

'There is a question that asks the patients what their language, ethnicity and religion are. We will always tick that box so that we know that the patient has a religion' (Dorothy, 37).

'In the patient's file, there is always a ticked box if they have told us in the past that they are religious' (Jeremiah, 58).

'We ask everyone when they are admitted, and we tick a box' (Margarita, 36).

‘Conversation about religion and spirituality takes place at the first contact with the patient, if appropriate. But then, the tick box form is really what will tell others [professionals] what the patient wants’ (Carlita, 46).

‘There is a box about religion, and if that is ticked we know that the person has religious needs’ (Peter, 31).

‘If someone has ticked the box of religion in the assessment, then we will know to ask patients what they want for their dying’ (Carol, 42).

The answers here are raising numerous questions but are also worrying in the face of enhancing the quality of life in hospice care. How is it effective to assess in a first meeting ‘religious needs’? The word choice in the responses suggests that HCPs have a strong idea of what a religious need is and how it can be addressed. However, how is that possible if service users are still experiencing high levels of lack of satisfaction in service delivery? How is ticking a box equivalent to carrying out social policy that asks for consideration of diversity and integration of identities in care? Under what circumstances is the individual taken as religious, and, therefore, devout to their religious affiliation as well, the box is ticked and further ahead the individual, as present conclusions suggest, may refer to the chaplain?

All the above questions and many more are challenging HCPs’ approaches to religion and belief as social aspects of an individual that is dying or grieving. Hospice care reflects psychosocial and emotional support of the individual. Both types of support are far distant from the modern bureaucratic practices that undermine need, assessment, and service.

Outside of professional role

A small number of HCPs (5) argued that engaging with these aspects of the individual’s identity might fall outside of their professional boundaries. Therefore, calling the chaplain is the only

thing they could do, or inform a nurse or a professional who comes in an ongoing contact with the individual in order to contact chaplaincy.

‘Others are excellent doctors or nurses but they do not see it as part of their role, they do not know how to incorporate it and they do not have the confidence’ (Johannes, 39).

‘Obviously, saying prayers, or talking about their religious worries is not in my professional role, but I mean...every now and then you get asked these unusual requests to like talk about Allah and things, which you cannot always...you know, avoid’ (Mark, 61).

‘This is not really something that we have studied in medical school’ (Judith, 27).

‘I do not think that most of us have the time to be doing this, but also if you think of it, it is not my role as a doctor to provide such services’ (Peter, 31).

Relating this finding with the previous ones, HCPs appear to disown the part of their responsibility that calls for holistic approaches (Saunders 1992), integrated palliative care (Fowell et al. 2002), and enhancing quality of life versus prolonging life. I have found in this study that physicians, for example, consider their role as *treaters* perceived by themselves as more important than their role as carers in hospice care. There is ambivalence toward complementary roles of an HCP, which may be non-medically driven.

Identifying different religions and beliefs: further exploring RL

Healthcare professionals have indicated knowledge around differences and similarities among various religions and belief systems. The following findings complement the discussion insofar as they further inform the outcomes of the study in terms of HCPs’ challenges and controversies about religious literacy.

I have found that there is a general understanding of belief and faith. HCPs view belief in one God, but also consider that even non-religious people believe in a God, ‘just not religious one’ (Alex, 44). It is argued that religious beliefs and practices promote social support while rituals promote their beliefs and maintain them in time. The following two tables (12 & 13) show disparities and similarities among distinguished beliefs, as the research participants have described those. Both tables include the induced categories in terms of how HCPs cluster differences and similarities between different religions. The concept of belief and faith outside of the religious is also considered here, as HCPs acknowledge unique beliefs on an individual basis.

Table 12: Differences among faiths

Differences	
Category	Examples
Unique beliefs	‘Individual expressions are quite different’ (Margarita, 36).
Disposal of the body	‘...what happens with the body at the end is much different from my belief system’ (Carol, 42). ‘In my belief we do not cremate bodies for instance’ (Dorothy, 37).
Rituals	‘There are many practices after death that are so different from what I know’ (Michael, 43). ‘...all religions have rituals that will make them different from my beliefs’ (Gita, 59). ‘Like Muslims, when they want to do all the prayers in their day. I do not do that, so that is different’ (Carlita, 46).

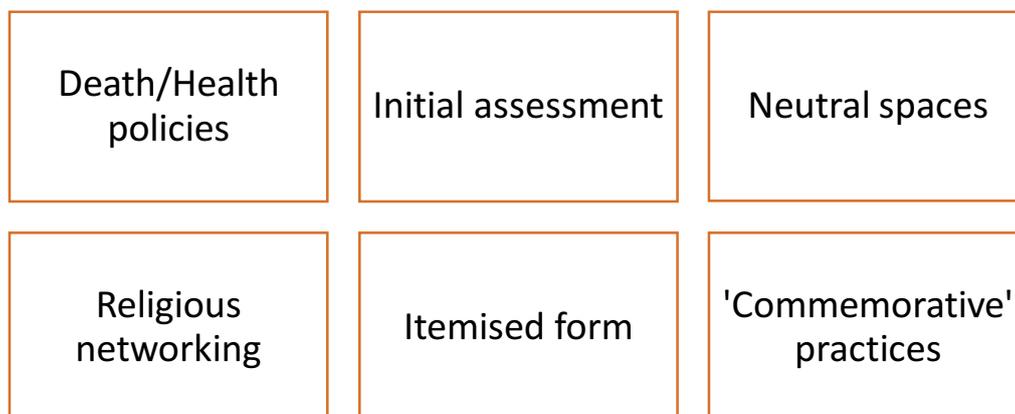
Table 13: Similarities among faiths

Similarities	
Category	Examples
One God	<p>‘The similarity is that there is a god, there is a greater belief system’ (Nick, 41)</p> <p>‘Believing in something higher than the humans is always the same’ (Jenny, 24)</p>
Social Support	<p>‘Also, what you get [from all religions] is the support from people of a similar religious belief. From the community; the religious community that you are part of’ (Peter, 31)</p>

Religion and belief in Healthcare: Integration

HCPs were asked to give their opinion on how have religion and belief as distinctive aspects of an individual’s identity been integrated or presented in healthcare. The following categories emerged:

Figure 11: Religion and belief being integrated in health care/EOL care: HCPs’ perceptions.



Death/Health Policies

A large number of HCPs identifies religion and belief as they have been integrated with social policies that are influencing professional practice in hospice care. Therefore, data shows that HCPs consider integration in social policy equivalent to integration in professional practice.

‘Well, it has been integrated because it is part of the policies, you know, diversity policies and all that. And also, NHS guidance documents always talk about universal care’ (Alex, 44).

‘It is within everything and also policies on diversity.it is prevailing everything and we (professionals) did not see that coming. Religion is part of it as well, so it is very present, and integrated in healthcare’ (Cirik, 46).

‘Well, you know, it is in our policy to ask patients when they come in. And...you know, it is sort of part of the diversity thing...’ (Carl, 51).

Of course, this questions the ability of individual professionals to comprehend social policy documents, or otherwise the organisational abilities to transcend policies to the employees. Inability to distinguish or to perceive the steps necessary to attain policy suggestions, with practice-based evidence to support it, is a major controversy in hospice care.

This has been fully examined by Catto and Perfect (2015), too. In their account, they state that ‘following the enactment of the Equality Act 2010, religion or belief is protected specifically in employment and the provision of goods and services in England and Wales’ (Catto & Perfect 2015, p.135). Professional practice in hospices is also informed by social policy, and the Equality Act 2010 to name one. The extensive responsibility of organisations and institutions to ‘foster equality and good relations’ (ibid., p.135) is also part of the guidelines and the organisational culture in hospices. This finding reflects on the above, while it shows current HCPs’ perceptions on when, how, and in what way religious sensitive care is delivered.

Initial Assessment

All the research participants (22) supported that having the availability to ask service users their religion, belief, and spiritual identities during the initial assessment and admission of the service user is also a grounded proof for the integration of religion and belief in professional practice. Following there is a list of quotes that illustrates this:

Participants' responses

- 'Proof of that is that we do the initial assessment with all patients, and the initial assessment includes a question about religion' (Michael, 43).
- 'The initial assessment, which is done by nurses and doctors, also asks questions about spiritual beliefs and religion. So, religion has been integrated I guess' (Shahid, 33).
- 'When a person is admitted, that person is asked about his or her religion or faith or spirituality, what is important, and if the patient is too unwell to speak we often ask the relatives' (Johannes, 39).
- 'We always ask people when they are admitted' (John, 53).
- 'What, generally, healthcare does is that they usually ask it as a certain question; what is this person's race, what is this person's religion. And I think this is what we do. It is at a very superficial level, without any real understanding about what that means and without really paying any great care attention' (Nick, 41).
- 'In the beginning we will ask if they have a religion and if yes we can contact the right person from that religion' (Mirna, 48).
- 'So, we have got a form which will say {looking through paperwork}...here we go, 'what is your ethnicity, religion and language?' So from that we will know what to do at the end' (Alex, 44).
- 'We ask patients in the beginning. That is a general practice that the doctor or nurse who are doing it will always remember to ask. If they do not, then at some point someone else will do so' (Gita, 59).

Similar to *death/health policies*, this theme has emerged to highlight the technocratic and bureaucratic methods used in hospice care, and which often clash with professional practice.

This happens either by adding administrative work to the already overwhelmed roles of HCPs, or by confusing and misleading HCPs from their primary role; that is to provide quality care and enhance the well-being of the service user. In the debates of secular ideas, it is underlined that religion is privatised and far from public discussions (also see Davie 2013). Therefore, technocratic approaches in hospice care also seem timely and appropriate, but not necessarily effective.

Neutral spaces

Another argument brought by HCPs refers to neutral spaces. The development and usage of neutral spaces in the hospice, according to HCPs, shows that religion and belief have been integrated into professional practice. This study suggests that there is ambivalence toward religious diversification among service users, which is covered by neutrality and nude to religious affiliation or language approaches in professional practice.

‘We want to be neutral so that the hospice is friendly to all spiritualities’ (Alex, 44).

‘I think it is integrated. I mean this hospice is multi-faith, so in order to become very welcoming to all religions, we are neutral. There is no religious preference, and we try not to present religious signs often so that people of other groups are not offended’ (John, 53).

‘We have got a spiritual care coordinator within our hospice, who facilitates our chaplaincy team, and therefore a variety of different religious denominations, and actually non-religious denominations as well. We have a humanistic chaplain, which deals with people that believe in something but don’t actually pertain to any religious order as such’ (Dorothy, 37).

‘Well, here it used to be an extremely Catholic institution and then it opened itself up, and it is now a very beautiful, holistic, and neutral space. And people around here have

changed. They have understood that not everybody wants crucifixes and icons all around, so we have quiet rooms for prayers, etc. So people have learned to be district with their religion too' (Anna, 59).

This is a notion already discussed in chapter 4 of this thesis. Nevertheless, it is worth highlighting here the common understanding among HCPs that neutrality not only addresses religion, belief, and spiritual identities, but also responds to the Equality Act 2010. Similar to the previous theme, debates about secular ideas promote neutrality for addressing diversity on religious grounds. Woodhead and Catto (2012) report on the place of religion and belief in the UK today, while it is accentuated that more and more new religions and spiritualities enter the domain of religious affiliation. That said, the vast variety of faiths and none has been treated as a problem that needs a solution, as it will be discussed later. In relation to this theme though, neutral spaces have been found to be the most effective in response to a multi-religious environment. Further comments about this are included in the concluding chapter of this thesis.

Religious networking

HCPs largely accept that attaining an enriched network of religious leaders and resources that service users can be signposted to also mirrors the integration of religion, belief, and spiritual identities in hospice care.

‘And we also have contact with leaders of religious groups within the local area, who can come and facilitate religious ceremonies for patients, if that is unable to be provided by the chaplaincy teams available at the time’ (Mary, 29).

This is an area where HCPs indicate that good relations are a critical aspect of delivering religious sensitive professional practice, or otherwise demonstrating religious literacy as described in this thesis.

‘We have good and close relationships and collaboration with religious leaders and priests and other chapels in the community. So, they come in and provide services if necessary’ (Janice, 47).

‘So it is just recognising that it is like a bucket full of options that you can pick from and use different people at different times according to what is the highest need at the time. So, spiritual care comprises from a whole range of people; chaplains, sometimes the Imam, sometimes it is the holy man, whomever, but we have got a range of people to meet the range of people we provide service for’ (Anna, 59).

‘You respect all people’s beliefs, and support them... what they need in their final days, and how to cope with the dying process, and that is fine. And one of the good things about this place is, you name your own religion, we will have somebody available for it. Yes, we have a Rabbi who comes visits, we have an Imam, who is available to be called on, we have a Catholic priest, we have got a Church of England, and when we need somebody from any religion...we just call someone’ (Carol, 42).

This is relevant to organisational networking and inter-professional work. Hughes and Wearing (2013) suggest that effective professionalism is always benefited by extensive and multi-skilled network. This is to highlight the importance of involving all available professionals and skills toward working with the service user. An enhanced religious networking serves a purpose but defeats another one, however. It enriches the experience of the service user by providing an additional service that seeks to promote further the care of the individual. On the other hand, it undermines the capacity of HCPs to meet the service user needs, but through other practitioners, i.e. chaplains. This may as well jeopardise the rapport that HCPs build with service users, as the latter are referred to chaplains commonly after they request from a HCP to be supported spiritually by them. In other words, service users request support by the HCP,

and instead they get a reference to the chaplain. Despite my argument here, chaplaincies are very important in the care of service users in EOL care, nonetheless professional roles overlap and confuse different professionals. Also, chaplaincies are as well in need of ‘becoming more religiously literate’ (Clines & Gilliat-Ray 2015, p.237).

Itemised form

Rarely have HCPs suggested that an itemised form is available in order to facilitate the individual’s preferences that relate to religion and belief, such as food and disposal of the body. An example includes Carlita (46): ‘There is a checking form making sure that we have done everything that we should have done, also religious requests, like food preferences and disposal preferences’.

On the contrary, HCPs claimed that a form is necessary and helpful in meeting such needs of a service user. It is the most efficient tool in order to register needs and respond to them.

Focus Group 1

Dorothy (37): Without a form how are you going to know what the patient wants? I mean, that form will have all the info, and updated info so that you can do your job according to that.

Shahid (33): Definitely. It gives you knowledge...

Carl (51): I agree.

Even so, this finding is questionable for many reasons. A main one would be that having ticked a box, or filled in any form saying that someone is religious, the person who is reading it does not know explicitly what that means. Is the service user overly devout and requests daily prayers and religious teachings, or is he/her traditionally religious and shows no relation to the beliefs, values and/or principles of the religion registered in his/her form?

This is reflected in the *vicarious religion* thesis (Davie 2007), perhaps. Similar to what Davie argued about, itemised forms address religious affiliation and keep the necessary record in order to meet policy requirements and organisational guidelines as a HCP. Regardless to whether this is practiced by all HCPs – whether they ask the questions and tick the boxes – these are practices that represent the vast majority of HCPs, and who, according to this study (also read Chapter 5), agree with them. The itemised forms are both good and bad toward quality care and religious literacy in hospice care.

‘Commemorative’ practices

An additional way of how HCPs appreciate the integration of religion, belief, and spiritual identities into professional practice includes commemorative practices:

‘A ceremony; light up a life, which is a commemorative ceremony where the death of somebody is remembered and respected, and the light is to represent their life. We have [] those... we spoke about, with people’s names on the metal leaves’ (Margarita, 36).

‘There are commemorative books with names and the opportunity for people to write how they feel in commemoration. That might include a lot of feelings because of their religion’ (Mirna, 48).

HCPs appear to conclude that such practices are as well means for expressing one’s religion or belief, and, therefore, a supplementary way of showing comfort in engaging with belief, as well as religious literacy. Nonetheless, this study also concludes that religious literacy is not a concept well understood in healthcare and HCPs in general, a point that is also stressed in the next chapter, conclusions, and which predominates in making suggestions for the future.

This is relevant to the debates about religious practice, as well as Day’s (2011; 2009) thesis about performative religion and cultural Christians. Traditional or culturally inherited practices

act as means for expressing belief or faith, whether that is embedded within the person's individual consciousness, or it is a tradition to be followed down by generations.

Conclusions

This chapter concludes my thesis. It discusses the findings of research and their potential implications in terms of promoting religious literacy in hospice care, and EOL care more broadly. I do this by looking at three different areas of implication; social policy, professional practice, and Higher Education Institutions (HEIs). Future trends are then discussed.

Religious literacy in end of life care

Overview

Dinham and Francis (2015, p.270) conclude that religious literacy ‘is best understood as a framework to be worked out in context. In this sense, it is better to talk of religious literacies in the plural than literacy in the singular’. In my thesis, I have used religious literacy as a framework to explore and understand the challenges and controversies that HCPs face in hospice care, when responding to religion, belief, and spiritual identities of service users. In particular, the study was set out to explore how HCPs who practice in hospices respond to religion, belief, and spiritual identities of service users. The study has also sought to know whether, and if so how, HCPs are challenged by the religious and spiritual diversification of service users. Some of the empirical evidence from this project that outline the conclusions are as follow.

This study made clear that HCPs are willing to engage with religion, belief, and spiritual identities of service users, but often lack the appropriate language and skills to do so. This study also underlines that HCPs are always acting to the best interest of the service users, nevertheless with limitations that they may be unaware about. In other words, HCPs suggest to be self-confident about their skills and abilities to engage with service users in this field.

However, and commonly, they will put the blame on other professionals about poor service delivery in this area (also see, Nolan 2012). This is evidence that surfaces a few of the conclusions as those will be discussed later.

Additionally, this project found that HCPs believe that knowing more for more religions will result to religious literacy, or otherwise will better prepare them for working with people with different religious backgrounds. This is ambiguous, however. As suggested by Dinham and Francis (2015), religious literacy is not about knowing it all. Religious literacy, at least in hospice care and as it has been embedded in this project as a theoretical approach, is a process related to interpersonal skills. It is also a process for eliminating ambivalence toward difference. The lack of engagement with religion, belief, and spiritual identities might as well be due to feelings of unease. HCPs may feel intimidated to the difference, in general, and not necessarily to religious difference. This is, of course, a hypothesis to be examined in a different than this project, but yet worth noting. This assumption is also supported by the findings here; that is that HCPs often employ a Christian-centred approach or engage more and better when the service user is of Christian belief.

As discussed in Chapter 1, EOL care is contested when regarded within different contexts. Death, dying, and bereavement are unparalleled experiences, which deserve absolute and comprehensive attention. In the UK, by and large, EOL care is practiced in hospices, fitting into the concept of palliative care. That said, EOL care is often guided by bio-medical approaches, clinical and legal frameworks, and these are frequently far from psycho-social and interpersonal assessments and interventions. It is rather enticing to ask whether hospice care has turned into hospice cure. Despite the arguments around that, religion and belief remain marginalised from professional practice unless they are regarded as problems to be solved (also in Pentaris 2013).

Religion, belief, and spirituality are integral aspects of an individual's identity or intrinsic to their identity as a whole. They are also aspects that do not exist in a static form, neither do they take a descriptive character. In other words, these are lived experiences that can be understood through our actions and behaviours. According to Dollard (1983, p. 7), 'one simple way of understanding spirituality is to see that it is concerned with our ability, through our attitudes and actions, to relate to others, to ourselves, and to God as we understand Him'. Saunders saw this when setting up hospice care, and so did many more after her. Nevertheless, as the biomedical and clinical models took hold, hospice care became crowded with policies and regulations that were at times influenced by political ideologies and which naturally led to radical changes in the organisational foundations – if we treat hospice care as an organisation. In the course of time, hospice care was congested with many professionals that are willing to engage with multiple aspects of care but with limited or no proper language – and therefore skills (Furness & Gilligan 2010) – to do so in some areas.

This project explored the challenges and controversies that HCPs who work in death and dying settings face when in a position to engage with religious belief, non-religious ideals, and spiritual identities of service users. The findings show, as mentioned above, willing HCPs in abundance, who nonetheless, lack the religious literacy to adequately and sensitively address religion, belief, and spirituality. These conclusions are evident across chapters 4, 5, and 6. Additionally, this thesis has delved into social policy and how religion and belief are played out in those fields. It is noted, neither exhaustively nor comprehensively, that muddled and inconsistent guidelines cause distress and controversies within professional practice situations, i.e. itemised forms. In the remainder of this section, I will highlight the most fundamental outcomes of this research project. These are conclusions to which the project was led due to the findings. However, before I do so, it is important to briefly discuss the context and

generalisability issues regarding the findings of this study, and how that influences the applicability of the findings.

EOL is a wide context of field sites. There are various settings in which people live at EOL, hospice, elderly home, hospital, home to name a few. This variety may as well suggest a variety of approaches and attitudes toward religion, belief and spirituality in EOL care in overall, based on the setting in which it is explored. This is an important recognition as it influences the generalisability of the findings of this study.

This study, as mentioned throughout the text, has explored religious literacy within hospice settings only. This limits the application of the findings across other settings within the overall landscape of EOL care. It is evident from this study that the conversation about spirituality is not an unwelcome one in a hospice; a setting that provides conventional health care. Nevertheless, HCPs appear uncomfortable to be discussing religion and belief. This may be partially because of the institutionalised care setting in which the study was undertaken. Perhaps in the community there is more freedom of discussion about religion and belief; when people at EOL are cared for in their home, separate rules may apply about what is acceptable or welcoming as a subject for a conversation.

Two of the fundamental outcomes of this study, that are explored later in this section, refer to the general ambivalence toward religion and belief and the tendency to treat religious diversification as a problem that requires appropriate solutions. Both are key to understanding how religion, belief and spirituality issues are perceived and embedded in hospice care, or health care in general. However, this may not be as representative of service provision in the community. Perhaps HCPs in the community overcome their ambivalence to approach this subject with service users because policies inform practice differently in that area. Similarly,

HCPs may show more religious literacy when working in the community, and as a result engage with that aspect of the service user's identity while avoiding to treat it as problematic.

An example that further illustrates the importance of having this brief discussion, prior to delving into the presentation of the fundamental outcomes of the study, lies within policy. A few months after the submission of this thesis, PHE (2016) publishes a resource guide for professionals and commissioners in the community. The guide addresses faith in EOL. This is the first time that social policy, and death policies, has addressed religion and belief by name, and not used the term spirituality as a proxy to discuss it. Nevertheless, the main difference between this recent resource and previous policies and guidelines is that the former relates to work in the community, whereas the latter address the issues within the remits of institutionalised care of the dying.

Further to this discussion, service users that are cared in hospices might have specifics that inform some of the findings from this study. In particular, spiritual care is the responsibility of HCPs in hospices and palliative care units (also see DoH 2009) but this may change when people are cared in the community. Religious belief and practice normally take place in the community, in an everyday context. HCPs may not consider spiritual care a priority when working in the community, therefore, and this is because service users already appear to have the support they need in that perspective.

Service users in hospices receive holistic care that addresses all of their identified needs. Social policy recognises the responsibility of HCPs to meet spiritual needs of service users in hospice care, but not necessarily when working in the community (ibid.; DoH 2008). This makes the research question that was explored with this project even more pressing. If policies highlight such a responsibility within institutional care, then logic requires that HCPs would be

adequately prepared for this task. I now move on to the discussion of the key outcomes of the study.

Secular hospice or hospice with its religious fur cast off?

The origins of hospice care are strongly religious, and in particular Christian. In many ways, hospice care continues to retain this religious identity even now. Nonetheless, considering the changes in religious practice and religious belief, discussed in chapter 2, hospices have been challenged and had made certain adjustments in order to respond to the increasingly diverse religion and belief environment.

This study uses empirical findings (outlined in Chapter 4) to demonstrate that hospices have considered diversity in religions as a problem to be solved, as well as reviewed that the solutions were related to equality and diversity laws and procedures. In an effort to be inclusive and non-judgemental, as well as to avoid stressors, neutral spaces were embraced and promoted in hospices. From this project, it is clear that the space has become less and less religious; icons and crucifixes have been removed, religious signs have been withdrawn, and the language on signs has changed; all these with few exceptions.

The neutrality concerning hospice space opens up an additional dialogue. Dinham and Francis (2015) note that *secular* is often regarded as *neutral* and vice versa. This study was not concerned with examining this argument in depth, but rather concludes that hospices are either in the process of secularising *or* that anything religious related is shed from the public space within the organisation. Regardless, the lack of presence of religious evidence in space further facilitates the argument that there is a lack of religious literacy in hospice care, as this study shows with empirical findings. This is not to undermine the positive developments in hospice care, but to highlight that there is still a long way to cover toward religious literate professional practice.

Religious belief and practice in neutral spaces

Service users are still in need of a space where they are comfortable to pray or find peace of mind. Chapels have changed radically, and the use of prayer rooms has become popular in public institutions. As this study describes, prayer rooms have been transformed into quiet rooms, to promote equality and inclusivity. Gilliat-Ray (2005, p.288) suggests that the space of worship is necessary and that institutions should “create rooms that can be used by people of ‘all faiths, or none’”. Hence, quiet rooms. The removal of the word *prayer* opens up space for all religions or none.

Despite that, findings of this study suggest that hospice service users do not make use of the quiet rooms as it is expected, but with exceptions. During the one year of participant observation in the hospice, the only times that a service user made use of the quiet room was when other family and guests were visiting the inpatient. In those occasions the quiet room served as a lounge. Nevertheless, service users still look for the appropriate space for prayers or calming down. This is evident with the findings that have service users making use of the garden in order to find peace and pray. This boosts the hypothesis that quiet rooms are not used as one would expect them to be used.

The conclusion from this study is that people with religious beliefs still find themselves lacking an appropriate space to express their beliefs and values. The study concludes that from quiet rooms, we now find service users retreating to the garden as a temple of peace and worshiping; a place for prayers and believing. This finding informs us in terms of service user needs and further illuminates whether, and on what density, professional practice meets service user needs in all.

Willingness vs. ability

One of the most fundamental outcomes of this study is concerned with the ability of HCPs as opposed to their willingness to talk about and engage with religion, belief, and spiritual identities of service users. As noted by Dinham and Francis (2015, p.5), ‘...the problem is not people’s willingness to have the conversations; it is their ability to do so’.

Chapter 2 went into detail discussing the new and changing religious landscape in the UK, together with the challenges that society faces concerning the way in which religion and belief are treated publicly. Religion and belief have been considered absent from public life, with the discourse on secularisation increasing. Post-war Britain saw many developments and transformations in the nation, one of which was to do with the composition of its population. Britain publicly identified with its heavily diverse environment, while that increased radically in those years, in which many and varied religious beliefs found a place, and solutions were sought in order to accommodate diverse identities. In this space, however, secularity took hold in conversation while the decline in religious practice was seen as a decline in belief. As explored in the second chapter, the changing religious landscape in the post-war years, the change of language – from religious to secular – within the welfare state, as well as the lack of common understanding of contested notions, such as belief and faith, have all led to people losing their ability to talk about religion and belief when necessary or needed.

Religion became a private matter with limited attention given to it in the public sphere. This led to the inability to address this issue properly either in policy, practice, or education. Concurrently, in health and social care, bio-medical approaches took hold at the expense of the psycho-social, and consequently the spiritual, as the latter finds place under the psycho-social, discussed in the preceding chapters. Spiritual care became integral in hospice care and got more publicity in the late 20th century (McSherry 2001). Spirituality was now used as a proxy for

religion and belief. This thesis has not been concerned with the binary of the two (if there is one). It, otherwise, suggests that religion, belief, and spirituality are all to do with unique lived experiences of an individual. Those may be momentous in terms of perceptions and meaning making in life, also explored in Chapter 1. Death and dying are often experienced through the lens of belief or faith, whether religious or not.

It is essential that HCPs who support people toward the end of their lives or when grieving, have the ability to engage properly, and address needs that relate to religion, belief, and spirituality unitedly with the person's experience of dying and/or grieving. Religious literacy in EOL care does not refer to a 'knowing-it-all' attitude in terms of learning more about many different religious traditions or denominations. The latter was indicated in the interviewees' responses (Chapters 5 and 6), where all participants suggested in various and different ways that they seize learning opportunities in order to learn practical information about different religions. They do so in order to avoid *acting surprised* when they work with a service user from that religious tradition. HCPs suggested that being aware of something also makes you prepared to respond to it. This leads us to think that HCPs lack appreciation of the general sensitivity in which difference amongst different people is treated. Religious literacy is not concerned with any of the above, but with the ability to ask appropriate questions when needed, as well as the ability to comfortably engage with the subject as necessary.

It is obvious that nobody can know everything about every religion and belief, and religions and beliefs are not homogeneous slabs of knowable 'stuff' in any case. The reality is of religion and belief as shifting aspects of contested identity. But engagement in the detail and the reality of at least some religion and belief, and an ability to ask appropriate questions with confidence about others, is an essential part of the journey (Dinham & Francis 2015, p.14).

The findings of this project have shown that HCPs in hospice care have a misled perception about what is beneficial and efficient in terms of responding to religion, belief, and spiritual

identities. This is perhaps the result of secular-minded education in health and social care professions, which prepares professionals to efficiently and sufficiently perform in a secular context. There is the general understanding that acquisition of further knowledge about more and various religions will lead to the desired outcome. That outcome being sensitive professional practice when it comes to the personal characteristics of service users and their family members or friends. HCPs appear to consider that having knowledge of particular religious' practices equates to having the abilities and skills to work in a sensitive multi-faith environment. This project contests this idea and suggests that religious literacy is necessary to perceive the duty of professional practice clearer, and in light of the ongoing changes and needs of the service users.

Ambivalence

Lack of proper abilities to engage well with religion, belief, and spirituality, has led HCPs to become ambivalent toward talking about religion and belief. HCPs in this study have verified that they do not wish to talk about religion and belief. As it is reported with the findings in chapters 5 and 6, HCPs choose to use the term spirituality when engaging in a conversation about religious and non-religious belief. It is presented as almost a taboo; for example, to talk about Judaism, or Hinduism in particular.

HCPs appear to be fairly ambivalent toward the subject of religion, and most of their reasons hinge upon the concepts of equality and diversity. Lack of engagement or disengagement seems to be rationalised by employing neutral behaviours that accommodate all difference within the service user composition.

The findings of this study highlight that when service users are asked, during the initial assessment, what their religious affiliation is, that automatically responds to the part of care that regards spirituality. HCPs consider practices of this like (Chapter 6) proof of religious

literacy in hospice care. Nevertheless, concurrently HCPs suggest that they do so, employing these practices, because those are embedded in policies and guidelines for hospice care. This is problematic in itself, while it supports the conclusion of ambivalence. It further suggests that if policies and guidelines (mostly equality and diversity laws) did not require HCPs to ask service users these questions, HCPs would not do so. There is a mix of willingness to engage, being ambivalent toward difference, lacking appropriate language to interconnect, and needing to follow the rules as the technocratic culture of hospice care suggests. This makes for a much more complicated context in which ambivalence is one aspect alone.

Finding solutions

Another significant outcome of this project regards the way in which religious diversity is treated in hospice care, about professional practice. Chapter 6 discusses in-depth the findings in connection with how HCPs respond to religion, belief, and spiritual identities. The common attitude that has been observed relates to a solution-focused approach, rather than ways of becoming more comfortable to engage with the individual and the impact that their belief system has on how they experience dying and grieving. This approach is observed in Dinham's and Francis's account (2015) in terms of how religion and belief are treated in different parts of public life.

...it would be much more effective – and much more realistic – to set religion and belief in their proper context as normal, mainstream and widespread, and to seek engagement *with* them rather than solution *for* them. (Dinham & Francis 2015, p.7).

It is unforeseen that in a care system that is led by the principles of inclusivity, interpersonal communication, and service user engagement, it is evident, from this study, that service user characteristics are seen as elements that prevent service delivery from being efficient. A distinctive example of this is evidenced in chapter 6, where HCPs respond to service user

requests in relation to religion, belief, and spirituality with a phone call to the chaplaincy team – or any other form of referral. This response seems rather dismissive.

In their narrative on religious literacy and chaplaincies, Clines with Gilliat-Ray (2015) suggest that ‘developing religious literacy within the chaplaincy and collaborating with others in an organization...can be responsive to the breadth of religion and belief identities of its constituents’ (p.237). The findings in this study are far from suggesting that such is the attitude employed by HCPs in hospice care; i.e. form of collaboration. What is shown, on the contrary, is that HCPs lack engagement with the religious and non-religious diversity of service users’, unless on a pragmatic level. An example of this includes signposting service users to the chaplaincy team with which there is little connection or collaboration (for communication and collaboration across and within human service organisations also see, Hughes & Wearing 2013).

Additionally, and according to the findings, HCPs consider that knowing about a service user’s religion, belief, or spiritual identity, they have to find practical ways for accommodating it. For example, if one is Muslim, HCPs will start preparing to assist the dying of the patient the way that is treated in Islam. Again, this is problematic and only supports that there is a problem-solving attitude rather than one that leads to better understanding of what one’s beliefs mean for themselves and to their experiences. Also, it supports that HCPs retreat to the pragmatic and general practice that will safeguard their professionalism, rather than reaching realms of intangible and unmeasurable care.

The above example also conceals a risk: generalising. Reminiscing Day’s work (2011; 2009), being affiliated with one religion means no more than that. Belief is not measured with affiliation or religious practice. HCPs in this study did not address different religions in terms of different ways of believing or different beliefs. On the contrary, the study suggests that HCPs

generalise among large parts of the service users to respond to religious and/or spiritual needs in the form of solutions, i.e. call the chaplain.

Christian-centred lens

A different conclusion from this study is relevant to the way in which HCPs comprehend and address religion, belief, and spiritually related challenges. There is an undeniable Christian-centred approach which opens up a whole discussion about whether professional practice is *neutral*, as suggested in death policies (Chapter 1), or, at times at least, biased due to a Christian framework. Findings demonstrate that when the conversation is focused on religion, HCPs, at large but with exceptions, consider the discussion to be focused on any other than Christianity religion. This is strengthened by the biblical language that is used by HCPs when informally and indirectly referring to service users, angels to name one (also reported in Chapter 4).

The above conclusion becomes more complicated when conceptualised through a religious literacy lens. Religious literacy, as it has been addressed in this thesis, seeks to prepare professionals to have the abilities and skills to engage with the religiously diverse service user population with whom they work. This, however, is accountable to the capacity of HCPs to consider themselves part of the diverse environment, rather than the knowledgeable and distant from the overall population member who will solve problems. Examples of this can be found in the findings, and those are drivers for plans when moving on from this project.

Hospice as a machine

Additional evidence of religious illiteracy regards organisational context. Drawing from the organisation metaphors by Hughes and Wearing (2013), hospice care seems to be significantly informed by bureaucratic and technocratic theories. Having a look at the End of Life Care Strategy 2008 (DoH 2008), as well as the latest guidelines by the National Council for Palliative Care (NCPC) entitled *The Road Ahead*, hospices are described as machines, which

have ‘complex parts and mechanical dynamics that are designed for efficiency and productivity’ (Hughes & Wearing 2013, p.35). HCPs in this study demonstrate accuracy and consistency when it comes to assessments via a legal framework, as well as carrying out tasks according to regulations and guidelines. Naturally, if hospice care has turned into a mechanical institution that is concerned with productivity and efficiency, this is washed down to professional practitioners, who, in turn and in spite of their willingness to engage otherwise, respond to service user needs in a mechanical way, being goal oriented and ticking boxes. An example from the findings is in chapter 6, where HCPs say that they will ask the service user whether they have a religious affiliation, during the admission interview, because this is one of the questions in the respective form.

Integrating religion and belief into professional practice

One final, and equally important, conclusion from this study associates with how HCPs understand and appreciate integrated with religion and belief services in hospice care, and healthcare in general. This study has concluded that HCPs consider that there are six examples to demonstrate how religion and belief have been embedded in professional practice; i.e. service delivery. Those are death and health policies, the initial assessment, neutral spaces, religious networking, itemised forms, and rituals.

There is a broad perception among HCPs about the following. Since death and health policies have included guidelines and regulations on how religion and belief shall be treated in professional practice in death and dying settings, this essentially addresses the challenge. Nevertheless, outlined in Chapter 1, social policy in EOL care is as well an area that lacks religious literacy, a characteristic that is fed down to practitioners in the field.

Similarly, HCPs consider the question of what is one’s religion and belief in the initial assessment forms an adequate measure before the challenge of providing sufficient services.

Neutral spaces is another aspect of how HCPs appreciate religion and belief having been adequately addressed in professional practice. In detail, HCPs suggest that maintaining religious neutrality in the space is enough of an approach toward being inclusive and respectful of all religions and none. However, this thesis argues a different position. Neutral spaces are merely another aspect of avoidance in the area. They show how care institutions, like hospices, refrain from responding to religion, belief, and spiritual identities of service users while this is rationalised in the concept of respecting difference by not talking about it. The *not talking about it* is the challenge here; is it due to pure rationalisation, or is it the result of lacking the religious literacy to plan properly, implement, and assess services. Very much alike initial assessments, HCPs contemplate forms inclusive of questions regarding religion and belief enough evidence of how religion and belief have sufficiently been integrated with hospice care.

Another example of how HCPs appreciate religion and belief as an integral part of professional practice refers to religious networking; a large network of religious leaders or representatives in the community, whom professionals can contact when necessary. This is complementary to the ‘calling the chaplain’ approach when service users have religious or non-religious beliefs (explored in chapter 5). Last, but not least, this study has found that rituals or commemorative acts in the hospice, post-death of a service user, serve as indicators of how religion and belief have been integrated well. Such rituals may include felting or making drawings in the memory of someone who has passed while an inpatient.

The remainder of the chapter covers the implications of this study in three different areas that I have considered important contributors to the enhancement of religious literacy in EOL care: social policy, professional practice, and education. Last, future trends are discussed.

Implications for social policy

The links between social policy and professional practice are undeniably strong (Higham 2006), while the process is, or at least should be, reciprocal; social policy informed by professional practice and vice versa. This study has unpacked a wide area of concern regarding the challenges that HCPs who practice in death and dying settings face in relation to religion, belief, and spirituality. The findings are reflective and particularly tied to current death and health policies. It is also evident that technocratic theories (Hughes & Wearing 2013) and materialised aspects of measurement for efficiency lead to misperceptions and misunderstandings, rather than sufficient and sensitive practice.

Dinham and Francis (2015, p.257) conclude that religious literacy 'is a fluid notion'. Drawing from that, religious literacy in hospice care may only be conceptualised within the particular context in which it is perceived. In other words, the findings of this study may inform death and health policies in providing further insight of the implications of the mechanical language used to communicate service delivery in the front line. This study can have a complementary role in all stages of social policy – planning, implementing, evaluating – with the following in mind. HCPs consider policy documents detrimental to how, when and whether religion and belief have been integrated with hospice care and healthcare. Further, social policies add significance to the formation of ethical and timely professional practice. These two are paramount to how the conclusions of this project can and shall inform death and health policies.

An outstanding example of implication is the following. The End of Life Care Strategy (i.e. 2008) is a document that requires revisiting and reconstructing of its content. Quality care, well-being, compassionate approaches, these are essential elements in the strategy and these are the principles that truly guide the intentions of EOL care. The findings of this study can inform areas of the strategy that apply either directly to how HCPs respond to religion, belief,

and spiritual identities of service users, or indirectly but efficiently to all areas in relation to quality care and enhancing the service user experience.

It is worth recognising here, however, the risk of conflict between religious literacy's fluidity and social policy's need for transparency and precision. Iatridis (2005), among other scholars, suggests that social policy documents need to be clear, as well as accurate. Policy sources that fail to directly address an issue and provide explicit guidelines about how to meet people's needs (also see Alcock 2014), also fail to successfully be applied.

In light of that, for religious literacy in hospice care, and end of life care broadly, to materialise in policy documents, further discussion is necessary, but most importantly the need for operationalising religious literacy is apparent. The main characteristics that have been identified from this project, and which shape religious literacy as a more measurable and tangible outcome, are the following; engagement with traditions, religions and beliefs, and developing understanding of religion and belief and their role in the context of hospice care (Table 14). Both are best understood through the lens of a value-based approach that includes self-awareness, self-understanding, interpersonal skills, and empathy; all important aspects of professional development in hospice care (Table 15).

It is important to understand that despite the religious reference of the concept of religious literacy, its operationalisation is not centred on religion. As this study has shown, professionals appear to demonstrate limited skills of interpersonal care when they mostly feel uncomfortable, or in a situation where they lack knowledge or understanding. A policy that addresses that is also a policy that comprehends the value of self-awareness and self-understanding of the HCPs'. Responding to a service user group from a multi-faith environment is essentially associated with demonstrating the right skills to respond, appropriately, to diversity; an area that social policy has, so far, done well in, but with room for improvement.

Table 14: Quantifying religious literacy

Religious literacy		
Measures	Description	Examples
Engagement with traditions, religions and beliefs	Engagement with traditions, religions and beliefs is not the mere acquisition of new knowledge, but it includes gaining an understanding of what the knowledge means and how it relates to the service users' experiences.	<p>Enlarge one's knowledge about various traditions; to use as a canvas for further development.</p> <p>Employ a person-centred approach by which the service user will become the educator who will inform the HCP about the meaning that his/her belief has to them and how it plays out with his/her experience.</p> <p>Have a spiritual needs assessment during admission that will involve a discussion with the service user.</p> <p>Actively engage in conversations with service users to understand what their request (religious related) mean to them.</p> <p>Set aside time to discuss the service user's intervention plan through the lens of their belief system.</p> <p>Do not avoid questions or comments about religion and belief.</p> <p>Refer service users to the chaplain only upon request.</p> <p>Record spiritual needs and feed them to the MDT meeting.</p>
Developing understanding of religion and belief and their role in the context of hospice care	Religious literacy in hospice care indicates a further need; professionals should develop a sound understanding of religion and belief, beyond the scope of spirituality, but inclusive of it. Thereafter, there is a need for appreciating the roles that these concepts play in the context of hospice care.	<p>HCPs in hospice care to familiarise themselves with hospice history and hospice ideology.</p> <p>Working with chaplains to gain further understanding of the role of faith in hospices.</p> <p>HCPs to participate in monthly focus groups to critically reflect on the roles of religion, belief, and spirituality in hospice care, and exercise their skills of talking about religion and belief.</p>

Table 15: Value-Based Approach

Value-based approach	
Measures	Description
Self-awareness	Professionals should develop the skill of introspection; the ability to recognise themselves as an individual separate from the wider context of the organisation.
Self-understanding	Self-understanding refers to the ability to reconceptualise oneself as part of a wider system, and organisation. With self-awareness and self-understanding, the professional shows understanding of their identities, as well as how those relate to the identities of other people.
Interpersonal skills	Interpersonal skills are essential when setting out to work with people. Excellent communications and listening skills will best prepare professionals to respond to the religiously (and non) diversified service user group in the hospice.
Empathy	The development of empathy and empathic approaches enhances the ability to build better and stronger rapport with people from different faiths and belief systems.

To conclude with, planning social policy is a process that requires multiple resources (Iatridis 2005). An ever-changing society is one of the primary resources in this case. Ongoing adaptation to the new changes that are faced in EOL care are also indicators for social policy planning. This study reports on findings that demonstrate the current self-understanding and professionalism of HCPs' in EOL care. These conclusions are part of the changes that shall become informers of new and restructured social policies in the area.

Implications for professional practice

Professional practitioners handle continuous education and adapt to a lifelong learning approach to better equip themselves according to the ongoing changes in society. Religion and belief have seen tremendous change over the last few decades, as it is explored in this thesis,

and this change is subject to consideration when it comes to efficient, adequate, and quality practice.

Health and social care literature (Hall & Roussel 2012; Melnyk & Fineout-Overholt 2011; McSherry 2001) is representative of the significance of the evidence-based practice. Professional practice ought to be informed by evidence and vice versa. It is real time experiences that can better inform practice that successfully meets the needs of service users. Similar to what Crisp (2008) suggests about subjective experience and its significance in a lifelong learning attitude. It is also worth adding that evidence is strained by time and space, which reinforces the need for lifelong learning approaches.

Religious literacy may be used as a framework to engage better with the new and challenging faith needs of service users, as well as better understand spiritual care. In other words, compartmentalise and reconstruct it as part of care that HCPs can more comfortably understand and assimilate. It is the acquisition of the right language that is important in order to be able to engage with such needs. Evidently, this is a task that directly links to the education of HCPs. Religious literacy may be an effective framework in which professional practice can further develop, however, the educational system shall be following same tactics in order for the HCPs to experience consistency and cohesiveness throughout their lifelong learning, which includes education and practice.

Implications for Higher Education Institutions (HEIs)

Lack of religious literacy of HCPs in death and dying settings is not merely a concern of social policy and professional practice. The long lasting assumptions of a secular society have influenced higher education that has seen consequences in designing and delivering curricula that employ a rather secular language. On that note, HEIs are preparing HCPs who are ill-equipped with regards to religion and belief, as well as preparing professionals to practice in a

secular context. Adequate and comprehensive education is paramount in how services are delivered. For example, Crisp and Beddoe (2013) have explored health and well-being as essentially linked to social work values. They suggest that social work education shall embed in the curriculum more and stronger aspects of social inclusion and better engagement with diverse service users. It is on this note that this conclusion is drawing; better engagement with diverse religious and faith identities of service users.

This study is an additional evidence of how HCPs are educated in the UK in connection with religion and belief. The findings indicate that little or no attention has been given in higher education with regards to working in a multi-faith environment, while adequate skills are developed about the legal framework and bureaucratic procedures. Nonetheless, especially in nursing (for example courses at the Cicely Saunders Institute), attention is given to spiritual care and spirituality, terms often used as a proxy for religion and belief, however important.

Spiritual care became an integral part of hospice care, especially after the EOL Strategy 2008. Chaplains were accounted responsible for providing spiritual care in hospices and hospitals, while nurses acquired, gradually, similar responsibilities. McSherry (2001) is one in a pool of many scholars who saw nurses accountable for the spiritual care of patients. Nonetheless, and for numerous reasons, this has been problematic and has caused more stress than offered relief. The addressing of this area of care seems secular in itself; addressing the notion of faith without being explicit or specific in any way. It merely includes aspects of care that have not been discussed otherwise, and which leaves professionals precarious in engaging with religion, belief, and spiritual identities of service users, as it has been well highlighted throughout this thesis.

Recommendations for future research

This study was concerned with a particular question, the answer to which raised many more in return. The scale of this project is extensive and multifaceted even across the NHS. To rebuild on current and generate new social policies toward service delivery that is led by engagement and partnership, as well as positive and full integration of religion and belief with EOL, there is need for more studies in healthcare in general to allow further assessment of quality care. Further, to explicitly enhance the service user experience in EOL care, and better prepare HCPs to meet the needs of service users with diverse personal characteristics, there is need for more research in hospice care, inclusive of its nature and aims in the 21st century. Religion, belief, and spirituality need be examined from the service user's standpoint to appreciate better how these play out in parallel to the experiences of DDB. Additionally, there is a need for research to comprehend whether, and if so when, hospices hold the responsibility for causing spiritual distress. Exploring the following as future research strategies can facilitate the achievement of these targets:

- Further case studies in hospitals and hospices,
- Experimental research in hospices across the whole nation,
- Experimental research in hospitals across the entire nation,
- Expand further with grounded theory studies in EOL care,
- Qualitative research to gain understanding of the organizational foundations as those play out in relation to religious illiteracy,
- Qualitative research to gain understanding of the senior management's position in relation to religious illiteracy,
- Considering of practice-based research.

The above list is not exhaustive but rather highlights some of the research strategies identified in order to advance from what we have learned from this project and aim toward some of the different facets of this discussion. The framework remains religious literacy, and the urgency to investigate the challenges that are faced across and within the healthcare system altogether is both necessary and timely.

Concluding note

In spite of the signs of remarkably effective professional practice in hospice care, religion and belief are still marginalised in policy and practice while spirituality is used as a proxy. The increasingly diverse service user population, multi-faith, in particular, causes the need for the right responses. In the face of such diversity, death and health policies, and professional practice, have responded with equality laws, and neutral attitudes and spaces. This has led to avoidance of the issue and a solution-focused approach that seeks to problematize the situation, rather than facilitate it. This is the result of lack of religious literacy; skills and abilities to ask appropriate questions, and engage properly with religion and belief as identities of service users. There is a much more complicated story though regarding how HCPs came to lack religious literacy, and this relates to the changes in the religious landscape, as well as the modification of language in care. This experimental study has shown that HCPs partly recognise the need for further expanding their knowledge and expertise with religion and belief. Nevertheless, it is evident that professionals have also been misled, believing that further knowledge of different and various religious traditions will as well increase comfortable engagement. Religious literacy in EOL care is the ability to be open and accepting to difference in relation to faith or belief. It is the intention to engage regardless of own different beliefs, and a framework from which professional practitioners can learn and further progress in their development.

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Internet sources

<http://humanism.org.uk/about/our-values/>

<http://www.nice.org.uk/>

Appendix A
Reflective Researcher

Researching religion and death: a learning process

This project is a research account about religion and death; two notions that can only be acquired in a conceptual manner. These are also two areas that have been treated as taboo subjects in society, at different times. The sociology of death has explored death and its revival in contemporary societies (Walter 1994). On the other hand, religious studies have been concerned with the ongoing changes of how religion and belief play out in different parts of public life (Dinham & Francis 2015).

The combination of the both in connection with the death and dying settings in which research was undertaken, made for a sensitive project, congested with challenges at most times and in various and different stages. It is those challenging moments that adorned my learning process further, not merely in completing this PhD thesis, but in growing as an academic, and acquiring skills and knowledge that will enable future development. Most importantly, this project can only be described as a process; a fruitful, productive and worthwhile process that equipped me with greater understanding of the intersection of thanatology and religion as well as with robust research skills.

As a postgraduate student, your work is rather independent, with little intervention in terms of when, how and why. This is stressful in itself; the student is expected to not only complete the project but also build up the 'how to.' Nevertheless, and as contradicting as this may sound, the PhD is never a lonely process. Professor Michael Craig-Martin, on February 16th, 1995, delivered an inaugural lecture at Goldsmiths. The topic was 'Giving Permission.' In his talk (Craig-Martin 1995), he suggests that it is the lecturer's/supervisor's role to enable the student to give permission to themselves in order to attain goals and gradually thrive in their projects.

With this in mind, it is with supervision that I have given myself permission to try over and over to meet my goals successfully and cherish those attempts with love as I was working toward completion. This reflection is divided into three parts, where I share selected observations of my learning as that was experienced. Next I am discussing some of the challenges that I had faced before I started collecting data.

Before the fieldwork

This thesis is far from what I thought it would be when I first started. This is not because it took a different turn, but because in the beginning I was yet not aware of how I am framing my research question; this is what made for challenge one.

Neither my academic, nor my professional backgrounds covered knowledge of the sociology of religion literature. The desired outcomes for this project would have me use sociology of religion, and religious literacy in framing my research design, undertaking research, and reporting on and interpreting findings. Prior to fieldwork, I spent most of my time familiarizing myself with literature from religious studies, theology, and sociology of religion. With further understanding of this literature was I able to frame my research question, and choose appropriate research methods, methodologies, and epistemologies.

Suffice to say that literature review is not merely the review of the work of others' already available. It is a process that serves three primary purposes, as far as my experience goes. The first one is twofold; an overview of what the literature says on multiple aspects of your project, in addition to a comprehensive and exhaustive understanding of the intersection of different discourses and how those link, as well as in what areas, with your own research. It is during this part of the process that I came to fully appreciate that there is not irrelevant literature to the research project that I was preparing to undertake, but only literature that may be more or less relevant to my research question, according to its overall framework.

Furthermore, a literature review is vital in framing your research question, defining epistemologies, choosing methodology and methods, and finally interpreting and reporting on research data. Drawing from Crotty (1998), the designing of my research project was neither linear nor one-way. I had to go back and forth to my literature review and methodology chapters in order to make informed choices, but also in terms of adjusting my proposed research to the gaps identified in and across previous knowledge and research.

Last, but not least, literature review serves a particular role that is directly linked with the researcher. It assists the researcher's academic position about the research question and project. Blakeslee and Fleischer (2009) suggest that the research question, and consequently the research project in all, should not be a product of promiscuous choices. A good research project is the result of a well framed and well-structured research question and design. This is one of the biggest challenges that I have faced prior to entering the field for data collection. It has been this challenge that helped me appreciate research and knowledge more, in addition, to understand better that my research project is a multi-dimensional process that has no consecutive steps, but all may be (re)visited at different times and for various reasons.

Before I move on to share some thoughts from during my field work, I find necessary to mention the upgrade process as part of my learning. It is unforeseen how unique the challenge to present (or defend) your work before it happens is. I was faced with the challenge to support that my idea and framework, in relation to the intended outcomes of my proposed project, were significant enough to be undertaken at a postgraduate level. Yet, I was only able to appreciate this challenge only after it had happened – probably long after! The only person I was presenting or defending my project to was myself. This was the very first time that, without excuses and delays, I had to confront my fears and support my learning so far while I gain the confidence of my knowledge insofar.

During fieldwork

The very first step at the stage of fieldwork was to approach hospices and seek collaboration to carry out my research. This was the first most challenging moment of my fieldwork. I contacted 34 organizations and trusts, from which I received 12 responses. Out of the twelve, 5 suggested that due to lack of resources it was unable for the project to be undertaken with them. I met with team members from all the rest of the hospices (seven in number). In our initial meeting, the project's aims and scope were adequately communicated, and the opportunity was given for potential participants to ask questions and seek clarity, if necessary at that point. A comprehensive presentation was delivered to the managerial team of each hospice. The presentations were heavily engaged with the ethical considerations of the study, especially in terms of participant observation when service users were involved. Managerial teams examined my proposal extensively while the procedures had several delays with no particular reasons at first. Three hospices agreed, within the timeframe set for decision-making, to invite me in for research purposes. The rest had yet not decided whether my proposed area of research was necessary as "hospices are very good at providing spiritual support" (M.G.H. 2013, pers. comm., 29 November). There has been a general ambivalence observed with hospices in terms of participating in this study. It was commonly suggested that professionals in hospices are very good at responding to religion, belief, and spiritual identities of service users, and, therefore, found the aim of the project lacking validity.

Ethical approval was challenging but with positive results. What was hard to overcome during the fieldwork was the lack of consistency in terms of the hospices' engagement with the project and commitment on their part. To further unpack this, professionals from three hospices in Greater London engaged with the project, and ethnography was carried out in one hospice. The first step in data collection was in connection with the pilot study. This involved interviews with HCPs from two of the hospices. Prior to that, ethical approval was sought, and

presentations were delivered, in addition to four consecutive meetings in order to highlight the importance of the study as well as its integrity and ethical considerations. At the end of the pilot study, and right before the main research and ethnography were scheduled to commence, one of the hospices appointed a new CEO. The new CEO stopped the process and requested to revisit the aims of the project while it was specifically communicated that “our hospice is doing very well with religions, so what are you looking for?” (C.B. 2014, pers. comm., 22 March). Similarly, the process froze with the second hospice for a different reason; the team of physicians in the senior management team decided that what the project was studying was very sensitive and perhaps not appropriate.

At the stage of interviewing research participants, general ambivalence toward the language used to frame the questions was noted. Research participants had the tendency to substitute the words religion and belief in spirituality. This made them feel more comfortable to talk about it. This was not a direct sign of uncomfortable language, however. It was mostly evident that research participants found themselves confused when in a conversation about religion and belief the term ‘spirituality’ was not dominant.

On a similar note, focus groups were a challenging process. Research participants came across more willing to engage in the conversation due to elements of competition among colleagues within and across the organization (Hughes & Wearing 2013). This has opened up the space for considering data from different angles, i.e. attitudes toward religion and belief in relation to cross-professional collaboration and communication.

After the fieldwork

The synthesis and interpretation of the data had commenced before the completion of fieldwork. Parallel with carrying out interviews and focus groups, I had begun the process of analysing and coding ethnographic and participant observation data. When data collection was

complete and all interviews and focus group discussions had been transcribed, I revisited themes and (re)worked toward integrated analysis and coding, employing thematic analysis (Boyatzis 1998). This process called for revisiting the literature review in order to fit better my framework into the interpretation of the data.

Interpreting the data and reporting on the findings was not a one-way process either. On the contrary, this was an iterative one. Themes from ethnographic notes informed the coding of the interview data, and vice versa. The topics and categories that emerged from this process shaped the nodes that arose from focus group data. Different sets of data were considered and examined against each other, but also as a unity. I have at times lost focus due to the overwhelming information that was collected in this project. Nonetheless, with the right guidance in place, and adequate peer support I accomplished to materialise an appropriate framework for my data, and keep them in good structure.

An additional element that enriched my learning process at this stage was the need for ethical and sensitive treatment of the data, as well as informed reporting on them. This is paramount in undertaking ethical research, i.e. to safeguard the data and avoid misinterpretation. The only possible way to accomplish this is by ensuring that you keep well informed of the process at all times and hone your skills in research and ethics. Apart from that, this is a constant battle between the researcher's interests, values, and intended outcomes. It would be irresponsible of me not to come to terms with my intentions about this project, prior to engaging in the interpretation of the data. It is the researcher's responsibility to safeguard objectivity to the best of their ability (Bryman 2004).

After the fieldwork the process became more personal and independent than before. My goals at this stage included answering my research question as it was framed in the beginning and revisit my literature review to support further my claims that I evidenced with my data. This

does not feel like the end of my learning from this project. It is merely the opening of the gates, and toward a vast area of research and knowledge. My thesis has answered one question but has simultaneously raised many more, in addition to whether religious literacy can be used as a framework to understand healthcare better and, if so, further explore the ways in which this framework can be helpful in order to enhance the quality of services and the service user experience.

Appendix B

Cover Letter

Dear participant,

Thank you in advance for your participation in this study. I am a PhD Candidate at the Faiths & Civil Society Unit and the Social, Therapeutic and Community Studies (STaCS) Department, Goldsmiths – University of London. My PhD project has a particular focus on health care practice associated with death, dying and bereavement issues. There is strong evidence in research suggesting that people tend to find hope in their belief systems, and also tend to make sense of death and dying through their religious or non-religious beliefs and values. This research project examines religious literacy of health care professionals who practice with people facing challenges toward the end of life.

The current request is with regards to the main study, which consists of three phases. The first one refers to *participant observation*. That will run for three months and under discussion and agreement with the professional who is the subject of observation. The second phase regards a 40-50-minute interview. The interview will be voice recorded for research purposes. The interview will take place in a private room at your place of professional practice, which will ensure confidentiality and reliability of privacy during the process. I will be the only interviewer in the room while you have the right to withdraw from the inclusion of the interview data within two weeks upon recording. The last phase is to do with a focus group – one session – with other participants, which will facilitate a conversation on the main themes of interest that will arise from the previous phases.

Your participation in this project is completely voluntary, and you may choose to withdraw from this project any point during the study or skip any question you prefer not to answer. It is as well anonymous. You will be identified in the consent form agreement alone, which will be secured under the researcher's supervision, and separate from the data.

If you have any questions about this project or your participation in the pilot study, you can email Mr. Panagiotis Pentaris at p.pentaris@gold.ac.uk.

Thank you in advance for considering participation and assisting with the promotion of research in thanatology and death studies.

Sincerely,

Panagiotis Pentaris
Goldsmiths, University of London

Appendix C

CONSENT FORM*

** This form contains strictly confidential information and will remain with the researcher alone until the end of the research process. The researcher is responsible for maintaining confidentiality and privacy of the information contained here.*

Title of the Project: **'Religious Literacy in Thanatological Practice (RLTP)'**

Researcher for the Project:

Mr. Panagiotis Pentaris, MSW, QSW

PhD Candidate

Social, Therapeutic and Community Studies (STaCS) Department

Goldsmiths, University of London

E-mail: p.pentaris@gold.ac.uk

**Please Initial
Box**

1. I confirm that I have read and understand the information sheet (cover letter) 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 from the process at any stage; and I am free to withdraw my data up to the point of transcription which takes place 2 weeks post interview.

3. I agree to take part in the above study.

Note for researcher:

Include the following statements if appropriate, or delete from your consent form:

4. I agree to the interview / focus group / consultation being audio recorded

5. I agree to the use of anonymised quotes in publications

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

