

**Nurses' responses in spiritual encounters with patients, and issues that influenced these responses; a comparison of medical nurses, oncology nurses and Macmillan nurses**

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# Declaration

I declare the work in this thesis to be my own, except where otherwise stated.

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# **Dedication**

To my much loved niece Majsan,

I remember your warm smile, strong personality and amazing spirit.

## **Acknowledgements**

I would like to thank my supervisors, John Paley and Jean Bell, from the School of Nursing, Midwifery and Health at the University of Stirling, for their patience, support and encouragement throughout this long and at times very difficult process. After John's retirement, many thanks to Gill Hubbard for taking me on and providing me with much needed help and support.

I am grateful to the nurses who agreed to be interviewed for this study. They were willing not just to be interviewed, but to share some very emotional incidents and some very personal feelings with me. They shared sadness and humour, tears and laughter, as well as giving me a real insight into their relationships with their patients. I feel privileged to have listened to their accounts.

I would also like to thank the ward and department managers for their help in distributing the invites and in allowing the nurses to complete the questionnaires and attend the interviews within working hours.

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## Abstract

**Background** Spiritual care is considered an important aspect of palliative care. Patients with heart failure have palliative care needs, but are more likely than those with cancer to be cared for on general wards. **Aims** To explore the responses of nurses in encounters that could be considered spiritual and issues that influenced these responses, and to explore the differences between medical ward nurses, oncology ward/department nurses and Macmillan nurses. **Methods** The Critical Incident Technique, with semi-structured interviews of 9 medical, 9 oncology and 9 Macmillan nurses. Demographical data was collected using a questionnaire. **Setting** A regional hospital and the Macmillan nursing service in the Highlands of Scotland. **Results** Nurses constantly negotiated the boundaries between what is and what is not appropriate in the nursing role. There was a tension between their role to respect patients' beliefs and wishes and to minimise stress and suffering. The nurses were thrown into conflict when patients refused optimal symptom relief or when those who were not terminally ill refused life saving treatment. In this study, providing comfort, relieving suffering and saving lives that could be saved, took priority over patients' religious and spiritual beliefs or wishes. The Macmillan nurses felt less responsible for providing answers or resolutions, and were more likely to use a pathway of listening, discussing, exploring and clarifying. The medical nurses worked in an environment that often was not conducive to provide spiritual care, with less access to support than the other nurses. **Conclusion** Medical ward nurses need appropriate support and preparation, as well as the time and space to provide holistic care. Some of the Macmillan nurses' skills would be transferable to nurses working in any area of nursing. A greater understanding of the reasons for various religious beliefs and wishes may help nurses to accept them more fully, which may reduce stress both in nurses and patients.

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# **1 Introduction**

## **1.1. Introduction to the thesis**

My interest in the role of spirituality in the care of patients with life limiting conditions originates from my experiences of working with patients who were living with heart failure. In my work with these patients, I saw that in some instances, issues such as hope, meaning and a belief in God influenced how they coped with their condition. When patients raised spiritual or religious issues, I needed to respond, and I felt that how I responded was important. One patient, for example, told me that he must not die yet, as he needed more time to do ‘good things’ to make up for all the bad things he had done in this life. There has been an increased interest in the role of spirituality in health care over the past 25 years (see Chapter 2 for a review of the literature), and much interest has also been shown in the effects that religious and spiritual beliefs may have on health (Chapter 1.2.1). I found this an interesting and relevant area to explore further.

The World Health Organization (WHO) (2001: 30) believes that patients’ responses to disease, as well as the outcome of diseases, may be positively influenced by spiritual beliefs and practices. The provision of a holistic health care that addresses patients’ religious and spiritual needs is well established in palliative care (WHO 2002, WHO Europe 2004a), and in the past 10 - 15 years there has been an increased emphasis on the need to make palliative care available not only to patients with cancer, but also to those with other serious chronic illnesses (WHO Europe 2004a). It has been suggested that the positive influences of spiritual beliefs and practices can be of benefit in areas

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other than palliative care (WHO 2001: 30).

Health and social care policies and guidelines that include the role of spiritual and religious issues have been developed globally, particularly in palliative care (National Consensus Project for Quality Palliative Care 2004, National Consensus Project for Quality Palliative Care 2009), while the governments in the UK have stated their expectations with regards to the provision of religious and spiritual care to patients (Department of Health (DH) 2003, Scottish Executive Health Department 2002, Scottish Government 2009).

Despite the clear expectation that health care providers should consider patients' spiritual needs, there is limited guidance on how nurses and other health care staff should do this, as well as how they actually do it in practice. This study seeks to expand the knowledge and understanding in this area.

This Chapter provides the background to the study and I will start with a discussion of the connection between religion/spirituality and health care, and the role of spirituality in the care of patients with heart failure, as well as in palliative care. I will then continue with a discussion of policies and guidelines relating to the expectations of spiritual care in health care, and end with the study aims.

## **1.2. Background**

### **1.2.1. Spirituality and religiosity relating to health**

This review is brief, as my aims for this study relate to how patients' spiritual needs are met, and not to whether religion or spirituality is beneficial to health. When patients raise religious or spiritual issues, nurses do need to respond, and it's important to patients that this response is appropriate (Ross and Austen 2015, Murray et al 2004, Murray et al 2002).

The correlation between religiosity/spirituality and health has been much explored with varying results (Chida et al 2009). This is likely to be influenced by spirituality and religiosity being measured in very different ways (Chida et al 2009) and also by multiple confounding factors (Chida et al 2009, Koenig et al 2001, Salmoirago-Blotcher et al 2013). It has also been suggested that religious influences can have both a positive and a negative effect on patients' health (Koenig et al 2001).

Salmoirago-Blotcher et al (2013), in an observational study involving 43,708 post-menopausal women, found that a higher frequency of private spiritual activity in older women was associated with an increased cardiovascular risk, which they suggested may be the effect of women with chronic diseases using spiritual activities as a coping strategy, as well as a possible survival bias. A meta-analysis of 69 studies of healthy people and 22 studies of patients with a diagnosed disease that were published between 1977 and 2008 by Chida et al (2009), on the other hand, found that religiosity/spirituality had a positive effect on survival.

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In a prospective, double blind, randomised study of 393 patients admitted to a coronary care unit in San Francisco, US, where one group was assigned to being prayed for and the other not, Byrd (1988) found a statistically significant better outcome in the group that had been prayed for. This study is different, in the sense that it did not involve patients' own religious and/or spiritual beliefs or practices. Koenig et al (2001) suggests that this is a finding that cannot be explained.

### **1.2.2. Heart failure**

Symptomatic heart failure is a life-limiting, terminal condition that affects patients' lives very severely (Cowie 2002, Jhund 2009, McMurray et al 2012, Riegel and Carlson 2002). Heart failure is common in advancing age, with prevalence and incidence increasing progressively with age (Davis et al 2000, Mosterd and Hoes 2007, Murphy et al 2004). Patients experience physical limitations and repeated hospital admissions (Cowie 2002, Iqbal 2010, Jhund 2009, McDonald et al 2002, McMurray et al 2012, Mosterd and Hoes 2007, Riegel and Carlson 2002). Morbidity and mortality rates are high (Mosterd and Hoes 2007, Murray et al 2004), and Stewart et al (2001) found lung cancer to be the only cancer with a worse five-year survival rate in men and women than symptomatic heart failure, from first admission for the condition. Although improved treatment has resulted in improvements in survival (Mehta 2009), for many patients quality of life remain poor (Iqbal 2010).

Extensive research shows that these patients also suffer from anxiety, depression and reduced quality of life (Bennett et al 1998, Dracup et al 1992, Luijendijk et al 2010,

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Majani et al 1999, O'Leary et al 2009, Ross and Austin 2015), as well as struggling with self-care (Riegel and Carlson 2002). Murray et al (2002) found that heart failure patients received less health, social and palliative care services than those with lung cancer, and that care often was poorly coordinated. These patients have a great need for skilled care, including palliative care and a recognition of their spiritual needs, but are less likely to receive this, than those with cancer (Murray et al 2002).

Research on the role of faith and spirituality in patients suffering from heart failure is emerging; although, this has in the past focused mainly on other life-limiting conditions, such as cancer and HIV. Westlake and Dracup (2001), in their qualitative study of 87 patients with advanced heart failure, found that regrets regarding past lifestyles was a recurring theme, as well as a search for meaning within the present experience of heart failure, a search for hope for the future, and the reclaiming of optimism. Hope was related to God, faith and religion, including an afterlife, as well as hope for a heart transplant. Westlake and Dracup (2001) suggest that the inclusion of a spiritual element in assessments and interventions could facilitate adjustments to advanced heart failure. Ross and Austin (2015) conducted 47 semi-structured interview with patients diagnosed with end-stage heart failure and concluded that these patient had spiritual and existential needs, and would have benefitted from spiritual care within palliative care.

Murray et al (2004) explored the spiritual needs of 20 patients with inoperable lung cancer and 20 with severe heart failure, with qualitative, in-depth interviews every 3 months for up to one year. Spiritual needs were defined as the need to find meaning,



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purpose and value in life, whether specifically related to religion or not. Only five of the lung cancer patients and seven of the heart failure patients were still alive at the end of the study, highlighting the similar prognoses in these two patient groups. Many of the patients and their carers expressed a need for seeking meaning and purpose in life. There was a reluctance to discuss end-of-life issues within the family to avoid upsetting each other, while many spoke freely about spiritual issues when given the opportunity. Heart failure patients experienced a more uneven illness trajectory than those with lung cancer (Murray et al 2002, Murray et al 2004: 42), with death occurring more suddenly, and without a clearly defined terminal stage, and patients had a need for support long before the terminal stage, to help them come to terms with their impending death (Murray et al 2004).

To conclude, patients with heart failure have a different disease trajectory to those with cancer, but are likely to benefit from, and should have access to, palliative care adapted to their special needs (DH 2000: 5, Ellershaw and Ward 2003: 31, Gibbs et al 2002, O’Leary et al 2009). Further, as the above literature suggests, these patients are also likely to benefit from spiritual support.

### **1.2.3. Palliative care**

The WHO (2002: 84) defines palliative care as ‘an approach that improves the quality of life of patients and their families facing the problems 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,

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psychosocial and spiritual’, and further states that it should ‘integrate the psychological and spiritual aspects of patient care’. The Oxford Textbook of Palliative Medicine (Doyle et al 1998: 1) defines palliative care as ‘the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is on the quality of life’.

Palliative care, which includes patients’, their families’ and carers’ spiritual needs, has traditionally been associated with patients diagnosed with cancer, but the above definitions apply to conditions other than cancer, and Dunlop (2001: 189) points out that St Christopher’s Hospice in South London was originally intended to provide in-patient care to those with non-malignant diseases. The WHO (2004a, 2004b, 2004c) recognizes the need for the provision of high quality palliative care to all people suffering from serious chronic illnesses, such as cardiovascular, respiratory and dementia conditions. They also point out that this is an area that has been neglected, with regards to health research and policies.

As well as developing guidelines and policies in the UK relating to the provision of spiritual care, there have also been attempts made to make palliative care available to patients with life limiting conditions, other than cancer, who may be cared for in areas other than a hospice setting (Addington-Hall and Higginson 2001, National Consensus Project for Quality Palliative Care 2009, DH 2008, WHO Europe 2004a).

#### **1.2.4. Policies and guidelines**

The WHO's expectation that holistic care should include religion and spirituality has resulted in the development of policies and guidelines on a global level relating to the role of spiritual and religious issues, particularly in palliative care. The first clinical practice guidelines for palliative care, which included spiritual, religious and existential aspects, were released in 2004, by the National Consensus Project for Quality Palliative Care (2004) in the United States, with the second edition published in 2009 (National Consensus Project for Quality Palliative Care 2009). The importance placed on the inclusion of spiritual care in palliative care was further emphasised by the Consensus Conference, held in 2009 in California, which aimed to 'identify points of agreement about spirituality as it applies to health care and to make recommendations to advance the delivery of quality spiritual care in palliative care' (Puchalski et al 2009: 885).

In response to the importance placed on addressing patient's religious and spiritual needs in palliative care, the UK governments have stated their expectations with regards to the provision of religious and spiritual care to patients. Since this study was carried out in Scotland, I will focus on the developments in Scotland.

The Scottish Government (2009) asks that health care staff document patients' religious affiliations, if any, and, with the patients' consent, pass this information on to the chaplaincy service. Health care staff are also expected to advise patients and their carers of the spiritual and religious care that is available to them, establish whether patients wish to be visited by a religious leader or spiritual caregiver and keep this information

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up to date, as patients' wishes may change during the admission. In addition, there is a requirement that health care staff should assess patients' spiritual needs, identify any unmet needs and provide spiritual care at an appropriate level. The Scottish Government (2009 Appendix 1: 44) suggests that staff responsible for direct patient care are in the best position to take on this responsibility.

Spiritual care needs are not expected to relate exclusively to those within a religious faith community and many patients and their relative may have spiritual needs, particularly when facing serious or life threatening conditions (Scottish Government 2009 Appendix 1: 33-34). It is thought that those who belong to a religious faith community, and as such are in a minority, are likely to receive the spiritual care that they need from this community, while those in the majority, who do not have any religious associations, have spiritual care needs that require to be met in other ways (Scottish Government 2009 Appendix 1: 33-34). The Scottish Government (2009 Appendix 1: 33-34) states that 'the NHS must offer both spiritual and religious care with equal skill and enthusiasm'.

There is an explicit requirement that all health care staff in Scotland should 'provide spiritual care at an appropriate level', rather than relying on the Chaplains' rounds (The Scottish Government 2009 Appendix 1:44, The Scottish Government 2009 Annex B: 14). It is recognised that health care staff will be better able to fulfil their role with regards to spiritual care if properly trained (The Scottish Government 2009 Appendix 1:44).

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The Scottish Government (2009 Annex A, point 9: 2) expects NHS Boards in Scotland to:

‘promote research which broadens and enlightens the evidence base for the efficacy of spiritual and religious care in health, and continue the development of professional and research documents, journals and activities, both within Scotland and, where possible in a UK context, which will enable the advancement of NHS Chaplaincy towards self or national registered health profession status.’

The responsibility for providing spiritual care policies has been placed with the NHS Boards (The Scottish Government 2009 Annex A: 4). NHS Highland (2010, reviewed 2011) has provided a policy, which places importance on the provision of holistic care that includes the spiritual and religious needs of patients, carers and staff.

### **1.2.5. Expectations of registered nurses**

The Scottish Government (2009 Annex B: 6) suggests that staff responsible for direct patient care are in the best position to take on the responsibility of assessing and/or addressing spiritual care needs. Considering that nurses are responsible for assessing patients’ care needs and for providing direct patient care, it could be construed that nurses should take on this responsibility. Locally, the NHS Highland’s Policy for Spiritual Care (2010, reviewed 2011: 3) states that ‘it is the responsibility of all NHS staff to deliver spiritual care in its broadest sense and it should be seen as an integral part of the ongoing care given by staff’.

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The Nursing and Midwifery Council (NMC) (2010: 40, 113, 148, 149) expects registered nurses to practice in a holistic manner and make holistic assessments: 'A holistic approach to nursing considers physical, social, economic, psychological, spiritual and other factors when assessing, planning and delivering care'. Person-centred care is defined as 'care tailored to the individual needs and choices of the service user, taking into account diversity, culture, religion, spirituality, sexuality, gender, age, and disability'. Nursing students, at the first progression point, need to show that they have an understanding of how spiritual beliefs may impact on illness and disability (NMC 2010: 108). At the second progression point, they are expected to provide holistic care and assess spiritual needs, within their limitations (NMC 2010: 114,115). On entry to the register, nurses should be able to work with patients and their families to make systematic, holistic, person-centred assessments of physical, emotional, psychological, social cultural and spiritual needs (NMC 2010: 113).

The NMC's (2010: 113) expectation of nurses' abilities at the point of registration, matches up well with the DH's (2008: 126) statement that all 'relevant staff' should be able to carry out a comprehensive, holistic assessment with regards to patients', their families' and carers' spiritual needs, and the role of 'relevant staff' clearly applies to registered nurses. In defining nursing, the Royal College of Nursing (RCN) (2014) place an expectation on nurses to identify needs for spiritual support and to recognise spiritual responses in patients.

Despite the expectation of nurses to provide spiritual care, there is no clear definition of 'spiritual care'. The WHO (2001: 30) identifies 'adaptation and acceptance' as spiritual

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factors, and spirituality is seen to interact with cultural and social factors, while the Scottish Government (2009 Annex A: 1) states that 'it is widely recognised that the spiritual is a natural dimension of what it means to be human, which includes the awareness of self, of relationships with others and with creation'. Both the Scottish Government (2009 Appendix 1: 33) and the DH (2003: 5) agree that there should be a distinction in definitions between religious and spiritual care: 'religious care is given in the context of shared religious beliefs, values, liturgies and lifestyle of a faith community', while spiritual care 'is usually given in a one to one relationship, is completely person centred and makes no assumptions about personal conviction or life orientation', and that 'spiritual care is not necessarily religious, and religious care, at its best, should always be spiritual' (Scottish Executive Health Department 2002:76).

Guidance has been provided for nurses and other health care professional in the UK (DH 2008, Scottish Government 2009, Scottish Executive 2002, WHO 2001: 30), but there is evidence to suggest that definitions of spirituality and spiritual care may still appear vague to health care staff (McSherry and Ross 2002, Swinton and Pattison 2010), while a survey carried out by the RCN (2011b) indicated that while nurses regarded the provision of spiritual care as an aspect of their role, they lacked confidence in this area of patient care.

### **1.3. Aims of study**

The aims of this study was to explore how registered nurses working on acute medical wards, where patients with non-cancer life limiting conditions are cared for, as

compared with those working within an oncology department and those working as Macmillan nurses, caring mainly for cancer patients, respond in spiritual encounters with patients, and to explore issues that influence these responses.

### **1.4. Summary**

Palliative care, including spiritual care, is well established in oncology and hospice settings, while patients with palliative care needs in other care settings are likely to be cared for by staff with less experience and training in this area. There is evidence that patients with conditions other than cancer, such as heart failure, would benefit from having any spiritual concerns identified and addressed. All health care staff are expected to consider patients' spiritual need; however, because of their close and ongoing contact with patients, nurses have a key role in the provision of spiritual care (NMC 2010, RCN 2014, Scottish Government 2009, The Scottish Executive Health Department 2002 point 48). Despite this expectation, there is a lack of more specific advice on what is, and what is not, considered appropriate, when addressing spiritual issues in health care. Chapter 2 will show that there is a lack of evidence with regards to how nurses manage situations that could be considered spiritual.



## **2 Literature review**

### **2.1. Introduction**

Chapter 1 introduced the thesis and showed the background to the study, with a review of policies and guidelines relating to spiritual care (Chapter 1.2.4). It showed the expectations that come from official bodies in relation to spiritual care in palliative care (Chapter 1.2.3), the need of palliative care for patients diagnosed with heart failure (Chapter 1.2.2), as well as the expectation that nurses, specifically, should take an active part in spiritual care (Chapter 1.2.5). These expectations have led to much discussion by health care professionals and academics concerning the definitions of spirituality, as well as its role in health care, which this chapter will address. This chapter links the expectations of official bodies, as shown in Chapter 1, with their implementations in health care, which has resulted in a certain amount of overlap of information.

I will start with a discussion of the various suggested definitions of spirituality and spiritual care, followed by a rationale for the Operational Definition (De Vaus 2005) used in this study and a discussion of belief categories. The chapter ends with a review of what is already known about nurses' responses in situations that can be described as spiritual and a summary of the rationale for the study.

### **2.2. Spirituality and spiritual care**

Chapter 1.2.5 showed that registered nurses have been expected to assess and address patients' spiritual needs for a number of years. While improvements have been made

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since Ross (1994) and McSherry and Ross (2002) commented on the lack of guidelines in this area of nursing, uncertainties remain with regards to what is and what is not appropriate. There is also a lack of consensus as to what spirituality actually is, and the literature is overflowing with conflicting views. At one end of the spectrum, spirituality is viewed as relating only to religion, while at the other end it is very broad and inclusive, and viewed as applicable to all people regardless of any beliefs that they may or may not hold. This will be discussed further on in this chapter.

Spirituality has been strongly linked to the search for, and finding of, meaning in life, suffering and death (Association of Hospice and Palliative Care Chaplains 2006, Frankl 1984: 140-141, McSherry and Jamieson 2011: 1763, Murray et al 2004, Puchalski et al 2009: 887, Saunders 1988, Scottish Government 2009 Annex A: 2, Speck 2011: 109), and meaning is commonly included in definitions of spirituality:

‘Spirituality is 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.’

Puchalski et al 2009:887

‘Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.’

European Association for Palliative Care (EAPC) 2010

‘Spirituality is about: hope and strength; trust; meaning and purpose; forgiveness; belief and faith in self, others, and for some this includes a belief in a deity/higher power; peoples’ values; love and relationships; morality; creativity and self expression.’

RCN 2011a

‘Needs for meaning and purpose, love and harmonious relationships, forgiveness, hope and strength, trust, expressions of personal beliefs/values and creativity.’

McSherry and Jamieson 2011: 1763

Walter (2002: 134) questions whether or not the search for meaning in life can be considered a spiritual concept. He suggests that ‘existential’ has been replaced with ‘spiritual’, mainly by English speakers, and that Saunders (1988) made the first link between the search for meaning and spirituality, and introduced this into palliative care, based on the work done by Frankl (1984). Saunders (1988) identified the feeling of meaninglessness that she saw in some patients diagnosed with terminal illness as spiritual pain, and understood Frankl’s (1984) account in his book *Man’s search for meaning* to mean that it is possible to find a deeper meaning, even in an apparently hopeless situation. Frankl (2004, 1984) refers to religion and spirituality in relation to existing through the unbearable, and in the English translation, the term ‘meaning’ is used extensively. Frankl puts the human ability to find meaning in suffering in relation to another dimension, another world outside our own, where we may find an ultimate meaning of human suffering. He describes the importance for survival of having hope, of having a goal, of having a reason to go on, and links the loss of this hope to an increase in mortality in concentration camp inmates: those who lost hope and could see

no reason for, or meaning in, their on-going lives, were likely to give up and die. However, neither the German title *Ein psycholog erlebt das konzentrationslager*, nor the original English title *From death-camp to existentialism* include the term ‘meaning’. Translations and interpretations can alter intended meanings and it is difficult to judge whether Walter’s (2002) or Saunders’s (1988) understanding of Frankl’s (1984) intentions are correct.

Vance’s (2001: 265) definition of ‘an interconnection with God or god being that enables a human being to transcend the circumstances at hand and give purpose and meaning to life’ applies only to those with a belief in God or a god-like being. However, much broader factors have been linked to spirituality, such as ‘connectedness to the moment, to self, to others, to nature, and to the significant or sacred’ (Puchalski et al 2009: 887); attitudes, beliefs, ideas, values and concerns around life and death, hopes and fears regarding the present and future (Association of Hospice and Palliative Care Chaplains 2006); and adaptation and acceptance (WHO 2001: 30). Some of these definitions are broad enough to apply to most, if not all, people, and spirituality has been presented as something that is inherent in all human beings, with the Scottish Government (2009 Annex A: 1) stating that ‘it is widely recognised that the spiritual is a natural dimension of what it means to be human’ and the DH (2008) supporting the view of the Association of Hospice and Palliative Care Chaplains (2006) that all people are spiritual beings with spiritual needs. This can be disputed, as not all people regard themselves as spiritual beings with spiritual needs (Paley 2008b: 5) and some may object to having spirituality imposed on them (Milligan 2011).

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The definition of spirituality appears to have been stretched to justify the claim that it is present in all people, although no evidence has been provided for these claims (Paley 2008a, 2008b). Paley (2008a, 2008b) suggests that these are existential concerns that would be better incorporated into health psychology, social psychology, neuropsychology and pharmacopsychology. Existential has been referred to as the human mode of being (existence); the meaning of existence; and the striving for a concrete meaning of this existence (Frankl 1984: 123). Reinert and Koenig (2013) suggests that experiencing a lack of purpose and meaning in life relates to worthlessness, while a lack of a sense of peace relates to sadness, loss of interest or pleasure, and are markers of mental health issues, rather than spirituality.

In health care, the Scottish Government (2009 Annex A: 2) suggests that some of the basic spiritual needs to be addressed are ‘the need to give and receive love’; ‘the need to be understood’; ‘the need to be valued as a human being’; ‘the need for forgiveness, hope and trust’; ‘the need to explore beliefs and values’; ‘the need to express feelings honestly’; and ‘the need to find meaning and purpose in life’, and these suggestions are supported by NHS Highland (2010) in their Spiritual Care Policy. According to the Association of Hospice and Palliative Care Chaplains (2006), spiritual needs may relate to an individual's sense of meaning and purpose in life; attitudes, beliefs, ideas, values and concerns around life and death; and hopes and fears regarding the present and future for themselves and their families/carers. Spiritual care can also be seen to relate to the needs of people to make sense of difficult experiences (Speck 2011).

Hussey (2010) describes a naturalistic framework for nursing that is sensitive to

patients' religious or spiritual beliefs, but is based on a natural world, which can be revealed by science. The supernatural is rejected, as not evidenced by science, while different aspects of beauty and human friendship are viewed as profoundly spiritual experiences that can be enjoyed without any supernatural beliefs. While acknowledging that some people do hold non-naturalistic beliefs, Paley (2008b) too rejects non-naturalism, but also rejects the suggestion that aspects of naturism, such as close relationships and appreciation of nature and art, are aspects of spirituality. However, in health care, some patients will have supernatural beliefs that have an influence on their health, and simply discarding these beliefs as not evidenced by science would appear disrespectful and very unlikely to be helpful to patients.

Taking a very broad and inclusive view of spiritual needs, where spirituality is taken to include just about everything, risks the concept becoming meaningless (King and Koenig 2009, McSherry and Cash 2004). Spirituality may be better viewed as something that is subjectively experienced, in different ways by different people, perhaps in response to what they regard as a higher power (Bash 2005, 2004). It is also possible that one person may experience an event as spiritual, while another does not, or an event may be experienced as spiritual on one occasion, but not another (Pesut 2008). Swinton and Pattison (2010: 232) suggest that a practical approach in a health care and nursing context may be to focus on what spirituality does and its practical use, rather than trying to provide a definition for what it is. An appropriate approach to take in health care may be that a 'spiritual experience is what each person says it is, and the task of nurses is to identify and respect *that person's* expression of their spiritual experience and to offer them appropriate support' (Bash 2004: 14). In patient

encounters, this would allow for care that is based on individual patients' beliefs and needs, rather than the beliefs or disbeliefs of governments, academics or health care professionals.

It is unlikely that a definition will be agreed on (Bash 2005, 2004, McSherry 2005), but when patients express needs or concerns that may be considered 'spiritual', nurses need to respond, using their own interpretations of what constitutes an 'appropriate level' of spiritual care (Scottish Government 2009) (Chapter 1.2.4). This lack of clear boundaries, and potentially very different interpretations of nurses' roles in spiritual care, leave nurses vulnerable in their professional practice, as highlighted by the incident involving a nurse who was suspended, although later reinstated, by her employer for offering to pray with a patient (Nursing Times 2009). The expectation of health care staff to collect information with regards to patients' religious affinity on admission; to review this information during patients' admissions; to make patients aware of their right to be visited by a Chaplain or a representative of their faith community; and, with patients' consent, pass this information on to the Chaplaincy (DH 2008, Scottish Government 2009, Annex B: 6) is unambiguous. More ambiguous is the expectations that nurses should take an active part in spiritual care, including the assessing and addressing of patients' spiritual needs (NMC 2010, Scottish Government 2009) and that health care staff should provide spiritual care 'at an appropriate level' (Scottish Government 2009: 6). It is not surprising that nurses have been found to lack confidence in this area (McSherry and Ross 2002, RCN 2011b, Swinton and Pattison 2010).

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The Scottish Government (2009 Appendix 1: 44) states the need for training to enable health care staff to fulfil their roles with regards to the provision of spiritual care, and it cannot be presumed that all health care professionals will be able to address all patients' religious and spiritual needs (Walter 2002: 133-134). Over the past 5-10 years, efforts have been made to provide spiritual care guidance for nurses' and other health care professionals. The Scottish Government (2009 Appendix 1: 34-35) states that the spiritual care service provided by the NHS should:

- 'be impartial and accessible to persons of all faith communities and none, and facilitate spiritual and religious care of all kinds
- function on the basis of respect for the wide range of beliefs, lifestyles and backgrounds found within the NHS and Scotland today, in particular in relation to age, gender, ethnicity, sexual orientation, disability and religion/belief
- value such diversity
- be a significant NHS resource in an increasingly multicultural society
- be a unifying and encouraging presence in an NHS organisation
- never be imposed or used to proselytise
- be characterised by openness, sensitivity, integrity, compassion and the capacity to make and maintain attentive, helping, supportive and caring relationships
- affirm and secure the right of patients to be visited (or not visited) by a chaplain or their faith representative by incorporating flexibility into the means of obtaining informed consent to spiritual care both at the time of admission and during a patient's time of treatment
- be carried out in consultation with other NHS staff
- and acknowledge that spiritual care in the NHS is given by many members of staff and by carers and patients, as well as by staff specially appointed for that purpose.'



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*Care of the dying: a pathway to excellence* (Speck 2011: 107-127) provides guidance in spiritual and religious issues with regards to dying. In Scotland, the publication *Spiritual care matters; an introductory resource for all NHS Scotland staff* (NHS Education for Scotland 2009) seeks to provide health care staff with information with regards to spiritual care, its role in health care and how it can be provided. It describes spiritual care as:

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

NHS Education for Scotland 2009

The Chaplaincy Service is expected to make information easily available to help staff understand the needs of those from a variety of faith and belief communities (Scottish Government 2009) and, as a result, has provided *A Multi-Faith Resource for Healthcare Staff* (NHS Education for Scotland 2006). Another expectation of the Chaplaincy Service is to provide training to help staff fulfil their role in spiritual care (The Scottish Government 2009 Annex A and Appendix 1), while the RCN (2011a) provides the following guidance for what spiritual care should not be:

- ‘not just about religious beliefs and practices
- not about imposing your own beliefs and values on another
- not using your position to convert
- not a specialist activity
- not the sole responsibility of the Chaplain’

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Nurses and other health care staff should not impose their own beliefs or values, or proselytise (RCN 2011a, Scottish Government 2009 Appendix 1: 34-35); however, the statement that all people are spiritual beings with spiritual needs (Association of Hospice and Palliative Care Chaplains 2006, DH 2008, Scottish Government 2009 Annex A: 1) is a clear imposition of beliefs on patients who may not regard themselves as spiritual beings, with spiritual needs.

Paley (2009) goes further and argues that religion, spirituality and claims regarding God, transcendence and a higher power lack any evidence base and has no place in nursing or health care in a secular Europe, while agreeing that patients should have access to experienced religious practitioners. Religious and other non-naturalistic beliefs are classed as 'positive illusions' (Paley 2008c, 2009) and dismissed as 'false beliefs' that may still be of benefit to patients (Paley 2008b). Paley (2008b) questions the claim that spirituality has ancient roots; however, if spirituality is understood to be based on non-naturalistic beliefs, it would be reasonable to expect that such beliefs originally led to the emergence of religion. If that is the case, it would justify the existence of so called spiritual beliefs that are not linked to a specific religion.

God, afterlife, transcendental forces etc cannot be proven (Paley 2008b), but neither can they be disproven (Pesut 2008) and there are people, including patients, who do hold supernatural or, to use Paley's (2008b) term, non-naturalistic beliefs, including a belief in God, or a higher power. Claims about higher powers, higher levels of existence etc may not have a place in the literature of nursing discipline (Newsom 2008), and I will not enter into a debate on the existence of God, higher powers or anything else

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supernatural/non-naturalistic, as this relates to beliefs, rather than something that can be evidenced by science. However, beliefs that are important to patients, and may have an impact on their health, need to be considered in the provision of care (Pesut et al 2009).

*Spirituality in nursing care: a pocket guide* (RCN 2011a) avoids the presumption of religion or spirituality, and offers more practical suggestions for questions to use, when assessing patients' potential spiritual concerns. Questions such as: 'Do you have a way of making sense of the things that happen to you?; What sources of support/help do you look to when life is difficult?; Would you like to see someone who can help you?; Would you like to see someone who can help you talk or think through the impact of this illness/life event?' avoid the terms 'spirituality' and 'religion' and leave it up to the patient to raise any issues relevant to them.

It is uncertain if the guidance provided has given nurses and other health care staff a better understanding of their role in spiritual care. A survey carried out by the RCN (2011b) showed that nurses regarded spirituality and spiritual care as aspects of their role, but lacked confidence in this area and expressed uncertainties with regards to this part of their role.

Academics have conflicting views of what spirituality is and, while governments, health organisations, nurses and other health care professionals debate the definitions of spirituality, patients and their families may have their own, very different, understandings of spirituality and its role in health care (Bash 2005, McSherry and Cash

2004, McSherry et al 2004). If the need for love, to be understood and to be valued as human beings are to be regarded as spiritual needs, all patients can be expected to have spiritual needs, but it is uncertain whether patients themselves would describe these needs as spiritual (McSherry and Cash 2004, McSherry et al 2004). Just like academics have different understanding of what spirituality is, it is reasonable to expect that patients, too, have different views. Following this reasoning, it should not be presumed that ‘all people are spiritual beings, with spiritual needs’, but that some people believe that all people are spiritual beings, with spiritual needs, while others do not share in this belief. Cockell and McSherry (2012) identified that much of the research into spirituality in health care has been carried out without patient involvement and highlighted the risk of spiritual care being tailored around health care staff and academics’, rather than patients’, beliefs.

A definition for spirituality and spiritual care has not been agreed on in the health care section, but for the benefit of this study, there was a need to provide an operational definition, and this is addressed in Chapter 2.3.

### **2.3. Operational definition of spirituality**

Due to the lack of a consensual agreement on the definition of spirituality (Chapter 2.2), where definitions cannot be objectively proven and views vary dramatically, there was a need for an operational definition (De Vaus 2005) to clarify the concepts studied. Mason (2002: 39) associates the ‘operationalization’ of concepts with ‘validity’, and the ability to ‘demonstrate that your concepts can be identified, observed or “measured” in

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the way you say they can’.

The aim of this study was to explore how nurses deal with situations within the concepts of ‘spirituality’, as commonly described in health care and as understood by the bodies that expect nurses to provide spiritual care (DH 2008, NMC 2010, Scottish Government 2009, WHO 2001); for this reason, the operational definition needed to be based on these expectations.

The Scottish Government (2009 Annex B: 5-6) suggests that ‘spirituality’ is ‘a natural dimension of what it means to be human’, which includes ‘the awareness of self, of relationship with others and with creation, the finitude of life, the search for meaning, for the transcendent, and the need to be acknowledged, accepted, valued and loved’. The Association of Hospice and Palliative Care Chaplains (2006) does not focus on defining ‘spirituality’, but on ‘spiritual needs’, described as ‘attitudes, beliefs, ideas, values and concerns around life and death, hopes and fears regarding the present and future’. Equally, the WHO (2001: 30) does not provide a definition for ‘spirituality’, but suggests that ‘spiritual factors’, such as ‘adaptation’ and ‘acceptance’, may have benefits in health care, and states that ‘religious and spiritual beliefs are important aids in coping with serious diseases in a positive way, often remaining the central point of reflection in patients when biomedical treatments are no longer effective in terminal disease’.

As shown, the bodies that place the expectation to provide spiritual care on nurses take

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a very broad view on spiritual issues, while the operational definition (De Vaus 2005) had to be specific enough not to include every possible care situation that a nurse might encounter. At the same time, the trigger cues used in the Participant Preparation Sheet (Appendix IV) that was provided to the nurses to prepare them for their interviews (Chapter 3.3.1.3) had to be broad enough to encourage them to think about situations likely to encompass concepts commonly described as ‘spiritual’ and reduce the risk of missing relevant information (Silverman 2013: 97).

Meaning is compatible with the search for, and finding of, meaning in life, suffering and death, and has been strongly linked with spirituality in health care (Association of Hospice and Palliative Care Chaplains 2006, Murray et al 2004: 39-40, Puchalski et al 2009: 887, Scottish Government 2009 Annex A: 2, McSherry and Jamieson 2011: 1763, Saunders 1988). Hope, too, has been strongly linked to spirituality (Association of Hospice and Palliative Care Chaplains 2006, Frankl 2004 and 1984, McSherry and Jamieson 2011: 1763, RCN 2011a), while a belief in a higher power and/or in an afterlife is generally agreed on by all involved health care bodies (Chapter 2.2). For that reason, the operational definition of spirituality decided on in this study related to the concepts of:

- Meaning and purpose
- Hope
- A belief in a higher power and/or a belief in an afterlife

If the operational definition had been based on a very broad understanding of

spirituality, such as needs relating to ‘attitudes, beliefs, ideas, values and concerns around life and death’, ‘hopes and fears regarding the present and future’ (Association of Hospice and Palliative Care Chaplains 2006, Scottish Government 2009); ‘adaptation’ (WHO 2001: 30); ‘acceptance’ (Scottish Government 2009 Annex B: 5-6, WHO 2001: 30); ‘love’, ‘forgiveness’, ‘trust’, ‘being understood’, ‘being valued as a human being’, ‘expressing feelings honestly’, ‘awareness of self and of relationships with others’, ‘being acknowledged’ (Scottish Government 2009 Annex B: 5-6); ‘being connected to the moment’, ‘being connected to self, to others and to nature’ (Puchalski et al 2009: 887); and ‘beauty’ and ‘friendships’ (Hussey 2010), any health care encounter could have been included and the concept would have been meaningless (King and Koenig 2009, McSherry and Cash 2004). If the operational definition had included only a belief in God, another higher power or a belief in an afterlife, issue commonly described and understood as ‘spiritual’ in health care would have been missed, which was particularly relevant in the trigger cues used in the Participant Preparation Sheet (Appendix IV), as discussed in Chapter 3.3.1.3.

## **2.4. Belief categories**

Efforts have been made to categorise people who hold religious and/or spiritual beliefs. Based on the understanding that a majority of people in Britain no longer belong to a religious institution, while continuing to believe, Davie (1990) raised the concept of ‘Believing (religious believing) Without Belonging (to a religion)’. Neither believing nor belonging are completely clear concepts, and Voas and Crocket (2005: 12) claim that following on from Davie’s article, belonging has in some instances been interpreted as Christian belonging, while Davie’s understanding related to less orthodox beliefs.

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Davie (1990) noted that if basing 'believing' on fairly orthodox Christian beliefs, beliefs are dwindling, particularly in the younger age-groups, while believing may be redirected, rather than disappearing, if a wider definition that includes 'the meaning of life'; 'the purpose of mankind's existence'; 'the future of the planet'; and 'man's responsibilities to his fellow man and to the Earth itself' is used. Walter (2002: 137) suggests subsets of those who believe (in afterlife), but don't belong (to a church or other formal belief system); those who believe and belong; those who belong to a belief system, such as atheism or humanism, but don't believe in an afterlife; and those who neither believe nor belong.

Voas (2009) introduced the concept of 'fuzzy fidelity', as a description of those who are neither religious nor completely unreligious. Based on the findings of the *1970 British Cohort Study*, where a quarter of those who described themselves as agnostics believed in life after death, while nearly a third of those who stated a belief in God did not believe in an after-life, Voas (2015) developed this further, with the suggestion of 7 groups:

- 'Non-religious (28% of the 1970-born cohort): Does not have a religion or believe in either God or life after death.
- Unorthodox non-religious (21%): Does not have a religion or does not attend services. Believes in God or life after death but not both.
- Actively religious (15%): Has a religion and believes in God and life after death. Attends services.
- Non-practising religious (14%): Has a religion and believes in God and life after death. Does not attend services.
- Non-identifying believers (10%): Does not have a religion, but believes in God and life after death.



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- Nominally religious (7%): Identifies with a religion. But believes in neither God nor life after death.
- Unorthodox religious (5%): Has a religion and attends services at least occasionally. Believes in God but not life after death (or, in a few cases, vice versa).'

It is clear that the categorisation of religious/spiritual beliefs, like the definition of spirituality, is open to different understandings.

### **2.5. Nurses' responses in spiritual care situations**

Expectations of nurses have changed over the past few years, particularly in Scotland, where there is a very definite expectation that nurses and other health care providers should provide spiritual care (NHS Highland 2010, Scottish Government 2009 and 2002).

Research suggests that qualified nurses believe that patients, and especially certain patient groups, have spiritual needs and that nurses have a significant responsibility in the provision of spiritual care (Milligan 2004). However, there is also evidence to suggest that nurses feel ill prepared for, and uncertain of, their roles as spiritual care providers (Kuuppelomäki 2001, Milligan 2004, Narayanasamy and Owens 2001, RCN 2011b, Swift et al 2007, Vance 2001), and may find it difficult to identify patients in need of spiritual care, as well as meeting those needs (Milligan 2004). These uncertainties have resulted in a lack of confidence (Milligan 2004, Narayanasamy and Owens 2001, Vance 2001). Various barriers to provide spiritual care have been cited,

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including nurse or patient related issues, such as communication, faith, beliefs, personality and previous experiences (Kuuppelomäki 2001, Narayanasamy and Owens 2001, Ross 1994, Vance 2001); environmental issues, including lack of time (Gallison et al 2006, Milligan 2004, Ronaldson et al 2012, Ross 1994, Touhy et al 2005, Vance 2001); suitable space (Ross 1994); resources and provisions (Narayanasamy and Owens 2001); privacy (Ronaldson et al 2012); availability of, and problems with, the chaplaincy services (Kuuppelomäki, 2001 Ross 1994); and a lack of peer and management support (Milligan 2004).

Over half of the nurses in Ross's (1997) study that included quantitative and qualitative approaches reported that they would refer patients' spiritual needs, although three quarters considered it a shared responsibility between nurses and clergy. Twelve of these nurses were selected for a semi-structured interview and, in this very small group, nurses who gave spiritual care at a deep level were more aware of a spiritual dimension in their own lives; more likely to have experienced crises in their own lives that had forced growth; and were more likely to be prepared to give of themselves on a deeply personal level. Nurses in the study claimed to identify patients' spiritual needs, and evaluate their own actions by observing patients' non-verbal cues. The responses in this study may have been influenced by a difference in understanding among the nurses of the definition of spirituality. Further, the nurses were self-reporting, and numbers in the qualitative part were low.

To capture what nurses actually did, rather than what they thought they should do, Narayanasamy and Owens (2001) and Narayanasamy et al (2004) used the Critical  
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Incident Technique. Narayanasamy and Owens (2001) obtained written critical incidents from 115 nurses (88% response rate) describing real life situations that they had been involved in, and identified four different approaches to spiritual care provided by nurses, with some overlap between the groups: a personal, holistic approach, where nurses were personally involved, giving time and attention, and engaged in all aspects of patient care; procedural, which was a less personal approach, where nurses followed procedures, referred to the chaplains and tended to stereotype; cultural, with nurses taking patients' religion and culture into account, and making efforts to facilitate the meeting of patients' needs, as well as involving families; and evangelical, where nurses made great efforts to reaffirm patients' faith, if they shared a similar religious background. This study included data from 115 nurses, with a good response rate; however, it relied on nurses providing written information, which has potential disadvantages (Chapter 3.3.1.1).

Narayanasamy et al (2004: 11) found that specific responses included helping patients to participate in religious activities; various types of communication, with listening and talking, trying to give comfort and reassurance to help patients to feel better; showing respect for patients' privacy, dignity and spiritual needs, as well as helping patients to connect with family, friends or others; and helping patients to 'complete unfinished business'. Some of the nurses used their own personal religious beliefs to assist patients (Narayanasamy and Owens 2001; Narayanasamy et al 2004).

In a qualitative study, Touhy et al (2005) interviewed 25 participants (5 registered nurses, 5 practical nurses, 6 certified nursing assistants, 4 physicians and 5 advanced

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practice nurses) with experience of working with dying residents in nursing homes in Florida about real, rather than hypothetical, situations and identified four groups of responses: honouring the person's dignity, including providing physical, psychosocial and spiritual comfort; intimate knowing in the nursing home environment, which related to respecting other's beliefs, connections with residents 'like family', individualized responses, trying different things and giving permission; wishing we could do more, with clergy involvement and discussions of spiritual needs in care planning; struggling with end-of-life treatment decisions, including advocating for wishes to be honoured, helping families make decisions, medical futility, communication about end-of-life decisions to all staff and treatment decisions for residents with dementia. The authors described spiritual caring 'within the context of deep personal relationships, holistic care, and support for residents' (Touhy et al 2005: 34).

In a survey, using questionnaires, 204 (response rate 23%) hospice nurses working in the US were found to experience distress in situations where patients or their families questioned the nurses' personal religious beliefs and practices, or tried to impose their own beliefs on the nurses (Belcher and Griffiths 2005). Situations where patients believed in a punishing God or expressed fears relating to religion were challenging, and the nurses felt uncomfortable when asked to pray for healing, when this was an extremely unlikely outcome. A professional dilemma occurred when patients raised the issues of suicide and euthanasia, when this went against the nurses' own belief systems.

In a cross-sectional study, using questionnaires, of 42 palliative care nurses and 50

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acute care registered nurses in Australia, Ronaldson et al (2012) found that registered nurses working in palliative care had a more advanced spiritual care practice and a heightened sense of spirituality compared to registered nurses working in acute care. The authors considered that this could be explained by nurses with a high sensitivity to spirituality seeking work in palliative care; nurses working in palliative care being more exposed to patients' spiritual issues; the older age and advanced experience of the palliative care nurses; and a focus on a cure in acute care, where spiritual care may be more likely to be viewed as the role of clergy and pastoral carers.

Walter (2002: 138) supports the use of a team approach in the provision of spiritual care, where patients' individual needs and individual team members' abilities are carefully taken into account, while Koenig (2002: 22) suggests that the abilities of health care providers to manage patients' spiritual needs may be improved by addressing their own spiritual needs. Further, Koenig (2002: 22-23) highlights the lack of research aiming to identify the role of health care providers' spirituality, and any education or training interventions that could improve care of dying patients by boosting health care providers' own spirituality.

There is limited research exploring how nurses actually respond in spiritual encounters with patients, rather than how they say or think that they would respond, and there is, specifically, a lack of evidence for how nurses caring for patients with potentially life limiting conditions, other than cancer, respond in actual situations. Palliative care, where nurses have specialist knowledge and experience in this field, is mostly available to patients with cancer, and there is also limited research that explores nurses' responses

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in spiritual encounters with cancer patients, compared with patients with other life limiting conditions.

For this study, comparing medical, oncology and Macmillan nurses provided an option to identify skills and techniques held by nurses experienced in palliative care that could be transferable to nurses in other areas. It was considered relevant to explore the role of religious or spiritual beliefs in the nurses, as nurses' own beliefs may influence their approach to spiritual care (Belcher and Griffiths 2005, Ronaldson et al 2012, Ross 1997; Taylor et al 1999, Walter 2002).

## **2.6. Summary**

This study addresses the limited research on how nurses respond in real, rather than hypothetical, spiritual encounters with patients, and what influences these responses. Further, it seeks to expand the knowledge on any differences in this area between nurses working on medical wards, on oncology wards and in the Macmillan nursing service.

The background to the study include the spiritual needs of patients with life limiting conditions/palliative care needs, and particularly those with heart failure (Chapter 1.2.2); the expectations of nurses to provide spiritual care; the lack of evidence relating to how nurses fulfil their role of addressing patients' spiritual needs; and issues that influence their approach to spiritual care.

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There are conflicting views with regards to the definition of spirituality and spiritual care and for that reason, in this study, spiritual needs are based on definitions commonly used in health care settings (Association of Hospice and Palliative Care Chaplains 2006, McSherry and Jamieson 2011, Murray et al 2004, Puchalski et al 2009, Saunders 1988) that match those used by the bodies that require nurses to provide spiritual care (DH 2008, RCN 2011a, NMC 2010, Scottish Government 2009, WHO 2001), as discussed in Chapter 1.2.4 and 1.2.5.

## **3 Methods**

### **3.1. Introduction**

As shown in Chapter 1, nurses are expected to provide spiritual care to patients with life limiting conditions, regardless of where they are cared for. The literature review showed that there is limited knowledge with regards to how nurses do this (Chapter 2.5) and this study set out to explore:

- How registered nurses working on acute medical wards, where medical patients with non-cancer life limiting conditions are cared for, compared with nurses working within an oncology department and those working in the Macmillan nurse service, caring mainly for cancer patients, respond in spiritual encounters with patients
- Issues that influence the nurses' responses

Using the Critical Incident approach (Chapter 3.3.1.1), with semi-structured interviews (Chapter 3.3.1.2), it explored how nurses responded in encounters with patients that could be described as spiritual, and that the nurses viewed as spiritual, and what factors influenced their responses, based on definitions of spirituality that are commonly used in health care and held by those bodies that place these expectations on the nurses (Chapter 1.2.4 and 1.2.5). It also explored potential differences between three groups of nurses working in three different areas: oncology nurses and Macmillan nurses, who work more specifically with patients diagnosed with life-limiting conditions; and medical ward nurses, who work with more diverse patient groups. Finally, it examined how nurses' own spiritual or religious beliefs may influence their responses in spiritual encounters with patients, as it has been suggested that personal beliefs may influence nurses' approach to spiritual care (Belcher and Griffiths 2005, Ronaldson et al 2012,



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Ross 1997, Taylor et al 1999, Walter 2002).

A qualitative approach was selected, as the aim of this study was to add knowledge and explanations to an area with limited prior information (Mason 2002: 16), and this approach was seen as most likely to meet the aims of the study (Miles and Huberman 1984: 42, Robson 2002: 164, Silverman 2013: 12-16, Topping 2010: 129).

### **3.2. Qualitative research**

Qualitative research is well established in sociology (Silverman 1985: 17), and is viewed as a valid approach in nursing research (Gerrish and Lacey 2010: 127). While some researchers may prefer one methodology over another, the approach most likely to answer the research questions should be used (Robson 2002: 164, Miles and Huberman 1984: 42, Silverman 2013: 12-16, Topping 2010: 129).

Rather than hypothesis testing, qualitative research may be used to develop theories or produces hypotheses (Bryman 2001: 264-266, Silverman 2013, 4<sup>th</sup> edition) in areas with limited prior knowledge (Gerrish and McMahon 2006: 5). The aim is to search for meaning and understanding of, for example, the behaviour, values and beliefs of people, within the study's context (Bryman 2001: 285). It is linked to an interpretivist view, as opposed to a positivist, quantitative approach, where stable phenomena can be studied, measured and statistically analysed (Topping 2010: 129-141, Topping 2006: 163-164). An interpretivist view is described as an epistemological position where the aim is to gain 'an understanding of the social world through an examination of the interpretation

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of that world by its participants' (Bryman 2001: 264).

Qualitative research is flexible, and Robson (2002: 163-200) prefers the term 'Flexible Designs' to 'Qualitative Research', as quantitative methods can be incorporated, and a flexible approach allows for designs to develop during data collection. Mason (2002: 24) describes qualitative research as 'exploratory, fluid and flexible, data-driven and context-sensitive', with design and strategy 'ongoing and grounded in the practice, process and context of the research itself'. Robson (2002: 169) states that plans for qualitative research studies usually change during the course of the study.

There are different options for instrumentation and for obtaining the required information. Miles and Huberman (1984: 42) suggest that this can be very open, but doesn't need to be completely open: if the researcher knows what information is wanted, a focused approach can avoid collecting excessive data and overloading the analysis. Another option is to use instrumentation from prior studies (Miles and Huberman 1984: 43).

Silverman (2002: 4) suggests that having discovered a phenomenon in qualitative research, there may be good reasons to count how frequently it occurs. Combining quantitative and qualitative research methods (Blaikie 2000: 262-276, Bryman 2001, Simons and Lathlean 2010: 331-342) can help to provide information on how many people are involved in a particular phenomenon, details of who they are, such as gender, age, qualifications, as well as what their views are (Simons and Lathlean 2010:

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331-342). Bryman (2001: 446) discusses two versions of argument for and against combining qualitative and quantitative research. In the 'epistemological version', quantitative and qualitative research are viewed as 'grounded in incompatible epistemological principles (and ontological ones too, but these tend not to be given as much attention)' that cannot be combined, while those researchers in favour takes the position of a 'technical version' that 'gives greater prominence to the strengths of the data-collection and data-analysis techniques with which quantitative and qualitative research are each associated and sees these as capable of being fused' (Bryman 2001: 446).

As well as providing details of numbers, qualitative and quantitative methods can also be combined in 'Triangulation', to increase validity (Bryman 2001: 447-449, Mason 2002: 66 point 8, Silverman 2011: 368-375). In generating qualitative and quantitative findings in related issues, there is scope for findings to be corroborated, or not (Bryman 2001: 448). However, Mason (2002: 66, point 8) advises caution, as different methods cannot be expected to provide the same kind of data.

Validity, generalizability and reliability are more commonly used in quantitative research, but some authors believe that they also have a role in qualitative research; although their use needs to be adapted (Mason 2002: 38-39, Maxwell 1992: 279-300, Robson 2002: 168-177).

Generalizability relates to how far the research findings can be applied to an area wider

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than the specific area where the research took place (Mason 2002: 39). However, generalizations in qualitative research are used in a variety of different ways, as compared to their use in quantitative research (Mason 2002: 194-200). Coffey and Atkinson (1996: 153-164) suggests that data should be categorised and analysed, but most importantly, interpreted and used to generalize by developing ideas and theories relating to social processes. Maxwell (1992: 279-300) suggests, as more appropriate in qualitative research, an 'internal generalization', which generalizes within the community, group or institution where the study is taking place.

Validity relates to clarity with regards to the concepts studied; what the concepts were, and how they were used in the study (Mason 2002:39). As validity can be difficult, or impossible, to prove, it may be more helpful to focus on 'credibility or trustworthiness of the research' and 'threats to validity' (Robson 2002: 170-171). Mason (2002: 39) relates 'reliability' to how reliable the applied research methods are in producing accurate results.

Maxwell (1992: 279-300) describes five dimensions of validity: Descriptive Validity, which relates to if what was said to have happened actually happened and if there may have been any omissions; Interpretive Validity, which relates to the meaning of the findings, how the researcher interprets what was observed or told; Theoretical Validity, which relates to concepts or categories and their relationships; Generalizability (293), which Maxwell (1992) separates into internal generalization within a group or institution to others within this setting who were not directly observed or interviewed and external generalizing to other groups or institutions; and Evaluative Validity, which

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relates to the making of some kind of judgement of the account.

When using qualitative research to develop theory through the generation and analysis of data, analysis will most likely start while data collection is ongoing, using inductive reasoning to develop theoretical propositions or explanations out of the data (Mason 2002: 180). Cormack (2000: 332-333) suggests using inductive classification when using the Critical Incident approach (Chapter 3.3.1.1), and constructing a classification system while the data is being analysed, rather than devising a classification system prior to data collection and analysis.

### **3.2.1. Reflexivity**

Unlike quantitative research, where the influence of the researcher is removed, as much as possible, to avoid bias (Topping 2010: 130-131), in qualitative research, the researcher is more involved and likely to have an influence on the findings (Topping 2010: 135-136). The researcher cannot be detached from their research, and it is important that they are aware of their own role in the research process, and reflect on how their own views, values and beliefs may influence the research; this process has been termed 'reflexivity' (Bryman 2012: 393, Mason 2002: 7, Porter 2000: 142). Lincoln and Guba (1985) describes three threats to validity: 'Reactivity', which relates to the how the researchers presence may influence the study situation and the behaviour of research participants; 'Researcher biases', which includes the researchers presumptions and preconceived ideas; and 'Respondent biases', which involves research participants adjusting their behaviour or responses, by withholding information

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or obstructing the researcher in some way, or by trying to provide the answers or behaviour that they think the researcher would like. Although not always identified as reflexivity, the concept has developed in qualitative research over the past century (Finlay 2003: 3-4, Finlay 2002: 209-210), and has gained much in popularity in the past 20 years (Finlay 2003: ix). Understandings of the term 'reflexivity' are not unanimous, with Silverman (2013: 447) relating reflexivity back to ethnomethodology, and states that its use as self-questioning by researchers is incorrect.

It may be prudent to regard the concept as more important than the term used to describe it, and regardless of the interpretation of the term 'reflexivity', it is important that researchers critically consider how their selected methods and decisions, as well as their own interactions in the research, may influence the findings (Bryman 2012: 715). There is also a need for researchers to challenge their own assumptions and to consider the influence that these may have on the research (Mason 2002: 5), as well as considering unexpected findings (Robson 2002: 169).

During the interviews and analysis, it was important for me to be aware of my own beliefs and preconceived ideas. I have strong religious beliefs and was aware that this could influence my responses to the participants during the interviews (Mason 2002: 5). I did not volunteer my beliefs to participants, but some participants showed concerns about not offending me or any beliefs that I may hold. To try to counterbalance this I emphasised that I was interested in their beliefs and views, and how nurses with different beliefs or lack of beliefs may be thinking and responding. There was also a risk that participants would want to fit in with what they thought that I wanted them to

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believe. I felt that it was very important to display an attitude of acceptance and interest, without any form of judgement on my part.

### **3.3. Study design**

#### **3.3.1. Choice of methods**

A qualitative approach was selected using the Critical Incident Technique (Cormack 2000, Flanagan 1954, Kitwood 1980, Norman et al 1992), further discussed in Chapter 3.3.1.1, with semi-structured interviews (Chapter 3.3.1.2) preceded by a questionnaire (Appendix III) collecting demographic information. The Critical Incident Technique was used, in order to elicit information on how nurses actually responded, rather than how they may think that they would or should respond (Cormack 2000, Narayanasamy and Owens 2001: 448), as discussed in Chapter 3.3.1.1. The questionnaire (Appendix III) aimed to show any major differences between the three groups of nurses, such as length of nursing experience, bands/grades, post-basic education and courses relating to palliative care or spirituality. The research design was used dynamically and flexibly, with adaptations to the strategies (Cormack 2000: 327-335, Flanagan 1954: 335, Mason 2002: 25) during the process of the research.

##### **3.3.1.1. Critical incident technique**

The Critical Incident Technique was used in order to capture real life examples of how nurses respond in practice. This was in preference to eliciting data on how they thought that they *should* or *would* respond to a hypothetical situation (Cormack 2000, Narayanasamy and Owen 2001: 448). Lambert and McKewitt (2002) emphasize the

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problem, in self-reporting studies, of participants not always doing what they say they do, and recommend anthropological research, using participant observation in order to discover the real situation, while recognising that this is not always possible, due to limitations of funds, time and expertise.

The Critical Incident Technique evolved from techniques used during the Second World War in the Aviation Psychology Program of the United States Army Air Forces 'to develop procedures for the selection and classification of aircrews' (Flanagan 1954: 328). It provides a non-intrusive and cost effective alternative to participant observation (Narayanasamy and Owens 2001: 448) and has been used in health research in recent years by the collection of written incidents (Narayanasamy et al 2004, Narayanasamy and Owens 2001) and in combination with interviews (Ivarsson et al 2004). It was thought that the abilities of nurses to write about, and reflect on, critical incidents were likely to vary, and using interviews, rather than only written incidents, enabled the researcher to obtain more detailed information, by careful probing, to reduce the risk of missing relevant information (Narayanasamy and Owens 2001). An incident is understood to be 'any observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act' (Flanagan 1954:327). Therefore, incomplete incidents were not included in analysis.

In this study, a six-stage process (Cormack 2000: 327-335) was followed, starting with the decision of who should provide the critical incidents and the consideration of the number of critical incidents required (Chapter 3.3.5). The third step of designing a data collection form was modified, as data would be collected by interviews, rather than



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participants providing written incidents. Participants were provided with a Participant Preparation Sheet (Appendix IV), see Chapter 3.3.1.3, and an interview schedule was designed (Appendix V). A decision was made of where the critical incidents would be collected (Chapter 3.3.2), and the incidents were then collected and analysed.

When analysing critical incidents, Cormack (2000) developed a classification system that consisted of four major areas, each with a number of categories, and each of these with a number of subcategories. In this study the Critical Incident Technique was used in a flexible manner, rather than following rigid rules (Flanagan 1954: 335) and a classification system was developed to suit the aims of the study.

### **3.3.1.2.Semi-structured interviews**

Semi-structured interviews are commonly used in flexible, qualitative research (Mason 2002: 63-83, Robson 2002: 269-291), and has been used in the Critical Incident approach (DeJesse and Zelman 2013, Ivarsson et al 2004). The researcher can explore a number of topics, themes or stories, while allowing for unexpected themes to emerge (Mason 2002: 63-83). Using interviews, rather than written incidents, enables the researcher to encourage the interviewee to expand and provide further information (Narayanasamy and Owen 2001).

The use of an interview schedule (Appendix V) provides a certain amount of structure to the interview and enables the researcher to explore specific issues, while allowing themselves the flexibility and freedom to respond to the individual interviewees

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(Bryman 2001: 311-333, Robson 2002: 269-291). The interview schedule includes a series of questions to be asked, but the approach in the interview is flexible, with mainly open-ended questions (Bryman 2001: 311-333, Robson 2002: 269-291). The order of questions can vary and the researcher is free to explore further (Bryman 2001: 311-333). It is also possible for the researcher to observe and make note of non-verbal communications (Robson 2002: 269-291).

### **3.3.1.3. Participant preparation sheet with trigger cues**

The Participant Preparation Sheet (Appendix IV), which included a selection of trigger cues, was provided to the nurses to prepare them for their interviews, and aimed to encourage them to think about situations that would be likely to encompass the concepts that are commonly described as ‘spiritual’.

The selection of trigger cues was governed by various themes in the spirituality-in-health literature and compatible with the operational definition of spirituality used in the study (Chapter 2.3). The intention was to guide the participants towards particular types of situation, of the kind referred to in the literature, but without over-constraining their choice. The idea was to tread a path between being unduly prescriptive and being too vague (Silverman 2013: 97), to increase the likelihood of the nurses providing incidents relating to situations generally viewed as relating to spirituality in health care, rather than limiting incidents to those fitting their own definitions (with some selecting incidents only involving religion and God, and others using a much broader definition). As shown in Chapters 2.2 and 2.3, definitions vary, and a consensus on the definition

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for spirituality has not been reached, and nor was it sought.

### **3.3.2. Setting**

The study was carried out at a regional hospital in the north of Scotland, where, at the time of the study, there were six medical wards, one of those a medical rehabilitation ward, one oncology ward and an oncology outpatient department. The local Spiritual Care Policy (Highland NHS Board Policy Team 2003: 2), in place at the time of the study, stated an expectation that healthcare staff who came into contact with patients and carers, should provide holistic care, including the delivery of spiritual care; an expectation also included in the updated Policy (NHS Highland 2010, reviewed 2011).

### **3.3.3. Study population**

The study sample was drawn from a population of registered nurses working full-time or part-time on five general medical wards, where patients with life-limiting conditions other than cancer were most likely to be cared for; in the oncology ward/department; and in the Macmillan nurse service.

Following Cormack's (2000: 327-335) six-stage process in using the Critical Incident Technique (Chapter 3.3.1.1), the first stage was to decide who should provide the Critical Incidents. Palliative care is well established in patients with cancer, particularly in a hospice setting, while patients with other life-limiting conditions, such as heart failure, also have palliative care needs (DH 2000:5, Ellershaw and Ward 2003: 31,

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Gibbs et al 2002, Murray et al 2002). Patients with heart failure have a different disease trajectory to those with cancer, but also have a need for skilled care, including palliative care and recognition of their potential spiritual needs (Murray et al 2002). Patients diagnosed with heart failure, and their need for palliative care, was at the core of this study. These patients are known to experience frequent hospital admissions (Cowie 2002, Jhund 2009, McMurray et al 2012), and it would be helpful to identify factors that could realistically be expected to improve the abilities of nurses working with these patient to manage any spiritual concerns that they may have.

Three groups of nurses were included, as the aim of the study was to explore how nurses working with patients with potential palliative care needs, but in different settings (medical wards, oncology ward/department and the Macmillan service) responded in spiritual encounters with patients and what issues influenced these responses. Nurses on general medical wards were included, as they care for a very diverse group of patient, including those with potential palliative care needs, such as heart failure. These nurses may, due to working with a very diverse group of patients, focus on patients' physical needs, and have less time for spiritual needs, than nurses working with a more clearly defined patient group. Oncology nurses and Macmillan nurses were chosen as they work with a less diverse group of patients where many will have palliative care needs, and holistic care is well established as an important aspect of palliative care (Puchalski et al 2009: 885, WHO 2002, WHO Europe 2004a). A potential outcome was that different nurses may benefit from each others' knowledge, experience and skills.

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Different access to training, different expectations and different support systems may influence the approaches by different groups of nurses to the provision of spiritual assessments and care. Spiritual care is well established in palliative care, and is generally included in palliative care courses, which makes preparation for spiritual care more available to nurses working in oncology and/or palliative care than to those working in other areas. Oncology and Macmillan nurses may be better prepared to provide spiritual care than nurses working on medical wards, and may have skills that are transferable to nurses working in other area.

As expected, in this population of nurses the majority were female, with only 10 medical nurses and two Macmillan nurses being male.

### **3.3.4. Sampling procedure**

The aim was to use a sampling strategy that would aid in the selection of the participants best able to provide the information needed to achieve the aims of the study (Mason 2002: 120-144, Miles and Huberman 1984: 36-42, Morse 1991: 127) and that would enable the establishment of strategic relationships between the sample and the wider population of nurses (Mason 2002: 123-125). The sample was not expected to provide a direct representation of the wider populations, but a relevant range (Mason 2002: 124). The sample of registered nurses all worked on medical wards, in oncology or in the Macmillan service, and their work situation and nursing experience was representative of nurses working in these areas. There were differences, in terms of religious and/or spiritual beliefs, between the sample and the general population of

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nurses, and this will be discussed further in Chapter 4.2.

In order for a sample to be drawn, all registered nurses working on the five medical wards, the oncology ward/oncology department and in the local health board Macmillan nurse service were sent an invite to take part. To ensure that the nurses in the study were drawn from a population of nurses that had experience in the selected areas, an inclusion criteria was that they had at least one year's experience in their current speciality (medical, oncology or Macmillan nursing); although not necessarily in their current post.

### **Inclusion criteria**

- Registered Nurse
- Working in:
  - one of the five medical wards at the local hospital, or
  - the Oncology Ward or Department at the local hospital, or
  - the MacMillan nursing service in the local health board

### **Exclusion criteria**

- Less than one year's experience within speciality, but not necessarily in the same ward, department or hospital.
- Lack of informed consent

It was considered relevant to explore the role of religious faith in nurses, as it has been suggested that health care professionals with religious faith may be better able to provide spiritual care, or certain kinds of spiritual care, than those without (Ross 1997, Walter 2002), and little is known about how nurses' own religious faith affect their ability to provide spiritual care. Therefore, the questionnaire (Appendix III), which was provided to the nurses together with the Participant Information Sheet (Appendix I) and

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the Consent Form (Appendix II), asked the nurses to state whether they had any religious faith.

The nurses were divided into three categories, according to area of work; medical, oncology or Macmillan. Due to the low response and consent rate, all nurses who consented were interviewed. It was therefore by chance that the groups were of equal size. These groups were subdivided into those nurses with religious/spiritual beliefs, those with uncertain beliefs and those without any beliefs. The interviewed medical ward nurses came from four of the five medical wards, as no nurses from the fifth ward consented to take part in the study.

### **3.3.5. Sampling size**

In the literature, approximately 30 to 60 participants are considered appropriate for semi-structured interviews, with fewer for unstructured interviews (Morse 2000, Morse 1994: 225). There are no hard and fast rules for numbers needed in qualitative research, with much depending on the design of the study (Bryman 2004: 334-335, Mason 2002, Morse 2000). It has been suggested that the exact number of participants should not be decided on prior to commencing the study, but that sampling should continue until saturation has been reached (Bryman 2004, Robson 2002). Stern (1991: 148-149) suggests that qualitative researchers should estimate the numbers required, in order to submit proposals for funding and ethics approval. Cormack (2000: 327-335), who did not use interviewing when collecting critical incidents, but collected completed critical incident forms, suggests that incidents should be collected until the last 100 fail to

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provide new information about the issue researched. However, this is unlikely to be practical when collecting more in-depth information, using un-structured or semi-structured interviews.

DePaulo (2000) suggests a method of calculating probabilities in order to estimate sample size in qualitative studies, taking into account the likelihood of missing a characteristic (situation, incident, feature) in the population, and assuming random selection. A 'characteristic' in this study would be a specific way of responding to patients' spiritual concerns, or a specific reason for this response. DePaulo (2000) shows that, although there is no known best method for estimating numbers needed in qualitative research, a reasonable starting point is around 30 participants.

### **3.3.6. Non-participation**

The initial strategy was to use stratified random sampling and interview approximately 18 nurses from the medical wards and 18 nurses from the oncology department, who had completed the questionnaire and met the inclusion/exclusion criteria.

However, due to the low response and consent rate (Chapter 4.2), particularly in the medical nurses, following an amendment to the protocol and the granting of ethical approval for the modification, nurses from the Macmillan service were included, and all nurses who consented and were able to attend the interviews were interviewed. This resulted in a biased, convenience sample, as the nurses were self-selecting, rather than selected through stratified random sampling. However, the inclusion of the Macmillan



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nurses proved beneficial, as this group of nurses provided a rich amount of data that would otherwise have been missed. In this case, taking a flexible approach (Mason 2002: 24-25, Robson 2002: 164, Silverman 2013: 153-154) had benefits.

### **3.3.7. Recruitment procedures**

Ward/department managers were contacted and agreed to distribute Participant Information Sheets (Appendix I), consent forms (Appendix II) and questionnaires (Appendix III) to all registered nurses working on the five general medical wards and in the oncology department. The ward managers were provided with written and verbal information regarding the study, and agreed to allow nurses participating in the study to complete the questionnaires and attend for interviews within paid working hours. Participant Information Sheets (Appendix I), consent forms (Appendix II) and questionnaires (Appendix III) were distributed by the Macmillan secretary to all Macmillan nurses working within the local Health Board, with the agreement of their manager.

Where possible, the researcher arranged information meetings on the different wards before the study began, in order to provide the nurses with information, discuss reasons for why it would be relevant to them, and give them an opportunity to ask questions and make comments.

The consent form (Appendix II) that the nurses were asked to complete and enclose together with their completed questionnaires, asked permission for contact to be made

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at a later stage (with a view to organising an interview). Where the nurse consented to attend this interview, the researcher contacted the participant and arranged a mutually convenient time and place for the interview, and confirmed informed consent prior to commencing the interview.

Rooms used for the interviews were selected for providing privacy and making interruptions as unlikely as possible (Bryman 2001: 317-318), while placing participants with their backs against the door provided them with increased privacy, should anybody unexpectedly open the door. Where possible, participants were interviewed in a room in the hospital, away from their normal working areas; however, a small number of interviews took place in rooms within the nurses' wards/departments that provided an environment as undisturbed and private as possible, with no risk of being overheard from outside of these rooms (Bryman 2001: 317-318). The reason for this was that some nurses needed to be away from their wards for as short a time as possible, and some needed to be available in case of emergencies. The nurses who were interviewed in a room within their ward or department area may have been less able to relax, as they were closer to their area of work. However, as these nurses were willing to take part in the interviews, but would otherwise have been unlikely to be able to do so, this was viewed as justified.

### **3.3.8. Data collection**

#### **3.3.8.1. Phase 1**

Nurses on the relevant wards (Chapter 3.3.3) were provided with the Participant

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Information Sheet (Appendix I), Consent Form (Appendix II) and Questionnaire (Appendix III) by the ward managers, as well as a stamped addressed envelope to return the consent form and questionnaire. The questionnaire (Appendix III) was provided to participants to collect basic demographic information, and asked for the following data:

- Age (<30 yrs; 30-39 yrs; 40-49yrs; 50-59 yrs; >60 yrs)
- Gender (male/female)
- Current area of work (Medical, Oncology or Macmillan)
- Academic qualifications (Old style training, Certificate, Diploma, Degree, Post-graduate)
- Post-registration training completed, relating to 'palliative care', 'heart failure', 'oncology' or 'spirituality'
- Post-registration training studied for, relating to 'palliative care', 'heart failure', 'oncology' or 'spirituality'
- One year or more in current speciality (Yes/No)
- Number of years of nursing experience
- Grade/Band in current post
- Whether participants regarded themselves as having any religious faith (Yes/No/Uncertain)

### **3.3.8.2. Phase 2**

In Phase 2, nurses who returned their questionnaires, and consented to being contacted, were sent an invite (Appendix VII) to attend a tape-recorded, semi-structured interview based on the Critical Incident Technique (Cormack 2000, Flanagan 1954, Ivarsson et al 2004, Kitwood 1980, Narayanasamy and Owens 2001, Narayanasamy et al 2004, Norman et al 1992).

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The nurses were informed that they would be asked to talk about one or more incidents relating to spiritual issues in encounters with patients or relatives. They were provided with a Participant Preparation Sheet (Appendix IV) a few days prior to the interview, which included a list of trigger cues, based on the operational definition of spirituality (Chapter 2.3), to help stimulate recall of specific situations that they could talk about in their interviews. They were encouraged to recall situations that had occurred in the past two years, and that related to any of the trigger cues provided in the preparation sheet (Appendix IV). They were encouraged to make brief notes about these situations, to help bring the situations back to mind at their interviews. The rationale for the trigger cues provided in the Participant Preparation Sheet (Appendix IV) is discussed in Chapter 3.3.1.3.

Semi-structured interviews (Chapter 3.3.1.2) that were planned to last up to one hour were used to gather qualitative data relating to: how nurses respond to spiritual issues in line with the operational definition for spirituality used in this study (Chapter 2.3) in encounters with patients; their reasons for responding in that way; and to provide further information regarding any religious faith and/or spirituality of their own. The interview schedule (Appendix V) helped to provide a certain amount of structure to the interviews and to ensure that the required information was obtained. Interviews were carried out over a period of 13 months between May 2006 and June 2007. This was for practical reasons to account for busy workloads of staff and the research being conducted part-time.

### **3.3.9. Pilot work**

To ensure that the questionnaire and interview format was clear and to identify any problems or misunderstandings, the study was piloted with four nurses working on the medical rehabilitation ward. This ward was not included in the main study, as the rehabilitation aspect of it made it different from the other medical wards. Many patients in this ward were receiving longer-term rehabilitation following accidents, and their ability to communicate was often severely limited, which separated this ward from the other five medical wards. Although six nurses were invited from this ward, two withheld consent.

Not all participants in the pilot work had specific incidents in mind, despite having received the Participant Preparation Sheet (Appendix IV). This demonstrated the need to be prepared to use an interviewing approach that would help participants to bring relevant situations to mind. In talking about an emotional situation that had evoked strong feelings at the time, one of the nurses became tearful. After the interview, she commented that she had not anticipated feeling this emotional; however, despite having relived the emotions that she had at the time of the incident, she stated clearly that she did not mind having felt emotional.

In response to the pilot work, the decision was made to provide participants with the list of contacts for support (Appendix VI) at the end of their interviews, as nurses might be unprepared for the feelings that the interviews would evoke in them and might not have kept the list that they were sent together with the interview invitations. The following

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amendments were made to study documents:

### **Questionnaire (Appendix III):**

- A comment was inserted, asking participants to consider consenting to completing the questionnaire, even if not consenting to take part in the interviewing part of the project (the rationale for this was to obtain some information on the nurses who withheld consent to attend the interview).

### **Participant Information Sheet (Appendix I):**

- Comment inserted 'Should appreciate it if you were able to complete and return, even if not willing to take part in the interviewing part of the project'.

### **Consent Form (Appendix II):**

- Inserted comment 'Please tick, as appropriate'

## **3.4. Ethical considerations**

Ethical approval was obtained from the University of Stirling, Nursing and Midwifery Departmental Research Ethics Committee, as well as from the North of Scotland Research Ethics Committee (NRES). Approvals were also obtained for the amendment to the study. Management approval was obtained from the Health Board.

Participants were asked to provide their names on the questionnaires, if they were willing to be contacted by the researcher, with a view of being interviewed. To maintain confidentiality, completed questionnaires were coded, and the anonymised codes were used in the transcriptions, in the analysis and in the writing up of the data, rather than using participants' names.

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Although all participants were registered nurses, with at least one year's experience of working in the relevant areas, they were encouraged to recall and discuss real-life situations concerning encounters with seriously ill or dying patients that they had cared for, and it was anticipated that strong emotional reactions may be experienced, potentially, leaving participants emotionally vulnerable. Participants were also to be asked if they had any religious faith, and would be encouraged to discuss any awareness of spirituality in their own lives. These are potentially sensitive issues, and there was no pressure on participants to divulge this, or any other, information.

In order to avoid threat, anxiety or embarrassment, participants were treated sensitively, using a non-judgemental and caring approach, with interviews carried out by the researcher, a nurse with many years of varied nursing experience. Participants were advised, prior to the tape recorder being turned on, that they could indicate at any time if they wished the recorder to be turned off. The interview would have been terminated, had a participant become more seriously distressed. However, none of the participants became distressed, and only displayed emotions that they appeared comfortable with.

All participants were given the names of two suitably skilled, independent advisors (the clinical psychologist in oncology and one of the hospital chaplains in the hospital where the study was carried out), who agreed to act as independent advisors, and to be contacted for support and advice. Participants were also given details of the former ICAS – Employee Support Helpline, of the RCN counselling service and the Samaritans. Any participant displaying more severe distress would have been advised to see their general practitioner.

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There was an issue of confidentiality, both as far as participants were concerned, and in relation to the patients referred to in the tape-recorded interviews. Participants were assured of confidentiality and that identifying details of participants and patients would be anonymised, with the exception of referral to illegal activities, or where the safety of patients or others was compromised.

The Participant Preparation Sheet (Appendix IV) provided to participants prior to the interview advised participants not to use patients real names when making any notes or when discussing them in the interview. This advice was also included in the consent form and in the Participant Information Sheet (Appendix I), and was reinforced prior to turning on the tape-recorder in the interview. Details that could potentially identify patients or staff have been changed in the writing-up, to ensure confidentiality. The researcher is a member of staff in the Health Board, and subject to the same confidentiality agreement as other Health Board staff.

Written information identifying participants, transcripts and the audiotapes were stored securely for the duration of the study. Coded, non-identifiable data were saved on computer. Audiotapes were destroyed at the end of the study, while transcripts were kept for seven years in accordance with good clinical practice and local requirements.

### **3.5. Analysis**

The data was analysed manually using inductive reasoning (Mason 2000: 180-181),



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with the classification system being created during analysis (Cormack 2000: 327-335, Flanagan 1954: 335) and suggestions and explanations developing from the data (Mason 2000: 180-181. This was done on an ongoing basis concurrent with interviewing (Cormack 2000: 332-333, Mason 2002: 180).

I made notes of my impressions and reflections (Cormack 2000: 293-294) immediately following each tape recorded interview, and transcribed as soon as practically possible following each interview. Transcribing the data myself was a very time consuming process, but gave me the opportunity of starting analysis while each interview was still fresh in my mind. While transcribing, I highlighted incidents, responses, reasons for these responses and comments about religious or spiritual beliefs in the nurses.

A data classification system was developed with the incidents classified according to spiritual care needs, as perceived by the nurses and commonly viewed as such in health care (Chapter 2). The reason for classifying according to perceived needs was that the responses, and issues that influenced these responses, could not be presumed to be comparable in very different types of incidents. The coding scheme for 'perceived spiritual needs' was derived from the data itself, using inductive classification (Cormack 2000: 327-335). Subcategories were then created, principally characterising:

- how the nurses responded
- issues that influenced their responses

Major headings were kept neutral, without any judgement regarding positive or

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negative behaviours (Flanagan (1954: 345). Other categories or subcategories were added, as the data was analysed (Cormack 2000).

Level of importance of specific issues to participants were noted, to ensure that relevant data was not missed on grounds of not being mentioned frequently enough (Stern 1991). Extreme incidents, such as patients refusing analgesia and, as a consequence, dying in agonising pain, provided insight into a cultural issue that challenged the nurses' beliefs and biases. Silverman (1985: 157) describes 'atrocious' stories that would often be told by parents of handicapped children at their first interview and suggests that 'right or wrong, biased or unbiased, such accounts display vividly cultural particulars about the moral accountability of parenthood'.

The questionnaires (Appendix III) were not used with the aim of triangulation, but were found to have provided a basic form of triangulation (Bryman 2001: 448) when it became apparent during interviews and early analysis that there was a clear difference between the participants' beliefs, as stated in their questionnaires, and their beliefs or religious practices, as voiced in their interviews, and this will be further discussed in Chapter 4.3.6. Bryman (2001: 448) highlights the possibility of triangulation, whether specifically planned or not, failing to corroborate different findings, and the ensuring need to make a decision with regards to the inconsistencies. Using a flexible approach (Mason 2002: 24, Robson 2002: 164), I was able to explore this unexpected finding in the individual interviews, as well as in the following interviews.

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The nurses were divided into 9 groups depending on area of work (medical, oncology or Macmillan, as described in Chapter 3.3.3) and their beliefs, as stated in their interviews, rather than in their questionnaires (further discussed in Chapter 4.3.6). Due to the lack of consensus on the categorisation of religious/spiritual beliefs (Chapter 2.4), the nurses' belief categories were allowed to emerge from the data to form the following categories: beliefs that events in life happen for a reason not based in the physical world (meaning); that there is something after death; a belief in a higher being, such as God or gods. This matched the operational definitions of meaning, purpose and a belief in a higher power and/or in an afterlife. Hope was included in the fairly broad operational definition of spirituality (Chapter 2.3) to ensure that the trigger cues in the Participant Preparation Sheet (Appendix IV) would encourage the participants to think of situations viewed as spiritual by those bodies that expect nurses to provide spiritual care (Chapter 1.2.4 and 1.2.5). However, if all nurses who expressed any sense of hope had been judged to have spiritual beliefs, it is unlikely that any nurse would have fallen within the category of uncertain beliefs or no beliefs. The term 'spiritual beliefs' would then have become meaningless (Chapter 2.2 and 2.3).

No participants belonged to the groups 'Macmillan nurses without beliefs', 'oncology nurses with uncertain beliefs' or 'oncology nurses without beliefs', as all oncology nurses voiced religious or spiritual beliefs in their interviews and all Macmillan nurses voiced beliefs or uncertain beliefs.

Starting analysis of the interview data at the beginning of data collection enabled me to continuously reflect on my role in the study. As discussed in Chapter 3.2.1, I was aware

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that my own assumptions, based on my own beliefs, could influence the participants, as well as my interpretation of the data (Bryman 2012: 393, Mason 2002: 7, Porter 2000: 142). This was a challenging experience, and a particularly challenging issue was that of the role of the nurse in relieving suffering, verses patients' right to provide or withhold consents, and a subconscious attitude that some religious or spiritual beliefs are right, while others are wrong. I had no doubt that it would be right for a nurse to encourage a Christian patient who wanted to pray, but would it also be right to support a Jehovah's Witness in his or her refusal to have a blood transfusion?

## **4. Results**

### **4.1. Introduction**

As described in Chapter 1.3, the aim of the study was to explore the responses of registered nurses working in three different clinical areas (medical wards, an oncology ward/department and the Macmillan nursing service) in situations (i.e. critical incidents, Chapter 3.3.1.1) that could be described as spiritual encounters with patients or their relatives, and issues that influenced these responses. 27 registered nurses (9 medical, 9 oncology and 9 Macmillan nurses) attended tape recorded semi-structured interviews and provided a total of 86 critical incidents (see Appendix VIII).

### **4.2. Response and consent rate**

The purpose of this section is to describe the response and consent rates to show the representation of particular groups of nurses in this study. This information is useful for interpretation and possible generalizability of the findings.

Invites were sent to a total of 135 nurses (101 medical, 21 oncology and 13 Macmillan), with responses received from 56 nurses (30 medical, 16 oncology and ten Macmillan), and no responses from the remaining 79 nurses (Table 1). 33 nurses (14 medical, ten oncology and nine Macmillan) consented and were eligible to take part in the interview part of the study, with 23 nurses withholding consent (Table 2). 18 of the medical nurses, six of the oncology nurses and one of the Macmillan nurses who returned completed questionnaires withheld consent, while one medical nurse and one oncology nurse withheld consent, but did not return completed questionnaires. Some of the nurses

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who initially consented to being interviewed were subsequently unavailable (three medical and one oncology nurses), and two medical nurses withdrew their consent.

	Invited	Responded		No response	
Medical	101 (n)	30 (n)	29.7%	71 (n)	70.3%
Oncology	21 (n)	16 (n)	76.2%	5 (n)	23.8%
Macmillan	13 (n)	10 (n)	76.9%	3 (n)	23.1%

Table 1 Response rate

	Invited	Consented		Attended Interview	
Medical	101 (n)	14 (n)	13.9%	9 (n)	8.9%
Oncology	21 (n)	10 (n)	47.6%	9 (n)	42.9%
Macmillan	13 (n)	9 (n)	69.3%	9 (n)	69.3%

Table 2 Consent rate

Both response and consent rates were lowest in the medical nurses (Tables 1 and 2), with those who stated having a religious faith in the questionnaire more likely to consent to take part and attend for the interview (Table 3). The oncology nurses had a higher response and consent rate, and the Macmillan nurses the highest (Tables 1 and 2). This meant that medical nurses were under-represented in the study. It could be speculated that Macmillan and oncology nurses have a greater interest in spiritual issues, as their work is very much focused on patients facing life limiting conditions, and that they therefore were more interested in taking part in this study.

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	Macmillan Nurses			Oncology Nurses			Medical Nurses		
	With Beliefs	Uncertain Beliefs	No Beliefs	With Beliefs	Uncertain Beliefs	No Beliefs	With Beliefs	Uncertain Beliefs	No Beliefs
Responded	5	4	1	11	2	2	13	8	8
Consented	5	3	1	8	1	1	7	3	2
Attended Interview	5	3	1	7	1	1	6	1	2

Table 3 Beliefs in completed questionnaires

Of the nurses (medical, oncology and Macmillan nurses combined) who responded and consented most stated with religious faith in their questionnaires, a smaller number stated with uncertain religious faith and the smallest number stated no religious faith (Table 4). This meant that nurses without faith were under-represented and that the sample was biased towards those nurses who identified themselves as having religious faith.

	With religious faith	Uncertain religious faith	No religious faith	Data missing
<b>Responded</b>	51.8% (29)	25.0% (14)	19.6% (11)	3.6% (2)
<b>Consented</b>	37.5% (21)	14.3% (8)	7.1% (4)	0% (0)
<b>Withheld consent</b>	14.3% (8)	10.7% (6)	12.5% (7)	3.6% (2)
<b>Interviewed</b>	32.1% (18)	8.9% (5)	7.1% (4)	0% (0)

Table 4 Religious faith and consent in returned questionnaires

A total of 27 nurses completed their questionnaires and attended tape-recorded interviews; nine medical nurses, nine oncology nurses and nine Macmillan nurses. As just one male nurse attended for interview, all participants are referred to as female, in

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order to maintain confidentiality. It was not possible to draw any conclusions based on gender, other than that there were considerably more women than men (10 medical nurses and 2 Macmillan nurses were male) in the population that the sample was drawn from. This is an expected finding in a female dominated workforce.

### **4.3. Demographic and spiritual characteristics of participants**

The purpose of this section is to describe the demographic and spiritual characteristics of participants, which is useful information for interpretation and possible generalizability of the findings.

#### **4.3.1 Years of nursing experience**

The Macmillan nurses' nursing experience ranged from 13 – 36 years, with a mean of 21.4 years and a median of 22 years, which was longer than the oncology and medical nurses. The oncology nurses ranged from 1 – 31 years, with a mean of 17.7 years and a median of 18 years, and the medical nurses ranged from 6 – 26 years, with a mean of 13.6 years and a median of 12 years. This reflects the experience required for the Macmillan nurse role.

#### **4.3.2. Ages**

Reflecting the number of years of nursing experience, the Macmillan nurses were older than the oncology and medical nurses, while the medical nurses were the youngest (Figure 1).



## Results

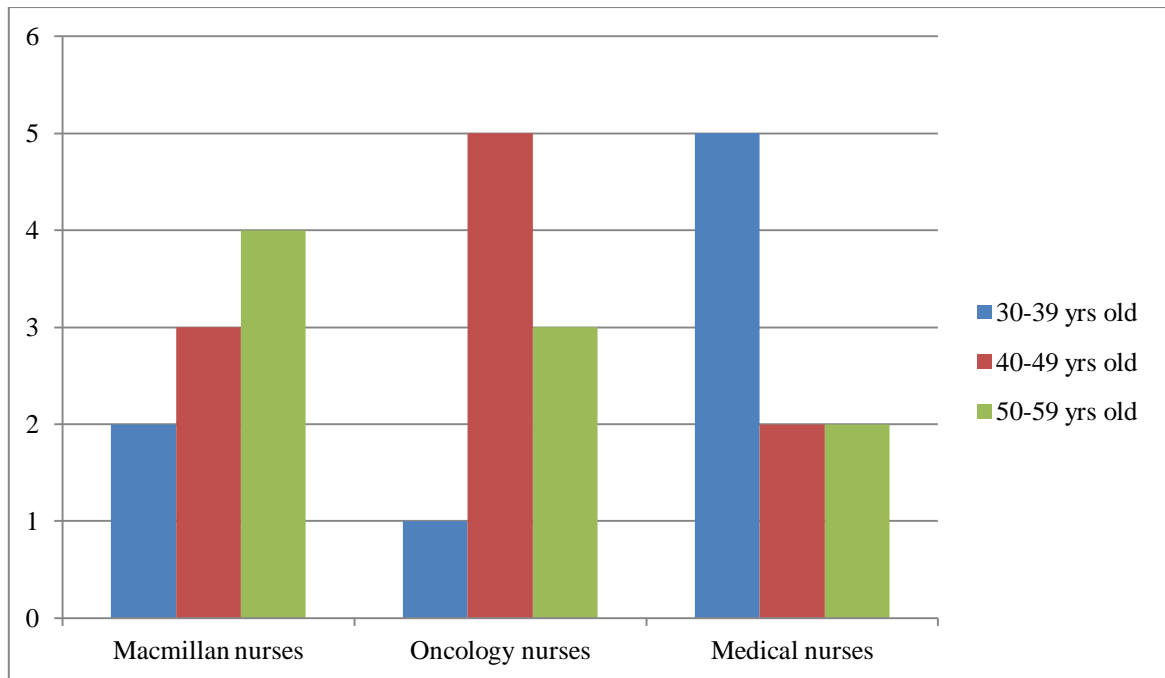


Figure 1 Ages

### 4.3.3. Bands/Grades

It was difficult to compare band/grade, as this study took place during the introduction of the Agenda for Change (AFC), when some nurses had moved onto the AFC banding, while others were still on the old grading.

Figure 2 shows the distribution of banding (and those on grading, estimated to a band). One of the Macmillan nurses on I-grade and five on H-grades were entered as Band 7, and one on G-grade included with Band 6. One of the oncology nurses on H-grade was entered as Band 7, one of G-grade as Band 6 and four E-grades and three D-grades entered a Band 5. One medical nurse on G-grade was entered as Band 6, three on E-grades and three on D-grades as Band 5. The remaining nurses had already received their bands. It is not known how those on the old grading were eventually banded, but

## Results

without further information this is likely to be the best estimate, and clearly shows the higher band/grades of the Macmillan nurses.

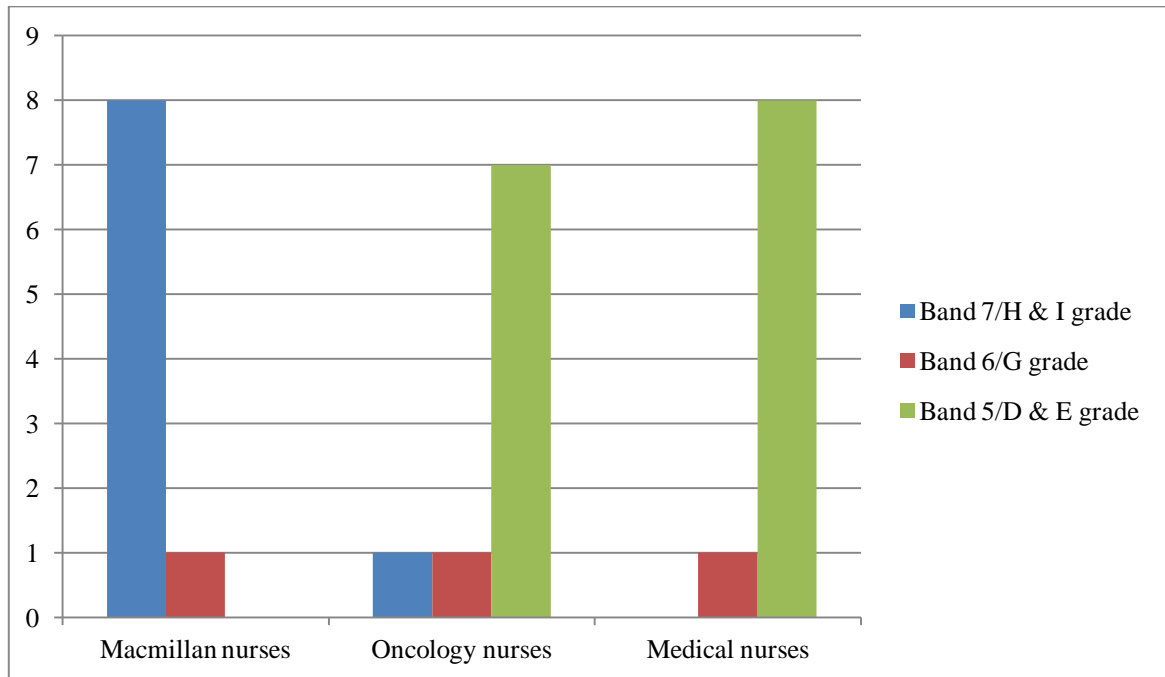


Figure 2 Bands/grades

### 4.3.4. Highest academic qualifications achieved

The Macmillan nurses had achieved the highest level of academic qualifications (Figure 3), with seven having completed degree studies, one diploma and one post-graduate study. Three of the oncology nurses had completed degree studies, four diploma and two certificate level studies. Two Medical nurses had completed degree studies, four diploma studies, two certificate studies and one 'old type training'. Certificate is likely to indicate a post registration certificate course but, in retrospect, the questionnaire should have been clearer on this.

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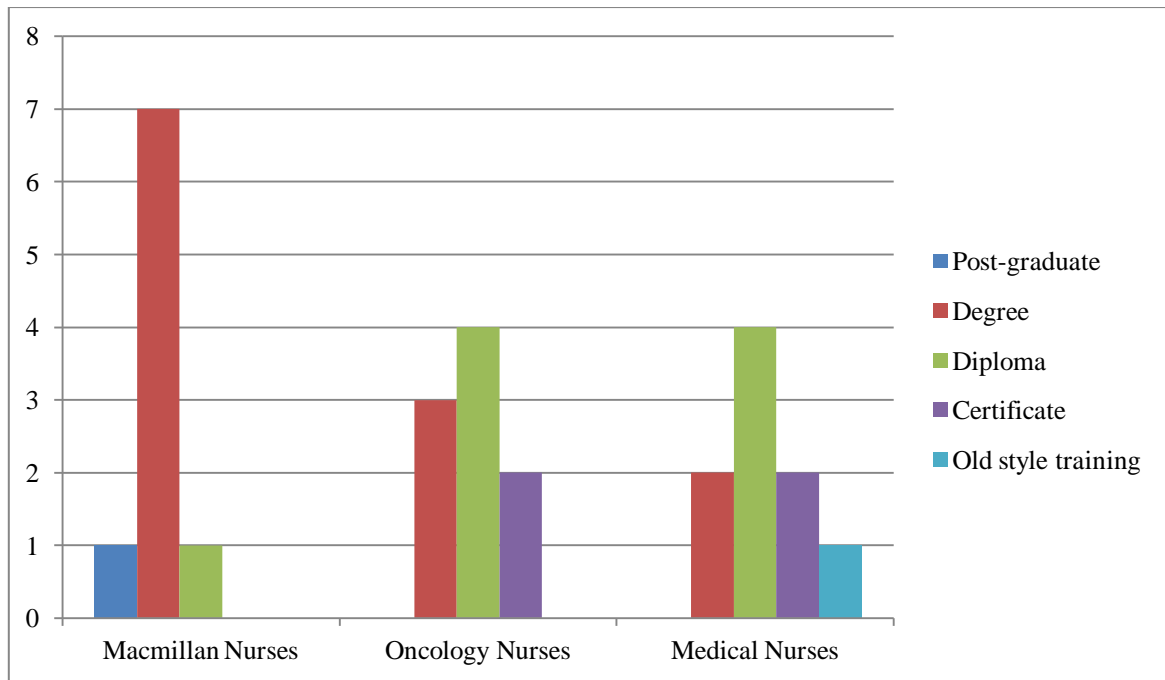


Figure 3 Highest academic qualifications

### 4.3.5. Palliative, oncology, heart failure and spirituality training

All the Macmillan nurses had completed or were undertaking an oncology course. Six had completed and one was undertaking a palliative care course. Three had completed and one was undertaking a spiritual care course. Eight of the oncology nurses had completed or were undertaking an oncology course. Six had completed or were undertaking a palliative care course. Two had completed a spiritual care course. One medical nurse had completed an oncology course, two had completed a palliative care course and two had completed a spiritual care course (Figure 4).

## Results

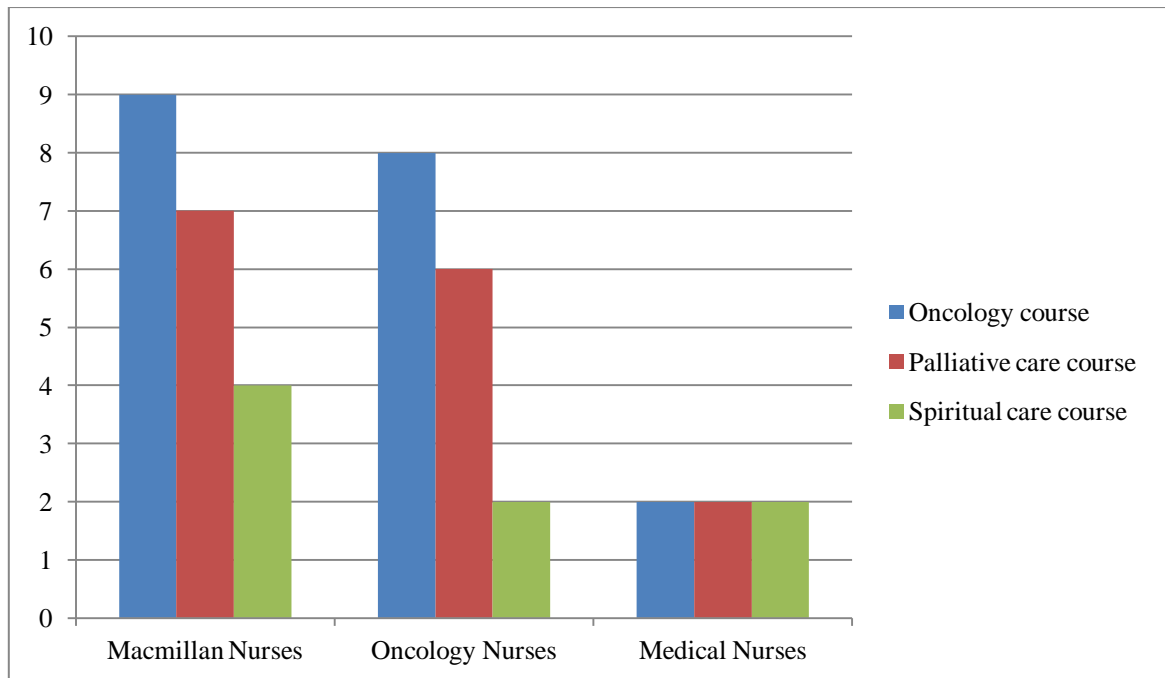


Figure 4 Oncology, palliative and spiritual care courses

### 4.3.6. Religious and/or spiritual beliefs in the interviewed nurses

There was much uncertainty with regards to religious faith in the nurses. The questionnaire (Appendix III) provided to the nurses prior to interview asked ‘Do you regard yourself as having any religious faith?’ with the options of ‘Yes’, ‘No’ or ‘Uncertain’, and this was completed by all nurses who consented to, and took part in, the interviews, as well as by some of those who did not take part in the interviews. A quarter of all the nurses who completed the questionnaire replied ‘Uncertain’, and for many of the nurses there was no clear connection between the answers given in the questionnaire and the information provided in their interviews.

The planned categorisation of ‘with religious faith’, ‘without religious faith’ and ‘uncertain religious faith’ used in the questionnaire (Figure 5) did not reflect the nurses

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beliefs, as stated in their interview (Figure 6). Thus, the nurses' beliefs were categorised according to the three categories that emerged from the data obtained in the interviews (Chapter 3.5):

- With religious and/or spiritual beliefs
- With uncertain religious/spiritual beliefs
- With no religious or spiritual beliefs

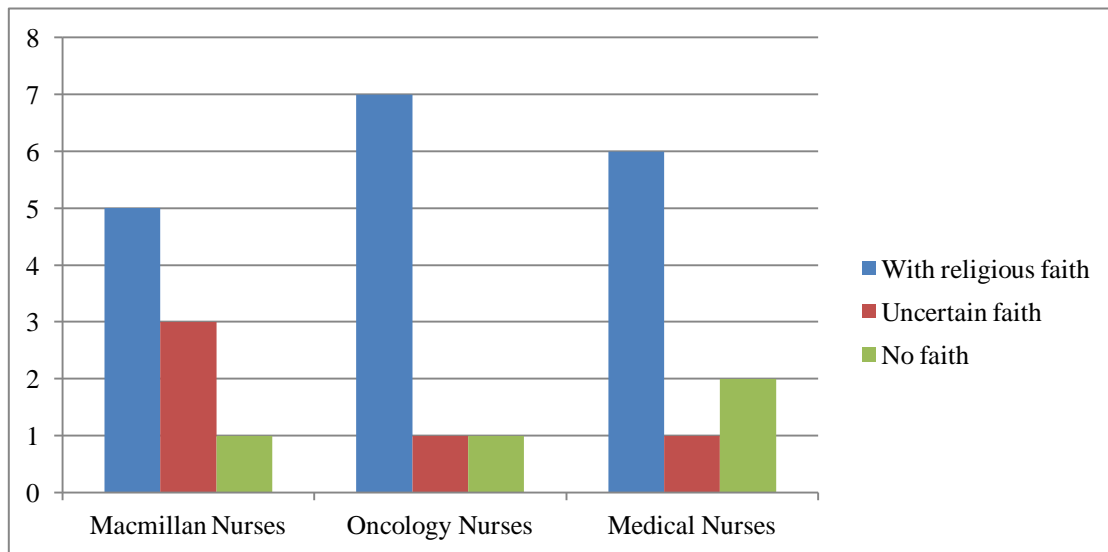


Figure 5 Religious faith in the sample, based on questionnaires

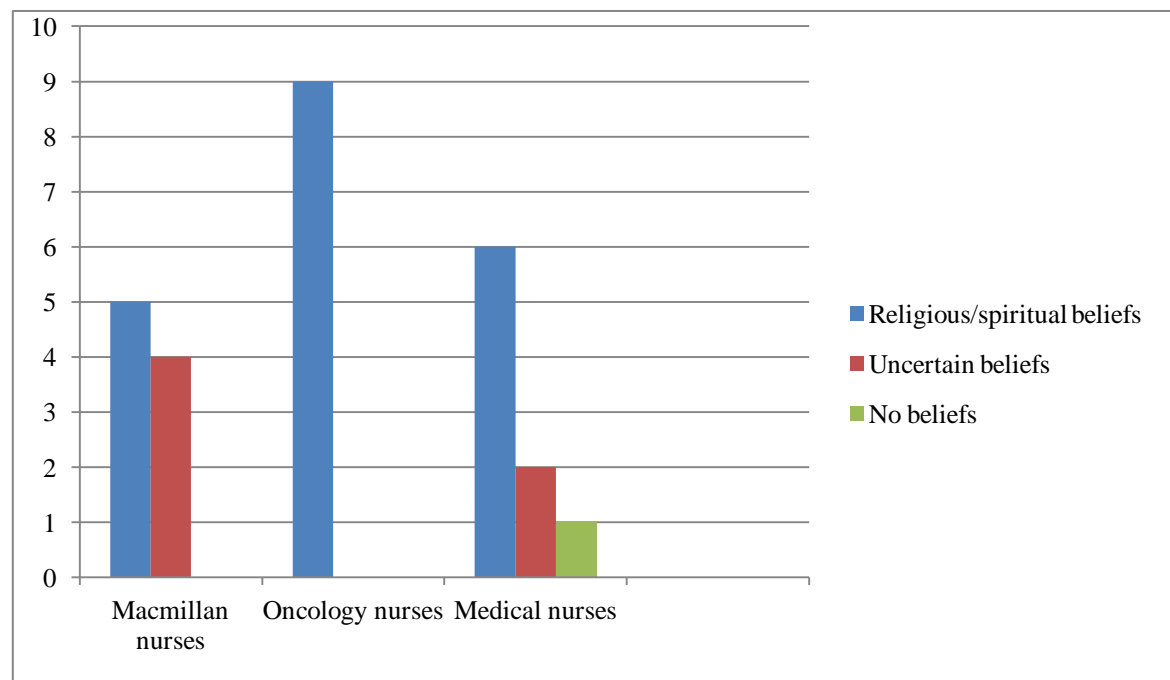


Figure 6 Religious/spiritual beliefs in interviews

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Medical Nurse 6 and Oncology Nurse 9 entered 'Without Religious Faith' in their questionnaires, but expressed spiritual beliefs in their interviews. Macmillan Nurse 5 entered 'Without Religious Faith', but expressed uncertainties in her interview. Oncology Nurse 5, who stated 'Uncertain Religious Faith' in the questionnaire, expressed spiritual beliefs in her interview. Medical Nurse 4's entered 'With Religious Faith' in the questionnaire, but did not fit her own definition of being religious:

'My definition of being religious is going to Church every week, or more, and reading your bible and praying; I don't follow that trend, but I think I am spiritual, because I believe in an afterlife.'

Medical Nurse 4

Spiritual beliefs were not regarded as synonymous with religious faith in this group of nurses and replies in the questionnaire did not give a reliable idea of religious belonging or religious/spiritual beliefs (Box 2).

Of those nurses who completed their questionnaires and consented to attend the tape recorded interview, the majority had indicated 'With Religious Faith' in the questionnaire, while in the non-consenting nurses there was a fairly even spread between 'With Religious Faith', 'Uncertain Religious Faith' and 'No Religious Faith', which suggests a bias towards religious beliefs in those consenting to be interviewed (Table 4). Only one of the interviewed nurses (Medical Nurse 7) expressed no spiritual or religious beliefs during the interview. Interestingly, Oncology Nurse 9, who identified herself as a firm atheist (but with spiritual beliefs), was the only nurse, in all the incidents, who used a clearly theological rationale in line with the patient's religion

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to give support to a patient who felt that it was God's judgement that she should suffer:

'I said that as far as I was aware the Church of Scotland wouldn't really view things like that, but if you owed up to your sins and asked for forgiveness then you get forgiveness.'

Oncology Nurse 9: Incident 46

**'Without Religious Faith' in the questionnaire, while expressing spiritual beliefs or uncertainties in interviews:**

'I don't have any religious faith; although, I have always been a fairly spiritual person, and spirituality is still important to me.' (Medical Nurses 6)

'I think anybody is a spiritual being, whether they believe in God or not.' (Oncology Nurse 9)

'I sit on the fence; if there is something it'll be a lovely surprise, and if there is not, I won't be disappointed. Maybe I am a Christian.' (Macmillan Nurse 5)

**One nurse, who stated 'Uncertain Religious Faith' in the questionnaire, expressed spiritual beliefs in the interview:**

'I don't go to Church regularly, I probably do believe in God. I believe that there's a reason for everything, even if we can't see it at the time.' (Oncology Nurse 5)

**Other nurses, who had entered 'With Religious Faith' in the questionnaire, expressed uncertainties, or no religious beliefs, in their interviews:**

'I'm not religious in any way, I'm quite spiritual, but I suppose the two go hand in hand.' (Medical Nurse 4)

'I don't go to Church. I'm not sure that I know where I'm going after death.' (Medical Nurse 8)

Box 1 Belief mismatches between questionnaires and interviews

With a female dominated workforce and study population, and 26 out of 27 participants female, a high level of religious belonging and spiritual beliefs matches the findings of Voas (2015) that women are more likely than men to have religious belonging and spiritual beliefs. However, it is also possible that nurses with religious or spiritual beliefs were more motivated to consent to take part in this study.

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The nurses were categorised, as follows, based on the information that they provided in their interviews:

### **Medical nurses:**

- With religious/spiritual beliefs
- With uncertain beliefs
- Without any beliefs

### **Oncology nurses:**

- With religious/spiritual beliefs
- With uncertain beliefs
- Without any beliefs

### **Macmillan nurses:**

- With religious/spiritual beliefs
- With uncertain beliefs
- Without any beliefs

## **4.4. The incidents**

For the purposes of this study, critical incidents (Chapter 3.3.1.1) were defined as ‘any observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act’ (Flanagan 1954: 327). As the aims of the study (Chapter 1.3) were to explore how the nurses responded and what influenced their responses, incidents were considered complete only when this information was included. There were a total of 86 complete incidents: 20 provided by the medical nurses; 28 by the oncology nurses; and 38 provided by the Macmillan nurses.



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In choosing the incidents, the nurses were influenced by the trigger cues in the Participant Preparation Sheet (Appendix IV), as described in Chapter 3.3.1.3. These trigger cues were based on the operational definition (Chapters 2.3 and 3.3.1.3), and resulted in the nurses describing incidents where they responded to needs in patients that may be considered spiritual, as discussed in Chapter 2.

The incidents were classified in line with the flexible approach of the Critical Incident Technique (Chapter 3.3.1.1) according to what the nurses appeared to perceive as the patients' main need in each incident (Chapter 3.5). This resulted in 12 categories of incidents, with sub-categories:

- Need for peace of mind (20 in total)
  - Relating to religious issues (11)
  - Not relating to religious issues (9)
- Need to overcome fears (12 in total)
  - Relating to religious issues (5)
  - Not relating to religious issues (7)
- Need to express feelings and to be listened to (10)
- Need for a resolution of family issues (8)
- Need for hope (8)
- Need for religious support (7 in total)
  - Need of support from religious/spiritual care provider (4)
  - Need for support with religious/spiritual activity (3)
- Needs relating to patient's medical decisions based on religious beliefs (6)
- Need to explore religious/spiritual beliefs (3)
- Need to explore what happens after death (3)
- Need to be valued and treated as an individual (3)
- Need to take responsibility (3)
- Needs relating to purpose (3)

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### 4.4.1. Need for peace of mind

In these 20 incidents, the nurses talked about situations where they had responded to a patient's need for peace of mind and they have been sub-categorised into those that related to religious issues (11) and those that related to non-religious issues (9). Incidents included aspects of justice, guilt and anger.

#### 4.4.1.1. Related to religion

These 11 incidents were provided by ten nurses: one medical, three oncology and six Macmillan nurses. Medical Nurse 6, Oncology Nurse 5, 8 and 9 and Macmillan Nurse 1, 2, 7 and 9 had religious and/or spiritual beliefs, while Macmillan Nurse 4 and 5 had uncertain beliefs (Table 5).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	1	3	4
Uncertain beliefs	-	-	2
No beliefs	-	-	-

Table 5

Patients were angry with God, and felt that they didn't deserve what was happening:

‘Why have I even wasted this time then?’

Medical Nurse 6: Incident 13

‘Why would a loving God do this to me?’

Macmillan Nurse 1: Incident 49

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‘He was angry about leaving his family, and he was angry at God.’

Macmillan Nurse 1: Incident 50

‘He just felt it wasn’t fair; he wasn’t ready to die. He was a Christian and had been very involved in the church, but didn’t want any clergy to come to visit.’

Macmillan Nurse 4: Incident 59

‘Why has God done this to me; why has he left me behind?’

Macmillan Nurse 7: Incident 75

Medical Nurse 6 (Incident 13) talked as much as possible with the patient and addressed physical symptoms. While spirituality was important to the nurse, she was aware of her own lack of belief in any specific religion and felt that this made it more difficult. She lacked confidence in this incident and referred to the Chaplain. The patient had been very angry with God, and she commented that anger is common and felt that while the patient’s faith didn’t give him any comfort, the anger with God might have served a different purpose, in giving his anger a focus, rather than letting it out on his family or the nurses. As the patient’s physical symptoms improved, his spiritual distress was also relieved. The nurse felt that faith and religion should give people comfort, and not cause distress.

One patient questioned God during spells of feeling physically very unwell, but accepted what was happening as being God’s plan and there being a reason for what was happening, when he was feeling better (Oncology Nurse 5: Incident 30). Oncology

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Nurse 5 used open questions to encourage the patient to think for himself why he was questioning his faith and also encouraged him to think about how his faith had helped him previously. She stated her own belief that there is a reason for everything.

Macmillan Nurse 1 (Incident 49) tried to give hope to the patient by sharing her own belief in an afterlife. She found communication with him difficult, as he didn't appear to want to listen to her and would cut her off, when she tried to explore. She tried to change the subject and cover other issues, but he kept coming back to the religious aspect of 'why would a loving God do this to me?'. She offered to refer him to the Chaplain, but he didn't want this. At the time of this incident, she lacked confidence, as she was new in the job.

Macmillan Nurse 1 (Incident 50) had a lot of discussions with the patient, and referred him to the Chaplain. She was helped by the patient being easy to talk to and open to discussions, and was influenced by wanting to share her own faith, without pushing it. Macmillan Nurse 4 (Incident 59) avoided any quick responses and offered to refer to the Chaplain, which the patient declined.

In the incident with an old woman, who had suffered a number of bereavements, including two children, Macmillan Nurse 7 (Incident 75) explored and rationalised, and suggested that the patient's daughter had needed her for support, as without her, there wouldn't have been anybody else there for her.

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Macmillan Nurse 9 (Incident 80) talked about a patient with strong religious faith. The nurse referred her patient to a lay preacher, as she didn't want to talk to a Church Minister. This worked very well, as they developed a good relationship, with the patient becoming much more peaceful. She was helped by knowing what the patient's religious beliefs were, and because she knew some of the spiritual care providers, she was able to choose the person to refer to that she thought would be best able to connect with the patient. The nurse was influenced by her personal experiences of bereavement.

Another patient, who was a committed Christian, was in pain and agitated all the time, and on one occasion he was reading his bible and then chucked it away (Oncology Nurse 8: Incident 40). The nurse picked the Bible up and put it on his locker. She was uncertain of whether she should explore further or not, but felt that his body language indicated that he wanted to be left alone.

Macmillan Nurse 5 (Incident 64) talked about patient who had been brought up in the Free Presbyterian church, but then turned away from it. She described him as a 'tortured soul', and thought this might be because of what he had done in his life. She listened and referred him to the Chaplain, but found it difficult, particularly as she wasn't very religious herself. Two of the incidents involved patients who viewed their disease and suffering as a judgement:

'This patient felt that her disease and prognosis were a judgement upon her and it was God's judgement that she should suffer like this'

Oncology Nurse 9: Incident 46

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‘She had a very strong Free Church belief and she’d led a good life, but as she was coming closer to death she was becoming more and more disturbed, and she said that she was going to be punished, for all the things that she had done wrong.’

### Macmillan Nurse 2: Incident 55

Oncology Nurse 9 (Incident 46), who described herself as an atheist, but with spiritual beliefs, was the only nurse, in all incidents, who responded with a clearly theological rational. She explained that as far as she was aware, the belief in the Church of Scotland [*which the patient belonged to*] was that if you owed up to your sins and asked for forgiveness, you would be forgiven. She suggested that the patient should speak to her Minister. She also stated that she found it difficult, as she wasn’t religious, and would not accept the concept of a disease and prognosis being a punishment from God.

Macmillan Nurse 2 (Incident 55) tried to judge whether the patient wanted to talk or be left alone. She also tried to reason, but this was difficult, as she felt that the patient wanted to believe that she was going to be punished.

There was a wide belief among the nurses that it may be helpful and important to refer to staff with more specialist knowledge and skills, and most of the nurses offered to refer to a Chaplain, Minister or other spiritual care provider. They also used communication extensively, and listened, discussed, explored and tried to rationalise with patients. Oncology Nurse 5 and Macmillan Nurse 1 shared their own personal

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beliefs, while being concerned not to impose these. Some were influenced by their own lack of any specific religious beliefs. The nurses found some of these incidents very emotional and felt that religion should give comfort, rather than cause upset.

### 4.4.1.2. Not related to religion

These nine incidents were provided by five nurses: four medical nurses and one oncology nurse. Medical Nurse 3 and Oncology Nurse 6 had religious and/or spiritual beliefs, Medical Nurse 2 and Medical Nurse 8 had uncertain beliefs, while Medical Nurse 7 had no beliefs (Table 6).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	1	1	-
Uncertain beliefs	2	-	-
No beliefs	1	-	-

Table 6

In some of these incidents, there was a sense of unfairness, justice and in some cases guilt:

‘I must have done something to deserve it, and I must have done something really bad to deserve this’.

Medical Nurse 2; Incident 5

‘He did say “why me?”, but then seemed to resolve it himself and said “why not me?”.’

Medical Nurse 3; Incident 8

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Medical Nurse 2 and Medical Nurse 3 rationalised and tried to reassure their patients that there wasn't anything that they had done wrong to deserve their illness. Medical Nurse 3 stated that a lot of people would ask 'why me?', and think that their diagnosis was a kind of justice.

A patient diagnosed and treated for leukaemia appeared to be very angry and upset, and when Oncology Nurse 6 (Incident 32) said to him that it was ok to have all those emotions he said that it was just so unfair. The nurse explored, using open questions. She was influenced by sharing the patient's feelings of unfairness. The same patient made similar comments about a fellow patient who had relapsed very soon after treatment:

'To go through all this, to feel so ill, and for him not to get even a few months out of it.'

### Oncology Nurse 6 Incident 33

Oncology nurse 6 rationalised again, and explained that the people he met on the ward, his fellow patients, would either be newly diagnosed or relapsed, while if he was to go to the outpatient clinic, he would meet those with good stories. After discussing her incident with a colleague, she felt that she would be gentler in her response, if a similar situation occurred, as she thought that she had been quite blunt initially. Her colleague also suggested that it wasn't always necessary to provide an answer. However, the patient responded well and they developed a very good relationship.



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Two incidents involved married men who died from liver failure, having hidden their alcoholism from their wives:

‘She [*the wife*] had a huge amount of guilt going on, because she hadn’t realised that he was drinking.’

Medical Nurse 2: Incident 6

‘He [*the husband*] felt really guilty. He fully accepted that he had himself to blame for what was happening, and he just wished he hadn’t done it.’

Medical Nurse 2: Incident 7

Medical Nurse 2 provided verbal support, and tried to help the wife to realise that what she was feeling was a normal reaction. She identified the difficult aspects of the wife being torn between anger, grief and guilt. Medical Nurse 2 expressed a strong belief that people do things for a reason, even if this reason is not obvious to others, and tried to convey a non-judgemental attitude. She was influenced by her own personal experiences and feelings, having had someone close diagnosed with cancer at a young age, which affected her general outlook on life and death.

Other incidents related to patients who wanted to die. Medical nurse 7 (Incident 15) talked about a patient with metastatic cancer, who knew that the treatment wouldn’t cure her. She wanted to be left alone to die, as she didn’t want to prolong the suffering. The nurse reassured the patient that staff would make any procedures as painless as possible, and encouraged her to ask for pain relief. She was influenced by the patient’s unexpected and very rapid deterioration over the weekend, while the notes stated that

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she was expected to respond well to chemotherapy, with a life expectancy of 6-12 months. She tried to stand up for the patient, by telling the doctors that the patient didn't want anything further done to her, but was influenced by the authority of the medical on-call staff and her own lack of autonomy.

Another patient refused food and drink and even asked the nurses for help to die, as she didn't want to be a burden on her family (Medical Nurse 8: Incident 18), which the family struggled badly with:

'I just can't put up with my mum asking to die, every day I come in.'

Medical Nurse 8: Incident 19

Medical Nurse 8 used reasoning and rationalising, and explained that staff were not there to help patients die. In contact with the family of this patient, she also used reasoning and rationalising, as well as involving other members of staff. She tried to support the family and even suggested that they didn't visit, as it caused them so much distress.

Most of the nurses tried to rationalise in these incidents, and there were an even spread of influences, such as compassion, not wanting to be judgemental and personal experiences of cancer.

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### 4.4.2. Need to overcome fears

In these 12 incidents, the nurses talked about situations where they had responded to a patient's need to overcome fears. They have been sub-categorised into those that related to religious issues (5) and those that related to non-religious issues (7).

#### 4.4.2.1. Related to religion

These five incidents were provided by four nurses: one oncology and three Macmillan nurses. Oncology Nurse 2, Macmillan Nurse 1 and 9 had religious and/or spiritual beliefs, while Macmillan Nurse 5 had uncertain beliefs (Table 7).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	-	1	2
Uncertain beliefs	-	-	1
No beliefs	-	-	-

Table 7

All of these incidents related to fears about not moving on to an afterlife, for example:

‘She was a Free Presbyterian and that her biggest fear was actually not getting to Heaven. The minister that’d been to see her said that she needn’t necessarily get into Heaven.’

Oncology Nurse 2: Incident 23

‘His parents were Presbyterians. He was scared that if he didn’t believe, then he would not move on to an afterlife after he died, which he knew from his parents that there was.’

Macmillan Nurse 1: Incident 51

## Results

‘Although he had gone to Church, he did not have the assurance that there was a life after death and that made him very, very frightened.’

### Macmillan Nurse 9: Incident 85

Oncology Nurse 2 (Incident 23) wanted to bring comfort to the patient in a religious way, because her own very strong belief was that it wasn't right for the patient, who she was very fond of, to spend her last days in fear of not getting into Heaven. She asked for support from the hospital Chaplain, and a hospital Chaplain had been able to make contact with the patient and spent a lot of time with her, which gave her a lot of comfort. Oncology Nurse 2 did not share or understand the patient's beliefs, but was concerned not to appear disrespectful.

Macmillan Nurse 1 (Incident 51) made sure that the patient had a selection of people to talk to (Hospital Chaplain, patient's own Minister and a health care professional, who had Christian faith). She had ongoing discussions with the patient over a period of time, and got to know him well, which was helpful. She prayed with him, having asked if he wanted that. The nurse found it helpful to have personal experience and an understanding of the patient's religion. She was concerned about not imposing her own beliefs on the patient, while wanting to share her faith with him. The outcome was good, as the patient died at peace.

Macmillan Nurse 5 (Incident 67) felt that the patient's religious, emotional and physical distress was 'tangled up' and this was a difficult situation. She referred to a Minister,

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but the patient died, without his fears having been resolved.

Macmillan Nurse 9 (Incident 82) responded by providing plenty of opportunities for the patient to talk to different people, including a health care professional who belonged to the same Church and who the patient had a good relationship with. She tried to reassure the patient that her faith wouldn't let her down, but didn't feel that she had been able to help resolve the patient's fears. Like other Macmillan nurses, she found it helpful to have been able to get to know the patient over a long period of time.

In Incident 85, Macmillan Nurse 9 tried to reassure the patient that what he had believed in over the years would not let him down at the end. She talked a lot to the patient and death was peaceful in the end.

All four nurses offered to refer to a spiritual care provider. Macmillan Nurse 5 and Macmillan Nurse 9 found these incidents difficult to deal with. Oncology Nurse 2 found her incident very upsetting, as she didn't think it was right that the patient's religion and her Minister should cause her such terrible distress. Macmillan Nurse 1 was the only nurse in the study to offer to pray with a patient; however, she knew the patient well and was familiar with his religion. As in the incidents relating to needs for peace of mind related to religion, Macmillan Nurse 1 wanted to share her beliefs, without imposing them.

## Results

### 4.4.2.2. Not related to religion

These seven incidents were provided by six nurses: two medical, one oncology and three Macmillan nurses. Medical Nurse 1, Medical Nurse 9, Oncology Nurse 8 and Macmillan Nurse 3 had religious and/or spiritual beliefs, while Macmillan Nurse 4 and 8 had uncertain beliefs (Table 8).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	2	1	1
Uncertain beliefs	-	-	2
No beliefs	-	-	-

Table 8

In five of these incidents patients or family members had fears about how they would die:

‘He was so frightened of dying, when he started to bleed and was aware of what was going on, and the bleeding wouldn’t stop.’

Medical Nurse 1: Incident 1

‘It’s more like the feelings of despair that she had and she was quite frightened of dying alone. She was quite distressed at the time [*during the night*].’

Medical Nurse 9: Incident 20

‘We had an older man, who was dying, and his daughter was so upset, because of how her mother died, and she had been in pain and distress.’

Oncology Nurse 8: Incident 44

## Results

Medical Nurse I (Incident 1) provided physical and emotional support; holding the patient's hand and letting him know that he was not on his own. This was very a distressing situation and she was praying that it would end soon. She commented on the limited time that they had with patients on an acute admission ward. Patients would often come in at the end-stage of their illness, being actually unwell, and either die or be moved on to another ward very soon after admission.

Medical Nurse 9 (Incident 20) also provided physical and emotional comfort, by holding the patient and reassuring her that she wouldn't be left to die on her own. The nurse was able to sit down and talk to the patient, and to go back to her throughout the night to check on her. The next morning, she asked the Macmillan nurses to come and talk to the patient. She was very aware that she couldn't promise that the patient's death would be peaceful and wanted to reassure, without being dishonest. The outcome was good, and the patient calmed down.

Oncology Nurse 8 (Incident 43) said to the patient that she would probably get more tired, not wanting to eat and, hopefully, slip away in her sleep. She reassured her that staff would do everything they could to make sure that she died peacefully. Like Medical Nurse 9 (Incident 20), she was very aware that she couldn't promise a peaceful death and did not want to be dishonest.

In the incident where the patient's daughter worried that her father would die in pain, like her mother had years ago, Oncology Nurse 8 (Incident 44) reassured the daughter

## Results

that things weren't like that anymore and that her father would be given symptom relief.

Macmillan Nurse 8 (Incident 78) listened carefully and explored what the patient was actually asking. She considered how much information he might want and how much he could cope with at the time. Over a number of visits, she conveyed to him that there would most likely be a gradual deterioration and that he would probably be bed-bound, and needing a lot of nursing care. Like other nurses, she was concerned about not being dishonest, but based her response on her professional judgement that the most likely outcome was a gradual deterioration. She felt that it was best to allow patients to keep their hope for whatever they were hoping for at the moment. She also commented on the importance of reviewing patients' needs at every encounter. She was helped by having been able to build up a good and trusting relationship with the patient over time.

Two incidents concerned fear of a recurrence of cancer:

'She appeared absolutely distraught, asking for an earlier appointment. "Why can't you cancel other people, to fit me in? What if they are old people and it just doesn't matter?".'

Macmillan Nurse 3: Incident 57

'We have had her through a whole gamete of things. She calms down for a while, but it is not lasting. It's always the assumption that it is cancer again. I think it is just fear.'

Macmillan Nurse 4: Incident 60



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Macmillan Nurse 3 tried to reassure the patient who wanted her appointment ahead of patients older than herself that a 2-weeks wait wasn't going to make a difference to the outcome. She explained to the patient that while she wouldn't be given priority over somebody who was older than her, neither would somebody younger be given priority over her. She tried to give hope, by saying that they would contact her if there were any cancellations, and tried to show compassion and care, while not giving in to the patient's demands. Macmillan Nurse 3 reflected that none of us know how we would react and behave in the patient's situation.

Macmillan Nurse 4 (Incident 60) was very much helped by working in a close and supportive team, where she did not have any difficulties communicating and making contact with other team members. Her responses were based mainly on providing reassurance, and arranging tests and investigations, as well as discussing the patient in clinical team meetings.

All the nurses responded by providing reassurance, physical and emotional support, trying to give some hope or by showing compassion. They also used communication, and Macmillan Nurse 8 used a structured approach of listening, exploring and establishing what the patient was actually asking. Medical Nurse 9 referred her patient to the Macmillan nurses. The nurses were influenced by wanting to provide reassurance, without being dishonest. Being able to get to know patients, to spend with them and to be able to go back to them was viewed as very helpful, and commented on particularly by the Macmillan nurses.

## Results

### 4.4.3. Need to express feelings and to be listened to

These 10 incidents were provided by six nurses: three oncology and three Macmillan nurses. Oncology Nurse 2 and 8 and Macmillan Nurse 2 had religious and/or spiritual beliefs, while Macmillan Nurse 5 and 6 had uncertain beliefs (Table 9).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	-	3	1
Uncertain beliefs	-	-	2
No beliefs	-	-	-

Table 9

Although these incidents involved fears and justice and other issues that could come under different categories, the main need that the nurses were responding to was the need for patients to express their feelings and be listened to:

‘This patient had a young child, when she was diagnosed with advanced cancer. She said that she didn’t want her daughter to come in, because she was so young. She asked me “do you think she should be coming in?”.’

Oncology Nurse 2: Incident 24

‘I remember her crying when I was on night shift and saying that she just didn’t want to leave her children.’

Oncology Nurse 2: Incident 25

Oncology Nurse 2 was influenced by her personal feelings. However, she recognised the need to respect the patient’s wishes, and that this patient just needed to be listened to. In Incident 25, she listened, emphasised and shared the patient’s feelings, and expressed a helpless wish to change her situation. She found these incidents difficult

## Results

and very emotional, but also felt privileged to share such special times with her patients and found this very rewarding. The young woman in this incident, like many other patients on the oncology ward, had recurrent and sometimes prolonged admissions, resulting in the nurse and patient getting to know each other very well. Being of a similar age and with children of similar ages, the nurse tended to identify with the patient. There was also the recognition that it is helpful to patients to be allowed the time and space when they are free to express their feelings, without worrying about upsetting their family.

Oncology Nurse 8 talked about a patient who had a terminal diagnosis, and was the main carer for his wife. He had promised her that she wouldn't have to go into a home, and felt that he was failing her:

‘He did speak to me about pain and things like that, but it was definitely the wife that was his main concern.’

### Oncology Nurse 8: Incident 38

Oncology Nurse 8 (Incident 38) felt that the most important response was to let him express how he felt, listen and empathise, but she also tried to rationalise. She was influenced by a sense of compassion, and was helped by having time and space for the patient. The ward wasn't busy at this time, and she was able to spend time with him. Like Oncology Nurse 2 (Incident 25), she expressed a helpless wish to change the patient's situation.

## Results

In the next incident, Oncology Nurse 8 (Incident 39) went through the admission documents with a patient who had lung cancer and asked him if he smoked. He said that he'd never been a smoker and asked how he'd ended up with lung cancer. Oncology Nurse 8 listened and allowed the patient to express his feelings, as well as exploring passive smoking with him. She commented that it is not necessary always to provide an answer always.

Oncology Nurse 9, who described herself as an atheist with spiritual beliefs, talked about a patient and family who attributed the patient's short remission to an intervention by God:

‘And the family actually said: “Praise be to God”, when they were told that the X-Ray had shown an improvement.’

Oncology Nurse 9: Incident 47

Oncology Nurse 9 thought that the doctor and the treatment were responsible for the remission, rather than God, but kept her thoughts to herself. In the next incident the patient had received a terminal diagnosis, but said that she had found God and felt greatly helped by this:

‘And she just thought it was great that people were praying for her and she felt that it had all helped enormously with this difficult time.’

Oncology Nurse 9: Incident 48

Oncology Nurse 9 viewed it as important to respect these beliefs and responded by

## Results

expressing pleasure with the good outcome and with how well the patient was coping. In both incidents, she encouraged the patient to get in touch with the Macmillan service if she should need any help in the future.

When Macmillan Nurse 2 asked a patient how he was coping with his diagnosis and prognosis, his wife said that he'd seen Heaven, when he'd had a cardiac arrest and been resuscitated, and had a beautiful experience of peace, with lights and trees:

‘And so, he had absolutely no fear of death at all, because that was such a pleasant experience for him.’

Macmillan Nurse 2: Incident 53

Using her professional knowledge, understanding and experience, she judged that there was no denial and that the patient had accepted the situation very well. She felt that all he needed was to be listened to, and expressed her pleasure with how well he was coping.

In another incident, Macmillan Nurse 5 (Incident 63) had a patient who had talked about going to Zurich to have a controlled death. She explored and encouraged the patient to talk through his fears, to try to identify his greatest fears. Over time, she was able to build up a good relationship with the patient and found it very helpful to have plenty of time for talking. Macmillan Nurse 6 (Incident 68) also talked about a patient who wanted it all to come to an end and asked if his death could be speeded up. Macmillan Nurse 6 went through a structured pathway of responding, exploring and

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clarifying. Through this process the nurse established an open relationship with the patient, and identified what the patient's particular fears and concerns were. She found that this patient had a fear of choking to death, and that this fear may have been one reason for why he was asking for help to die. This gave her an understanding of the possible reasons for, and seriousness of, the patient's wish for euthanasia, and she was able to provide reassurance that choking to death is extremely rare. She also liaised with other health care professionals. In retrospect, the nurse thought that it might have been helpful to ask more specific questions to start with, to help identify what the patient's worries were. However, she was also concerned about not putting fears into the patient that he may not have had before. In Macmillan 5's next incident, a patient expressed a lot of anger:

‘He'd never smoked or drunk and there were loads of anger about delays in diagnosis and other illnesses that the chap had; very angry situation.’

### Macmillan Nurse 5 Incident 65

Although this incident related strongly to unfairness, Macmillan Nurse 5 (Incident 65) responded most of all to the patient's need to express his feelings, to be listened and to get his anger and upset off his chest. Like Oncology Nurse 8, she commented that it was important not to feel compelled to provide answers; sometimes it's better just to listen.

All nurses the responded with talking and listening to patients, as well as exploring, and emphasising with patients' situations. In some instances, when the nurses didn't share the patients' beliefs, but felt the need to respect their feeling, beliefs and wishes, they

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got around this by sharing patients' feelings instead. Time and space was again found to be very helpful, as well as having had the opportunity to build up good relationships over time. Macmillan Nurse 6 used a very structured approach of listening, exploring and clarifying, which helped to establish the patient's actual concerns.

### 4.4.4. Need for a resolution of family issues

These eight incidents were provided by six nurses: one medical nurse, two oncology and three Macmillan nurses. Medical Nurse 1, Oncology Nurse 1 and 2 and Macmillan Nurse 7 and 9 had religious and/or spiritual beliefs, while Macmillan Nurse 6 had uncertain beliefs (Table 10).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	1	2	2
Uncertain beliefs	-	-	1
No beliefs	-	-	-

Table 10

In these very different kinds of incidents, the nurses responded to the patients needs to resolve family issues. In the first incident, a man who was an alcoholic and had been drinking secretly had told his wife that his illness was caused by a virus:

‘So when his wife came in, she said to me “I don’t understand how a virus can do this”, cause that’s what he’d told her. And after, he said to me “would I tell her?”.’

Medical Nurse 1: Incident 2

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Medical Nurse 1 told the patient that he would have to talk to his wife about this himself, but that she and the doctor would help to start it off for him, which they did. When he told his wife she was completely devastated, as she had had no idea that he was an alcoholic. The patient and his wife did, to some degree, come to terms with this, before he died a few days later. Medical Nurse 1 was influenced by compassion for the patient's family, who she found very likable, and for the patient, who was so afraid of dying. She commented that on an acute admission ward, where patients either move on quickly, or come in very acutely ill and die quickly, the nurses' opportunities to get to know patients and their families are very different to the opportunities of nurses in a setting where they can get to know patients over a longer period of time. Privacy was another issue, with the awareness that in a 6-bedded bay, patients were separated only by a thin curtain. Her own personal experiences of bereavement had a big influence on her approach to patients and their families, and having had a bad experience, she wanted to avoid that happening to other families.

In a very different type of incident, Oncology Nurse 1 talked about a patient, who was in the terminal stages of disease, with a primary school age child. He had been unwell, but not cared for himself, as he didn't have anybody to take care of his daughter:

‘By the time he came in, as an emergency, his disease was almost at the last stages, and the girl was in foster care, while he was in hospital.’

Oncology Nurse 1: Incident 21

Oncology Nurse 1 identified an unvoiced need for support in this patient and explored



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further, while providing hands-on nursing care. She identified that he had little social back-up and was finding it hard to cope. When asked, he said that he occasionally attended Church, and that the people in the Church were quite supportive. Like Medical Nurse 1 (Incident 2), in the previous incident, Oncology Nurse 1 was influenced by compassion for the patient. Having established that he occasionally attended Church, she explored more spiritual issues, and used her own beliefs and experiences to offer spiritual support; she said that she sometimes gained support from praying, but that this could be difficult when you were very ill. When asked, the patient replied that he did sometimes pray. With the knowledge that he sometimes prayed, and occasionally attended Church, she believed strongly that he would benefit from input from the Chaplain, who would be able to provide support that the nursing staff did not have time for, as this was a particularly busy time on the ward, and she offered to refer him.

The patient said that he didn't want to see the Chaplain just now. Having established that he wasn't opposed to the idea of seeing the Chaplain, the nurse wanted to provide him with the support that she believed that he was in need of, and she spoke to the Chaplain and, without telling him who the patient was, said that there was a patient on the ward who she thought would benefit from input from the Chaplaincy team. The Chaplain went around the ward and talked in general to patients. He found the relevant patient, who responded very well to this contact, and from then on the Chaplain visited regularly and provided support to the patient and his daughter. The nurse was very happy with how this contact turned out, as she could clearly see the benefits to the patient.

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In another incident, Oncology Nurse 1 (Incident 22) also identified a need for support in a patient with four children, who had just been given a very poor prognosis. The oldest knew her diagnosis, but not the implications, while the youngest didn't know her diagnosis; however, she didn't know how to go about dealing with this. Oncology Nurse 1 used the questions in the admission documents, which asks if the patient has any religion and if they would like a visit from the Chaplain or their own Minister. The patient replied that she had been brought up a Catholic, but wasn't a practicing Catholic, and didn't want to be seen by the hospital Chaplain at the moment. Having left the option for further suggestions of a visit from the Chaplain, the nurse documented this and continued with the admission.

The next incident concerned a patient with a young son, who was in a new relationship with a woman who the boy regarded as his mother. The boy's actual mother was an alcoholic and had not had any contact with him since he was a baby:

‘And when he was in and realised that he didn't have long to live, he panicked, because boy would have gone back to his mother, so just in a matter of days had to arrange a marriage, so that the boy could be officially adopted by his, what would then become, his wife.’

### Oncology Nurse 2: Incident 26

This was an incident that Oncology Nurse 2 found very emotional, but also very rewarding. She offered support and, together with other staff, arranged a wedding celebration on the ward, with balloons and a cake and all the relatives. She was influenced by compassion and shared the emotions with the patient and his family.

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Macmillan Nurse 6 talked about a patient who was terminally ill, and whose family had very different views of what should happen after her death; some thought she should be buried, others cremated:

‘She felt very much that she should try to get things as acceptable as possible for everybody, but her own views were seemingly getting a little bit squashed, although she had quite specific, very specific views as to what she wanted to happen.’

### Macmillan Nurse 6: Incident 69

This patient was very aware of what the effect on her family would be after her death, and needed to find a resolution quickly. There were a number of different issues that influenced Macmillan Nurse 6’s responses, such as difficulties in establishing rapport with this particular patient, and a lack of communication with other family members. She found it helpful to discuss the situation with other members of the team. Non-verbal cues from the patient triggered the nurse to explore further, to identify her main concerns, and then to address these. With the help of her contact with the Hospice, the nurse was able to refer to the Hospice Chaplain, who helped the patient to come to terms with her situation, recognise that she couldn’t please everybody and that she needed to have her own views and wishes listened to.

In another incident, a woman was discharged home with a very recently diagnosed terminal illness and only about a week to live. She had young children that she needed to prepare for her imminent death:

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‘She had an immense spiritual faith that gave her a huge peace. She made a huge impact on me, in the way that she said “this is what is going to be, I am going to die and I accept it and I’m going to prepare my children for it”.’

### Macmillan Nurse 7: Incident 70

Macmillan Nurse 7 asked the patient how she would prepare her children for her death, asked if she needed any help and talked it through with her. The patient said that she was going to read them a story, give them a cuddle and tell them that she was going to Heaven and would wait for them there. The strength of this patient made a huge impression on the nurse.

Macmillan Nurse 7 (Incident 74) talked about another patient, who expressed concern for her mother, whom she had a very close relationship with:

‘Would I tell her mother that she would wait for her and that she would always be there and that she loved her very much.’

### Macmillan Nurse 7: Incident 74

Macmillan Nurse 7 was concerned about how the patient’s mother would perceive this message, and she worried about being able to give the message without causing upset, rather than comfort. During the routine bereavement visit she explored and took cues from the mother and delivered the message in a way that she felt was appropriate. She found the situation very difficult, but the outcome was good. The nurse was helped by

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her Macmillan Nurse role, which allowed her to spend the time that she needed with the patient and her mother.

In the last incident relating to need for a resolution of family issues, Macmillan Nurse 9 talked about a terminally ill woman who had always taken responsibility for paying all bills and running the house:

‘And she wanted to try and pass some of these things over to her husband, but every time she did, he’d walk out. And she asked me to explain to him that she was dying and needed to talk about these things.’

Macmillan Nurse 9: Incident 83

Macmillan Nurse 9 explained to the husband that his wife was dying and that she needed him to listen to her. This was a very emotional experience, but the patient’s ability to deal with her illness and to prepare her husband for her death made a big impression on the nurse.

The most common response was to provide support and explore further. In one incidence, Oncology Nurse 1 established that the patient wasn’t opposed to seeing the Chaplain, occasionally attended Church and had positive contact with members of the Church. In view of this, she matched the need to respect the patient’s wishes and right to confidentiality, with his need for support, by asking the Chaplain to visit the ward, with the hope that he would find the patient. Macmillan Nurse 7 was helped by her role, which allowed her to spend with patients and their families and get to know them well,

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while Medical Nurse 1 commented on the situation on an acute medical ward, where there would be little time to get to know patients and their families, and also a lack of privacy.

### 4.4.5. Need for hope

These eight incidents were provided by seven nurses: two medical, one oncology and four Macmillan nurses. Medical Nurse 4, Oncology Nurse 7 and Macmillan Nurse 2 and 9 had religious and/or spiritual beliefs, while Medical Nurse 2 and Macmillan Nurse 5 and 8 had uncertain beliefs (Table 11).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	1	1	2
Uncertain beliefs	1	-	2
No beliefs	-	-	-

Table 11

The main needs in these incidents were for hope, and the first incident involved the family of an unconscious young man with a very poor prognosis:

‘They were like standing over his bed going “oh, this is it, isn’t it, I’m going to lose my son and he is dying and it’s awful.’

Medical Nurse 2: Incident 4

Medical Nurse 2 tried to stop the family talking over the patient’s head, as he might still be able to hear them. As he was receiving active treatment, she tried to leave the family with a little bit of hope, by pointing out that they wouldn’t still be treating him, if there

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was no hope at all. She felt that if everybody gave up hope, then the patient might also give up.

Medical Nurse 4 talked about two incidents where she felt the patients needed hope:

‘The person I was speaking to is a deep, very quiet and, I think, believed that when they were dead.’

Medical Nurse 4: Incident 9

‘He knew that he was dying, but, nobody else really thought he was going to die as quickly as he did, so I feel that maybe when a patient maybe gives up [*pause*] the will to live, they sometimes do die.’

Medical nurse 4: Incident 10

In Incident 9, Medical Nurse 4 was torn between wanting to give hope to the patient, in line with her own personal beliefs in an afterlife, and knowing that it wasn't her role to impose her own beliefs. To resolve this she encouraged him to believe that there is life after death, rather than stating it as a fact. The patient was quite withdrawn, which made communication difficult. Overall, the nurse was happy with outcome, as the patient listened and showed interest, but she would have liked to reassure him more directly that there is life after death. Medical Nurse 4 found the situation difficult to deal with, but tried to keep the patient's spirits up by encouraging him that he could still have good quality time left.

Oncology Nurse 7 (Incident 36) talked about a patient who felt very unwell, while

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going through radiotherapy, and felt that it would go on forever. The nurse discouraged her from thinking about how long it would go on, and suggested breaking it up into more manageable portions. She encouraged the patient to make short-term goals to pin her hope on; thinking about her husband coming in later in the day and making sure she got her anti-emetic in time, so that she would feel better when he visited.

Macmillan Nurse 2 (Incident 54) spoke of trying to change the patient's hope for a cure to hope for dying at home. While she couldn't promise the patient that he would die at home, she knew that in the area where he lived this would be likely and she reassured him that everything would be done for this to happen.

Macmillan Nurse 5 (Incident 66) talked about a patient who's just been diagnosed with chest metastasis, and appeared to have given herself up for dead and buried, while previously, she had always had the hope of some other treatment to come along. The nurse spent hours talking with the patient and encouraged her to set her hopes on short-term goals. The outcome was as good as could be expected, as she received much support from her faith and started to feel better.

A patient with a hospital acquired infection was feeling extremely ill and didn't realise that this was caused by an infection and not the cancer. He felt that there was no point in going on and asked his son to take him to Switzerland 'to be put down' (Macmillan Nurse 8: incident 79). The nurse explained to him that it was the infection and not the cancer making him feel so ill, and that when he got over



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this, he was likely to have a good quality of life for another year or two. With the hope of feeling better and having some good quality of life again, he became much more positive, and eventually recovered and went home.

The last incident in this category involved the husband of a patient with a terminal illness. At the wife's request, the nurse had told him that she was dying:

'I remember her husband saying that "you have just taken away all our hope, so what good is that, if you don't have hope then?">'

Macmillan Nurse 9: Incident 84

Macmillan Nurse 9 tried to convey to the husband that the hope was now for his wife's remaining time to be as peaceful and symptom free as possible, and that he could help her to achieve this. He didn't suddenly feel completely happy with the situation, but following this, he was much better able to support his wife. He later identified this as a turning point, when he recognised his role in helping his wife to die more peacefully.

Although many of these incidents were very emotional, the nurses did not find them particularly upsetting or stressful to deal with. All the nurses gave support and encouragement, and wanted to leave their patients with some hope, without making unrealistic promises. The Macmillan nurses tried to move the hope for a cure to a different and more realistic hope, which might be for a peaceful and comfortable end. Oncology nurse 7 talked about pinning hope on short-term goals and thinking about one thing at the time.

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### 4.4.6. Need for religious support

These 7 incidents have been sub-divided into ‘need for support from religious/spiritual care provided’ and ‘need for support with religious/spiritual activity’.

#### 4.4.6.1. Need for religious support from religious/spiritual care provider

These four incidents were provided by four nurses: three oncology nurses and one Macmillan nurse. Oncology Nurse 4, 5 and 8 had religious and/or spiritual beliefs, while Macmillan Nurse 8 had uncertain beliefs (Table 12).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	-	3	-
Uncertain beliefs	-	-	1
No beliefs	-	-	-

Table 12

In these incidents patients or their families asked for a priest, religious minister or chaplain:

‘It was a patient who died, roundabout 10 o’clock at night, and the patient’s family had not long left and I contacted the family and they came back. And the patient’s husband asked me if I could get the Priest’.

Oncology Nurse 4: Incident 29

‘There was a man who was dying and he requested to see his Priest. I think he had already had the last rites, and was ready, but he still wanted to speak to the Priest, but it was in the middle of the night.’

Oncology Nurse 5: Incident 31

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As it was in the middle of the night, Oncology Nurse 5 asked if the patient wanted to see the hospital Chaplain instead, but the patient said ‘no, I want to see my own Priest’. However, in both these incidents, the priests refused to come out. Oncology Nurse 4 explained that the family really wanted him to be there, but he said that he’d already given the Blessing and didn’t need to come out. Both nurses felt protective about the patients and their families, and did not say that the Priests had actually refused to come out. Oncology Nurse 4 relayed the information to the family that the patient had already received the Blessing, which was in place of the Last Rites, and that the Priest said that he didn’t need to come at the moment. Oncology Nurse 5 said that the Priest was unavailable, and asked if the patient would like her to call the hospital Chaplain, instead.

Oncology Nurse 4 (Incident 29) was helped by her understanding of the religion involved. She felt uncomfortable with the situation and was concerned about not hurting the family, as well as feeling disappointed in the priest on a personal level. She thought that the family felt very close to their priest and were hurt by him not coming out. Oncology nurse 5 (Incident 31) felt that the patient got on well with the Chaplain, who came to see him, and he died the following day without ever having known that the Priest had refused to come. Although aware that it was late evening/middle of the night, the nurses’ experiences was that, if called, priests would always come out to see patients who were dying, even in the middle of the night. The next incident was more positive:

‘One night I had a gentleman who was dying and quite acutely, his family  
[pause] I don’t think was particularly, I say Church goers, that sounds a bit

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off, but they really wanted a Minister. They really, really wanted a Minister, that night.'

### Oncology Nurse 8: Incident 42

Oncology Nurse 8 (Incident 42) was influenced by the urgency of the situation, as death was imminent, and she 'phoned the Chaplain on call. She very much appreciated how quickly he came and afterwards, the family told her that they had found it a huge help to have him there.

In the last of these incidents, Macmillan Nurse 8 (Incident 77) talked about a young woman with a child, who was given a very poor prognosis. She had no religious background, but her immediate response was to ask to see a Minister. Macmillan Nurse 8 explored why the patient, who didn't have a religious background, wanted to see a Minister, and this helped her to refer to the person she thought would be most helpful to the patient. Having known the patient before her illness, the nurse thought that a Minister would have been the last person she would have wanted to see. After having seen the Minister a couple of times, the patient's anxiety was much reduced, and the nurse was able to have very open discussions with her about her illness. The Minister continued to visit at times, until the patient died peacefully.

The nurses who talked about situations where a Priest had refused to come to see a patient or family found this upsetting and disappointing, and they were very concerned about protecting the patients and their families from upset. Although the requests had

## Results

been made during the night, the nurses did not hesitate to respond to the patients' or families' urgent wishes. In the other situations where the nurses referred to the Chaplain or a Minister, they felt that the involvements had been helpful and positive for the patients. Oncology Nurse 8 (Incident 42) and Macmillan Nurse 8 (Incident 77) both commented on the benefits and importance of teamwork.

### 4.4.6.2. Need for religious support with religious/spiritual activity

These three incidents were provided by three nurses: one medical, one oncology and one Macmillan nurse. All three nurses had religious and/or spiritual beliefs (Table 13).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	1	1	1
Uncertain beliefs	-	-	-
No beliefs	-	-	-

Table 13

These incidents involved specific needs that came directly from patients or families:

‘We had to tie a piece of cloth around parts of the body [*of a patient who had died*], now to me that was just tying a piece of cloth around a knee or something like that, but to them it was a religious practice.’

Medical Nurse 5: Incident 12

‘The family was from a culture where wailing is part of the grieving process.’

Oncology Nurse 7: Incident 37

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‘He wanted me to read something out of the bible to him, reading that bit about “in my Father’s house there are many mansions”.’

### Macmillan Nurse 9: Incident 86

Medical Nurse 5 (Incident 12) didn’t know what religion the patient belonged to. She found the request bizarre and could see no meaning in what she was asked to do, but recognised that it was an important religious activity for the man and his family. She found the situation difficult, due to her own religious beliefs and her lack of understanding for the patient’s religion. However, she did not hesitate to do as requested, as this was what the family wanted. She did not ask for explanations, as she didn’t want to appear disrespectful.

Oncology Nurse 7 (Incident 37) was influenced by respect for the family’s religion, and wanting to meet their needs, while also taking the needs of other patients into account. Initially, the body was in a bay of three and the other two patients were moved into other areas. The nurses then said to the family that the body had to be taken away, and that arrangements would be made for them to go to the mortuary, which was easier, as it was then away from other patients.

Macmillan Nurse 9 (Incident 86) had been able to build up a trusting relationship with the patient over time and shared his religious beliefs. She read the passage from the Bible to him and talked it through with him. She felt that he hadn’t been ready to die, but after this he seemed to relax, and in the end his death was very peaceful. She did not

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find it difficult to comply with his request, and felt good about the outcome. She commented that nurses on busy wards would probably not have the same opportunities to get to know their patients.

The nurses complied with the patients' requests or needs, whether they had any understanding of these or not. However, Oncology Nurse 4 (Incident 29) and Macmillan Nurse 9 (Incident 86) found it helpful to have an understanding of their patients' religions, while Medical Nurse 5 (Incident 12) found the situation more difficult because of her lack of understanding and also due to her own very different beliefs. Other influences were the benefits of good teamwork (Oncology Nurse 8: Incident 42), not wanting to be disrespectful (Medical Nurse 5: Incident 12) and having been able to build up a good relationship with the patient over a period of time (Macmillan Nurse 9: Incident 6).

### **4.4.7. Needs relating to patients' medical decisions based on their religious beliefs**

These six incidents were provided by five nurses: two medical, one oncology and two Macmillan nurses. Medical Nurse 1, Oncology Nurse 8 and Macmillan Nurse 3 had religious and/or spiritual beliefs, Macmillan Nurse 5 had uncertain beliefs and Medical Nurse 7 had no beliefs (Table 14).

## Results

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	1	1	1
Uncertain beliefs	-	-	1
No beliefs	1	-	-

Table 14

Three of these incidents involved Jehovah's Witnesses; two who died having refused blood transfusions (Oncology Nurse 8: Incident 45, Medical Nurse 1: Incident 3) and one who had not yet been seriously anaemic, but who would most likely refuse, even if that resulted in death (Macmillan Nurse 5: Incident 62). As far as the patients were concerned, these situations were very straight forward. The two patients who died were seriously anaemic, and their lives would probably have been saved by blood transfusions; however, there was no suggestion that this caused them any kind of dilemma or trauma.

The distress and frustration was entirely on the part of the nurses, with Medical Nurse 1 finding it extremely difficult, as the patient's son was devastated by the fact that she was dying. She felt like saying to the patient that she being was utterly selfish. Oncology Nurse 8 also found it very difficult, particularly as the patient wasn't old. Neither of these two nurses could understand how the patients would allow this to happen, when their lives could have been saved. The nurses were aware, on an intellectual level, that it is against the Jehovah's Witnesses' religion to accept blood transfusions, but this did not help them to understand on an emotional level, and they tried to persuade the patients to accept treatment.



## Results

Medical Nurse 1 (Incident 3) said to the patient that she respected her beliefs, but couldn't understand how she could allow herself to die. She said to the patient that it had nothing to do with God, but a lot to do with the blood bank. She even asked the patient's husband if he could influence his wife, but he was also a Jehovah's Witness and agreed with his wife. In Incident 45, the patient took Oncology Nurse 8's attempts at persuasion calmly:

'She even laughed about it at one point "not you as well", because I was saying: "why, why won't you have blood?" I knew it was because Jehovah Witnesses don't accept blood transfusions, but... She didn't get angry, she didn't say "will you stop going on about it".'

Oncology Nurse 8: Incident 45

Despite having tried to persuade the patient to have a blood transfusion, Oncology Nurse 8 acknowledged that patients have a right to choose. However, she still found it very difficult to think that the patient's life could have been saved. In Incident 62, Macmillan Nurse 5 recognised that the patient's right to choose, but was uncertain how she would react if the patient needed a blood transfusion. However, she had no doubt that he would be quite certain that he would not accept a blood.

The other three incidents involved terminally ill Free Presbyterians, who were in extreme pain and distress. They refused treatment that would have helped to control their symptoms and allowed them to die more peacefully, because they believed that God would want them to suffer and/or viewed the pain as their last fight with Satan:

## Results

‘She had advanced cancer, and she had a fracture, and she was a Free Presbyterian. She believed that she should suffer her pain.’

Medical Nurse 7: Incident 17

‘She was in a huge amount of pain, and she refused to take any opiates, because she believed that God had wanted her to suffer, and that was why he had given her this malignancy.’

Macmillan Nurse 3: Incident 56

‘What transpired was that this was her last fight with Satan, as she went through the dying process and she had to fight through this; all this distress. They [*the family*] were proud of her fighting the devil.’

Macmillan Nurse 5: Incident 61

Unlike the Jehovah’s Witnesses, these patients were in pain and suffered physical symptoms, but again, this was their choice, and there was no suggestion in the nurses’ accounts that these patients experienced any kind of dilemmas. The nurses found this equally stressful and difficult to understand:

‘I just think if there’s a God or whatever, they would want you to be as peaceful, as comfortable, as possible.’

Medical Nurse 7; Incident 17

‘My interpretation of God is a loving, forgiving God, who wouldn’t want me to suffer.’

Macmillan Nurse 3: Incident 56

The nurses found it very difficult to understand and accept their patients’ religious

## Results

beliefs and their responses were influenced by their personal feelings, beliefs and lack of understanding of the patients' and/or families' beliefs, while three commented that not providing symptom relief or life saving treatment for patients was contrary to their professional role. Macmillan Nurse 3 (Incident 56) felt that it wasn't natural to choose to have pain, and didn't understand how anybody could think that God would want that. Macmillan Nurse 5 (Incident 61) felt that, as a professional involved in patient management, not accepting pain relief was abhorrent. At the same time, they acknowledged that the patients' wishes were very clear and that they had a right to decide for themselves. Macmillan Nurse 3 and Macmillan Nurse 5 highlighted that the problem was with them, and not with the patients. However, Macmillan Nurse 5 kept asking herself if she or the team could have done anything differently.

### 4.4.8. Need to explore religious/spiritual beliefs

These three incidents were provided by two nurses: one oncology and one Macmillan nurse. Both nurses had religious and/or spiritual beliefs (Table 15).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	-	1	1
Uncertain beliefs	-	-	-
No beliefs	-	-	-

Table 15

In these incidents, the nurses were asked very directly about their beliefs:

## Results

‘And he asked me “do I go to Church?” He said “it’s just the way you say things, sometimes, makes me wonder whether you believe or not”.’

Oncology Nurse 6: Incident 34

‘The smaller children were thinking about “what happens after dying?”, and one said “Do you believe in God?” challenging me.’

Macmillan Nurse 7: Incident 72

‘And she was questioning her faith and said to me “do you have a faith?” and “why do you think I have been left behind?”.’

Macmillan Nurse 7: Incident 76

It was the first time that that Oncology Nurse 6 (Incident 34) had been asked her about her own personal faith and beliefs, but she didn’t hesitate to give a straight answer and tell the patient that she did have faith and believed in God. Macmillan Nurse 7 (Incident 72) also gave a straight answer about her own belief, but stated that not everybody does believe in God and that everybody has a right to their own beliefs. When asked by a relative (Incident 76), she also replied that she had faith.

However, when asked ‘and where do you think God is then?’, Macmillan Nurse 7 (Incident 76) took the opportunity to explore and lead the conversation onto the issue of the patient’s daughter’s beliefs, which was a subject that she wanted to raise. Instead of answering, she asked the mother where she thought God was. In her other incident, Macmillan Nurse 7 (Incident 72) again took the opportunity to move onto other issues of relevance that she felt that she should cover.

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The nurses replied with their own personal beliefs, openly and without hesitation, when asked. However, Macmillan Nurse 7 led it back the patient or the person they were talking about, and explored further, and she was influenced by not wanting to impose her own beliefs. Oncology Nurse 6 commented on the helpfulness of having been able to get to know the patient and/or family well, having worked with them over a long period of time.

### 4.4.9. Need to explore what happens after death

These three incidents were provided by three nurses: one medical, one oncology and one Macmillan nurse. All nurses had religious and/or spiritual beliefs (Table 16).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	1	1	1
Uncertain beliefs	-	-	-
No beliefs	-	-	-

Table 16

In these incidents, patients or their families were thinking about what happens after death:

‘I didn’t really know the man [*who had died*]. I didn’t know what religion or faith or anything he was from, but he died and I was attending to him, and his daughter just came out to me and said “what’s eternity, anyway?”.’

Medical Nurse 5: Incident 11

Medical Nurse 5 replied with what came first to mind, which was that eternity means

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forever. When the daughter continued to ask what that meant, the nurse replied with her belief that eternity meant that when you die, you either go to Heaven or hell, and the daughter then stated her belief that her father would go to Heaven. The nurse felt that she shouldn't impose her own beliefs, but her response was still very much based on her own beliefs. She was in-charge and had other pressures of the ward to deal with, and there was only a short time to respond, before the daughter left. However, she tried to explore the daughter's beliefs, which was difficult, as she was very upset and unapproachable. Medical Nurse 5 found this incident difficult to deal with, and it stayed on her mind for a long time afterward, as she felt that she hadn't been very helpful and considered what might have been a better response.

Oncology Nurse 7 (Incident 35) talked about a member of staff who expressed the feeling that while the body of the person who had died was still there, the person had left, and asked 'where has he gone?'. She replied that she didn't know the particular beliefs of the patient and she thought this would affect where we go after death. Like Medical Nurse 5, her reply was based on her own beliefs, although she too commented on not wanting to impose her own beliefs.

Macmillan Nurse 7 (Incident 71) was talking to a group of children about somebody who had died, and some of them asked if the person who had died had gone to Heaven. Macmillan Nurse 7 replied that the person who had died believed that she was going to Heaven and that God was waiting for her. She didn't think it would be right to impose her own beliefs onto the children who may not be brought up with any religious beliefs.

## Results

In these incidents, all three nurses were concerned about not imposing their own personal beliefs, but only Macmillan Nurse 7 (Incident 71) avoided a response based on her own beliefs, and reflected back to the person they were talking about. The responses of both Medical Nurse 5 (Incident 11) and Oncology Nurse 7 (Incident 35) were very much based on their own beliefs.

### 4.4.10. Need to feel valued and treated as an individual

These three incidents were provided by three nurses: one medical, one oncology and one Macmillan nurse. Oncology Nurse 8 and Macmillan Nurse 7 had religious/spiritual beliefs, while Medical Nurse 7 had no beliefs (Table 17).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	-	1	1
Uncertain beliefs	-	-	-
No beliefs	1	-	-

Table 17

The main needs in these situations related to patients needs to feel respected and valued as individuals:

‘This was a day or two before he died, and this time he said “I’ve had enough, I just want to go now; I’m tired”. He was calm and accepting.’

Medical Nurse 7: Incident 16

‘He said: “when the time comes, that I start to deteriorate, will you put me in a single room, so that other people don’t have to see me, and I don’t want to see anybody when that time comes”.’

Oncology Nurse 8: Incident 41

## Results

Medical Nurse 7 (Incident 16) held the patient's hand and told him that she and the other nurses would miss him and would never forget him. She was able to spend time with this patient, as the ward was quite. She also commented that patients sometimes don't want anybody other than their family; they might not want the nurse standing over them, and it is important to respect their privacy.

Oncology Nurse 8 (Incident 41) was very fond of this patient, having got to know him well over time and been able to build up good relationship. Aware that you can't promise somebody that they will not be in pain, and not wanting to be dishonest, she promised that she would do everything she could to make sure that he wasn't in pain. She shared information with other members of staff during report, so that they would be aware of his concerns and wishes. He was a very "private person", and she felt that this was one reason to why he wanted to be in a single room, as his condition deteriorated.

Another incident involved a patient who other members of staff thought was in denial about her prognosis:

'But this lady said: "I know I'm going to die of it; I just don't want to know it every day". Being talked to like a person was vital for her, to maintain her identity; to be somebody beyond the reason that all the doctors were seeing her.'

Macmillan Nurse 7: Incident 73

Macmillan Nurse 7 explored and avoided labelling the patient as 'coping' or 'not



## Results

coping'. She felt that it was very important for the patient to maintain her identity, and not just be viewed as somebody with cancer:

'Why can't they deny and do what they need to do that day, because the next day they know they've got it. She didn't want to talk about her prognosis to everybody, every time they met her. She was using denial very successfully, but always with the background knowledge. Just because she had this diagnosis, she didn't want her life removed from her.'

### Macmillan Nurse 7: Incident 73

Macmillan Nurse 7 felt that she learned from this patient that denial can be a useful coping mechanism that allows patients to gradually come to terms, as well as to live their lives as fully as possible until the end. She communicated with other health care professionals and conveyed to them that the patient didn't want to keep being asked if she realised that she was going to die. Sometimes she wanted to talk about what she'd watched on the telly last night and just have a 'normal' conversation. Being able to spend a morning with a patient, and being able to go back to, was appreciated, and the nurse highlighted that the district nurses and GPs would not be able to do this.

The nurses in these incidents knew the patients well, having got to know them over longer periods of time. Each nurse identified the need for the patient to feel cared for and to be treated as an individual.

#### **4.4.11. Need to take responsibility**

These three incidents were provided by three nurses: one medical nurse and two

## Results

Macmillan nurses. All three nurses had religious/spiritual beliefs (Table 18).

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	1	1	1
Uncertain beliefs	-	-	-
No beliefs	-	-	-

Table 18

Medical Nurse 6 (Incident 14) talked about a patient with terminal cancer, who appeared to gain great comfort and peace from her religious faith, while the nurse felt that her belief in God was so fatalistic that the patient didn't even care about her own children's well-being. Macmillan Nurse 2 (Incident 52) talked about an incident where the patient was turning down help from her family. Although these patients were getting comfort from their faith, the nurses did not view this as entirely positive:

'It was all in the hands of God and God would make sure they [*her children*] would all be cared for, and, actually that made me angry, to honest.'

Medical Nurse 6: Incident 14

'She was of the opinion that because she had handed everything over to her God, she should just take every day as it comes and see what he had planned for her. To me it seemed as if she wasn't, herself, taking responsibility for what was happening.'

Macmillan Nurse 2: Incident 52

Medical Nurse 6 felt so upset and angry with the patient's apparent lack of concern for her children that she didn't raise it again, as she felt that her role was to help the patient

## Results

through her situation, and not to respond with her personal feelings of anger. She also commented on the important of being aware of your own limitations.

At Macmillan Nurse 2's (Incident 52) first meeting with her patient, the patient said that she didn't need any help or support, as she was a born-again Christian and had handed everything over to God and to her family. However, the family appeared to struggle with the responsibility, and when they did make a decision or suggestion, the patient would very quickly reject it. Macmillan Nurse 2 listened and allowed the patient to express her feelings, but found the situation difficult, as the patient appeared to have put up a barrier around her and did not want help from the nurses. She provided her telephone number and shared information with other staff involved in the patient's care. She thought that it might have been easier, if she had met the patient earlier on and been able to build up a relationship with her over time. The fact that the patient was always surrounded by visitors, not just at visiting time, was also a problem, as she never got to see her on her on. She wanted to suggest to the patient that her God was helping her by providing health care professionals to support her, but didn't, as she didn't want to sound patronising.

### **4.4.12. Needs relating to purpose**

These three incidents were provided by two nurses: one oncology and one Macmillan nurse. Both nurses had religious/spiritual beliefs (Table 19).

## Results

	Medical	Oncology	Macmillan
Religious and/or spiritual beliefs	-	1	1
Uncertain beliefs	-	-	-
No beliefs	-	-	-

Table 19

Oncology Nurse 3 talked about a patient who kept having treatment, despite it not working. The nurse found it difficult to understand why this woman, who had very strong faith, did not feel able to ‘let go’ and stop treatment. The patient said that she just wasn’t ready yet. The situation was resolved, when the patient received a letter from a friend, and after this she was ready to die and stopped treatment. This was a very emotional experience, with both the patient and the nurse in tears:

‘She buzzed and I went in, “come and give me a hug” she said “I made a decision today. I got a letter from a very old friend and the words I wanted to hear”.’

Oncology Nurse 3: Incident 27

In the next incident, a patient was lingering on and even the husband was asking why it was taking so long. Oncology Nurse 3’s strong belief was that there is a time for everything and shared her belief with the husband that everything happens for a reason. The patient was unconscious and hardly responding, until the son came back from abroad:

‘He [*the son*] came in; she opened her eyes and said goodbye to everyone in the room and just died. And I thought, “Well, now we know”.’

Oncology Nurse 3: Incident 28

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In the last incident, Macmillan Nurse 9 (Incident 81) talked about a widowed patient who had set the goal of not dying until her youngest child had left school. Macmillan Nurse 9 found it helpful to know that the patient had some religious beliefs and went to Church. The patient initially declined the offer of a referral to the Chaplain, but later on agreed to be referred to a lay preacher, who the nurse felt that she would get on well with. The patient achieved her goal of staying alive until her youngest child had finished school, and also gained an inner peace, which the nurse believed was an effect of the contact with the lay preacher, who she had got on very well with.

### **4.5. Summary**

The medical nurses commented on a lack of privacy and on admission wards, a lack of time to get to know patients. The medical and oncology nurses felt more of a need to provide an answer than the Macmillan nurses. The oncology nurses tended to get to know their patients well and had close and friendly relationships with them. The Macmillan nurses were more prone to explore, and were helped by being able to spend the time they needed with their patients. This concludes the Results Chapter, and these findings will be discussed in Chapter 5.

## **5. Discussion**

### **5.1. Introduction**

In the previous chapter, we have looked at a lot of stories about the nurses' interactions with patients, but we now have to try and pull this together into a coherent summary. One of the study aims (Chapter 1.3) was to explore issues that influenced the nurses' responses, and I suggest that, in the context of spirituality, nurses are influenced by constantly having to negotiate the boundaries between what is appropriate in the nursing role and what is not. This is not so much a question of a specific health care intervention, which the expressions 'spiritual care' implies; it is more a question of nurses determining what is (or is not) a legitimate response to certain situations that arise during the course of nursing very sick people.

The account that emerges from this data focuses on narrative. Very frequently, this is a religious narrative, as when patients wonder whether their past actions will prevent them getting into the Christian heaven. But even where they are not expressly or formally religious, 'spiritual concerns' are about the stories patients tell, and about the link between the past, present and future, as in 'what have I done to deserve this?'

I will review the earlier material in the light of the 'negotiating role boundaries' concept, and note the principal differences between the nurses themselves. This will require me to remind the reader of some of the examples, but to keep the intrusions of examples to a minimum I will confine them to boxes in the text.

## Discussion

There were two main factors that influenced the nurses when negotiating role boundaries in religious and spiritual issues in their professional relationships with patients and their families; firstly, whether the patients' views, wishes or beliefs were legitimate or not, and secondly, what would be a legitimate response from the nurse. I will start with a discussion on the role of the nurse, and continue with the connection between what nurses judged as legitimate, or illegitimate, and what they judged to be legitimate responses in themselves, as nurses. This will be followed by a discussion on the differences between the three groups of nurses (medical, oncology and Macmillan), and end with limitations and implications for practice.

### **5.2. Negotiating role boundaries**

#### **5.2.1. The role of the registered nurse**

Registered nurses are expected to apply a holistic approach to nursing, which includes taking patients' spiritual needs into account (Nursing and Midwifery Council 2010a). The nurses saw an interconnection between physical, mental and spiritual wellbeing and recognised the importance of holism in nursing, and observed that, at times, distress in one area may increase symptoms or distress in another area, while reduced distress in one area may relieve distress or symptoms in another area (Box 2).

Considering the interactions between physical, mental and spiritual wellbeing, the addressing of spiritual and religious needs must be seen as part of the diverse nursing role, and the nurses agreed that they had a responsibility with regards to spiritual and religious issues. The definition of the characteristics of nursing has been stated as 'the purpose of nursing is (in addition) to minimise distress and suffering' and 'when death

## Discussion

is inevitable, the purpose of nursing is to maintain the best possible quality of life until its end' (RCN 2014). In palliative care the main object is to prevent and relieve suffering with the aim of improving quality of life (Doyle et al 1998: 1, WHO 2002: 84), as well as to include patients' religious or spiritual requirements (WHO 2002: 84). Many of the nurses expressed a firm belief that the role of the nurse was to provide comfort and symptom relief and, depending on the prognosis, to save or prolong life.

- 'As we fixed her physical symptoms, her spiritual health became more settled, and eventually she died peacefully.' (Medical Nurse 6)
- 'She wasn't a well lady, and she had to sort it out quickly. I'm sure that did have implications on how her symptoms were.' (Macmillan Nurse 6)
- 'Once she had sorted out some of the stuff with the lay preacher, she became much more peaceful. In those last few months she also talked about feeling an inner peace that she hadn't felt for a long time, and she had managed to, she said, make her own peace with God again.' (Macmillan Nurse 9)

Box 2 Interconnection between physical, mental and spiritual wellbeing

The nurses were thrown into conflict, with regards to their professional role (Box 3), when patients refused optimal symptom relief or when those who were not terminally ill refused life saving treatment. In these situations, there was a tension between the nurses' role to respect patients' beliefs and wishes, and their role to minimise stress and suffering. In these conflicting aspects of their roles, the nurses had to negotiate the most appropriate responses in the different situations that they experienced.

As seen in the previous chapters, there were a large variety of situations where the nurses had to negotiate the boundaries of their professional roles, and judge what would or would not be an appropriate way to respond. If asked a direct question concerning a



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religious or spiritual issue, should their answer be based on their own views or beliefs? Is it appropriate to try to volunteer, or reply with, personal views? Overall, when religious or spiritual beliefs provided comfort, these beliefs were judged to be legitimate, and when not, were judged to be illegitimate, and this had a strong influence on the nurses' responses. Similar conflicts and judgements have been found in physicians (Curlin et al 2005a, Curlin et al 2005b) and hospice nurses (Belcher and Gritffiths 2005). I will now move on to discuss this concept in more detail.

- 'You want to save those lives that can be saved. That's why we do the job that we do.' (Medical Nurse 1)
- 'It's not fair, us being angry at her, because that's not my job. You only have to help her through what she's going through. I just thought it was very difficult to watch.' (Medical Nurse 6)
- 'We just said that we couldn't help her to die, we're not here for that sort of thing; we're here to help people.' (Medical Nurse 8)
- 'That's why we are in nursing, to help, and you feel that you are letting people down if you don't.' (Oncology Nurse 8)
- 'I think we have to accept that people have a responsibility to themselves, and to make their own decisions. So I think it's our job to try and give people that control.' (Macmillan Nurse 3)
- 'Not accepting pain relief, to me as a professional, especially involved in pain management, was abhorrent.' (Macmillan Nurse 5)

Box 3 Role of the nurse

### 5.2.2. Legitimacy of patients' beliefs and decisions

#### 5.2.2.1. Legitimate

We have seen that the role of the nurse is to minimise suffering and distress, and to maintain the best possible quality of life until the end (RCN 2014). As a result, patients' religious or spiritual beliefs, wishes and activities were generally viewed positively, and

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judged to be legitimate (Box 4), when they gave comfort to patients and did not reduce life expectancy of those not terminally ill.

- ‘She had a lovely faith that really took her through things. She had a calmness about her, which obviously had come from this faith in God. If you could bottle that faith; it’s very valuable.’ (Medical Nurse 6)
- ‘She didn’t get any comfort from her faith, but it might have fulfilled some other purpose. She had a focus for her anger, somebody to be angry with. And it’s probably better to get it out.’ (Medical Nurse 6)
- ‘I’m all for religion when it does that for you (provides support and comfort).’ (Macmillan Nurse 5)

Box 4 Legitimate

### **5.2.2.2. Illegitimate**

On the other hand, beliefs that led to an increase in suffering or that would be likely to shorten the life of a patient who was not terminally ill were judged to be illegitimate (Box 5). These included situations where Jehovah’s Witnesses refused life saving blood transfusions, patients refused adequate pain relief for religious reasons and patients feared punishments from God or not going to Heaven. Although accepting that part of the nurses’ role is to respect, assess and provide spiritual care, the belief that their role is to minimise suffering and save lives was, over all, a stronger influence. In these situations many of the nurses felt justified in voicing their own beliefs/views and trying to change their patients’ minds (Box 6). All the nurses found these situations traumatic and difficult to deal with, although they all accepted that patients have a right to give or withhold consent.

## Discussion

- ‘I felt like saying “you are completely and utterly selfish [*in refusing a blood transfusion*]. Your son is devastated, and you could have done something”.’ (Medical Nurse 1)
- ‘The patient believed that she should suffer for her God. And I do find it very difficult to accept why anybody, of any religion, would think it was good to suffer pain.’ (Medical Nurse 7)
- ‘There is something wrong when she is leaving her family that she’s loved dearly, but her biggest concern is that she’s not going to get into Heaven.’ (Oncology Nurse 2)
- ‘This was her [*the patient*’s] last fight with Satan, as she went through the dying process and she had to fight the devil to get to God. I had to say “I disapprove of this, I feel very uncomfortable”.’ (Macmillan Nurse 5)

Box 5 Illegitimate, when faith not seen to give comfort or other benefits

Some nurses stated specifically that they did not feel justified in trying to change patients’ minds or voice their own views, and this tended to be situations that did not have any adverse effects on symptoms or life expectancy. In these situations the nurses felt that they should keep their own views to themselves (Box 7).

- ‘I asked the husband “have you got any influence here [*to make the patient accept a blood transfusion*]?”.’ (Medical Nurse 1)
- ‘She was having treatment, which wasn’t working, but she wanted to carry on and on. I challenged her one day and said to her, “why put yourself through this?”.’ (Oncology Nurse 3)
- ‘I asked: “why won’t you have blood?” although I knew it was because Jehovah Witnesses don’t accept blood transfusions. You have to accept other people’s beliefs, but when you know that something can be done about it.’ (Oncology Nurse 8)
- ‘The family said “she’s got to fight the devil to get to God”; she had to fight through all this distress. I had to say “I disapprove of this, I feel very uncomfortable about it”.’ (Macmillan Nurse 5)

Box 6 Justified in voicing own views and beliefs

- ‘I said “how is your daughter getting on?” and she replied “I think she is being bullied, but it’s in the hands of God”. It felt like she should have been a little bit more concerned for how her daughter was... It made me feel so angry, and at that point I thought, “don’t mention things like that again”.’ (Medical Nurse 6)
- ‘If it was me, I would want all the quality time I could possibly get with my child, but she didn’t want that, and that was awful! You had to go with what she said was right for her. It does hurt, but that’s her wish, it’s her child.’ (Oncology Nurse 2)
- ‘I just said that I was delighted with the outcome, but thinking that the remission was to do with the consultant and not God, because I am atheist.’ (Oncology Nurse 9)
- ‘I’m thinking, your God’s helping you to have people like myself and other staff to help to support you through it, but I thought “no, I’d better not say that”, because it sounds a bit patronising.’ (Macmillan Nurse 2)

Box 7 Not justified in voicing own views or beliefs

### 5.2.3. Understanding religious beliefs

The nurses’ own beliefs and understanding of different religions affected how they felt about their patients’ beliefs. A lack of understanding was an issue for nurses regardless of their personal beliefs (Box 8), and they found it easier when they shared or understood the patients’ beliefs. Just knowing that Jehovah’s Witnesses don’t accept blood transfusions did not help the nurses. Nurses cannot share the beliefs of every patient, but greater the understanding of reasoning behind these beliefs may help.

With most nurses expressing some religious or spiritual beliefs, it is not possible to draw any conclusions from the effects of nurses having or not having any religious/spiritual beliefs.

- Why somebody would do that [*refuse a life saving blood transfusion*], is just beyond me. I said to her “I don’t understand why you are doing this; it’s got nothing to do with God”.’ (Medical Nurse 1)
- ‘I didn’t understand why we were doing it. It was so bizarre to do these things, but to the man and his family it was a big religious thing. It was a situation which I did find difficult, because of my own religious convictions.’ (Medical Nurse 5)
- ‘I find it very difficult to understand why any religion would advocate that you should suffer in pain, but I have no beliefs.’ (Medical Nurse 7)
- ‘I’m the Church of Scotland, so I don’t know much about the Free Presbyterians, and it was obviously to do with her religion.’ (Oncology Nurse 2)
- ‘When it is somebody with Christian beliefs, I can probably relate to it more than I would to maybe a Muslim or something ‘cause I haven’t got a clue about what they believe and what they don’t believe.’ (Oncology Nurse 5)
- ‘Having met and mixed with a lot of people from this background, you then understand sometimes where people are coming from.’ (Macmillan Nurse 1)

Box 8 Relevance of understanding patients’ beliefs

#### **5.2.4. Supporting religious activities**

When the aim was to give comfort to patients, many of the nurses judged that it was legitimate for them to support, participate in or make suggestions of various religious or spiritual activities (Box 9). And the nurses judged this to be legitimate, regardless of their own beliefs or whether they had any understanding or not of the beliefs or religions involved.

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- ‘His friend came in and gave us these cloths and asked us to tie them around parts of the body. We took the cloth and did what he asked us to do.’ (Medical Nurse 5)
- ‘There are girls in the ward who are quite religious, so I may even put patients on to them, to have a wee prayer or something, because I think that is quite a comfort, just to share something.’ (Medical Nurse 6)
- ‘We also involved his Minister and the Chaplain in the hospital, and the patient wanted that.’ (Macmillan Nurse 1)
- ‘I prayed with that gentleman; I asked if I could pray with him’. (Macmillan Nurse 1)
- ‘The patient wanted me to read something out of the bible to him; that bit about “in my Father’s house there are many mansions”.’ (Macmillan Nurse 9)

Box 9 Nurses participating in, supporting or suggesting religious activities (examples)

### 5.2.5. Voicing personal beliefs

There was a general consensus among the nurses that imposing their own beliefs onto patients was beyond the boundaries of their roles as nurses (Box 11). Sharing beliefs, on the other hand, was judged to be legitimate, when the intention was to provide comfort to the patients or their families (Box 10); however, many of the nurses were still concerned about the boundary between sharing and imposing their own religious or spiritual beliefs (Box 11). Beliefs that the nurses did impose on patients related to the role of the nurse (RCN 2014, Doyle et al 1998: 1, WHO 2002: 84) and involved trying to persuade patients to accept treatment that they did not want (Box 6).

One nurse provided a straight answer, which was not related to giving comfort, in response to a completely unexpected and very direct question. Given more time, less stress and if she had been better prepared, this would not have been her preferred choice of response, as she was very aware that her own views would not be likely to give comfort to, or be shared by, the relative she was talking to.

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- ‘I tried to encourage them that when they die, it’s not the end of the world; there is another life after.’ (Medical Nurse 4)
- ‘I’d just say “I believe that there’s a reason for everything, even if we can’t see it at the time”.’ (Oncology Nurse 5)
- ‘We talked so far about what I believed, and that I believed in God and in an afterlife.’ (Macmillan Nurse 1)
- ‘I went on to explain what I thought; that when you die you either go to Heaven or to hell.’ (Medical Nurse 5)

Box 10 Sharing personal religious or spiritual beliefs

- ‘I just can’t put my views onto them. I just don’t feel that’s my role.’ (Medical Nurse 4)
- ‘I’ve got a strong religious faith myself, but you can’t project that onto somebody else. There’s one thing knowing what you know yourself and your faith, but you can’t really project that onto somebody else.’ (Medical Nurse 5)
- ‘You can’t push your own beliefs on them.’ (Oncology Nurse 5)
- ‘I don’t feel that it is my place to comment on the patient having found religion.’ (Oncology Nurse 9)
- ‘I am there to share my faith with them if they want that. ...but I don’t want them to feel that I am forcing anything on them.’ (Macmillan Nurse 1)

Box 11 Imposing personal beliefs was judged to be illegitimate

Some of the nurses found ways of responding without providing their own personal beliefs, even when asked direct questions, and they did this by commenting on a positive outcome, or by reflecting back to the patients’ beliefs and focusing on these, rather than their own beliefs (Box 12).

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- ‘I didn’t comment on the patient’s beliefs. I just said that I was delighted with the outcome.’ (Oncology Nurse 9)
- ‘I just said “she believed that she was going to heaven and that God was waiting for her”.’ (Macmillan Nurse 7)
- ‘I tried to provide some reassurance, that if this was her belief model, why would it let her down at the very end.’ (Macmillan Nurse 9)

Box 12 Avoiding sharing of personal beliefs

For some of the nurses there was a tension between the wish to share beliefs that would give comfort, and their professional knowledge that it would be wrong for them to impose their personal beliefs on patients or their families. This was one of the many issues that caused the nurses to feel uncertainties about their role in spiritual care.

### **5.2.6. Own limitations and/or concerns**

Nurses were, as discussed, concerned not to impose their own personal beliefs on patients. They also had a number of other concerns in relation to their roles in spiritual care (Box 13). There were concerns about getting into situations that were past their limitations and where they might not be able to handle the ensuing situation. Although some nurses expressed a wish to broach spiritual and religious issues, there were also fears of causing upset and making the situation worse.

One of the medical nurses felt that if she had known something about the patient’s and his family’s religious beliefs she wouldn’t have been so taken aback by the question put to her about eternity, but she had not even met them before the patient died. She was in charge and in the middle of a busy shift, with no time to think about how to deal with



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the situation, and as a result felt that she had not handled the situation as well as she would have liked to. Some of the nurses without any religious beliefs commented that this made it more difficult for them, and they would prefer to refer to somebody else, such as another nurse or health care professional with religious beliefs or the Chaplaincy team. The Macmillan nurses generally had easy access to support, and had the time to access that support, when facing concerns about a specific situation.

- ‘I was taken by surprise; I thought she’d say something, maybe, about her father’s medical condition, not “what is eternity?” I didn’t really know how to respond.’ (Medical Nurse 5)
- ‘Sometimes I’d really like to broach the subject of spirituality and religion, but there is always a fear in me that I would upset somebody.’ (Oncology Nurse 1)
- ‘This put me on the spot a bit, I hadn’t really thought of what if a patient comes up with this sort of thing [*that it was God’s judgement that she should suffer*] ... how do I handle this and, of course, we don’t get training for this.’ (Oncology Nurse 9)
- ‘You know your limitations. I’m not particularly religious. I can listen to people, but I can’t advise them or advocate anything, so I would pass on to somebody else.’ (Macmillan Nurse 5)
- ‘How am I going to say this in a way that is sensitive? For it to mean something, so that she can feel comforted by it. And I thought; I really don’t know how I’m going to do it.’ (Macmillan Nurse 7)

Box 13 Own limitations/lack of confidence

### 5.2.7. Summary

The nurses negotiated the boundaries for their nursing role in spiritual encounters with their patients and/or their families mostly based on the role of the nurse to minimise distress and suffering, to maintain the best quality of life until death (RCN 2014) and to prevent and relieve suffering, with the aim to improve quality of life in palliative care (Doyle et al 1998: 1, WHO 2002: 84).

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While agreeing that the role of the nurse includes a holistic approach that encompasses patients' religious and/or spiritual requirements (NMC 2010, WHO 2002: 84), when the nurses judged the legitimacy of patients' requests, wishes and beliefs, the main basis for legitimacy was whether or not they reduced suffering and provided comfort to patients and their families and/or saved lives. Based on the same principle, many of the nurses were happy to facilitate and participate in religious practices, sharing their own beliefs and making suggestions, as long as this was with the aim of reducing suffering and providing comfort or saving lives.

When the two aspects of the nursing role (to provide comfort/ reduce suffering and taking account of patients' religious or spiritual beliefs) clashed, and patients religious beliefs led to increased suffering or death, in somebody whose life could have been saved, this resulted in a conflict that caused a great deal of upset in the nurses. This was, to some degree, linked to the nurses understanding of the theology behind the beliefs, and a better understanding appeared to reduce stress and upset. There was a general agreement that imposing personal beliefs on patients and their families is wrong; however, in the situations when patients' beliefs, wishes or views were judged to be illegitimate, most of the nurses did impose their own beliefs, voiced their disagreement and tried to change patients' minds.

It may be that a holistic approach in nursing that includes religious and spiritual issues is well established, but there were uncertainties among the nurses, as seen in previous research (Kuuppelomäki 2001, Milligan 2004, Narayanasamy and Owens 2001, RCN 2011b, Swift et al 2007, Vance 2001), and an awareness of their own limitations, in

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relation to this area. In the middle of busy shifts, nurses were sometimes confronted with totally unexpected questions or requests, and needed to find an appropriate response with no time to consider the situations. Some of the nurses wanted to include spiritual issues more in their contact with patients, but were concerned that they may cause upset or that they may get into a situation that they would not be able to handle or have the time to deal with.

I will continue with a discussion of the noticeable differences between the three groups of nurse (Medical, Oncology and Macmillan), and the differences in their responses in spiritual encounters with patients.

### **5.3. Differences between the three groups of nurses**

There were some noticeable differences between the three groups of nurses, both in their working environment and in their relationships with their patients, and these differences affected and influenced the nurses in their responses. The influences of courses completed or undertaken relating to palliative, oncology and spiritual care were uncertain, and differences could be attributed to the different roles and environments that the nurses worked in, as well as their ages and length of nursing experience. I will now examine the differences in the nurses' working environments and in their relationships with their patients, followed by a discussion on the differences in responses between the three groups of nurses.

### **5.3.1. Working environments**

The nurses worked in three very different environments: medical wards, oncology ward/department and Macmillan nursing (hospital and community). The medical nurses were based in an environment where the focus was on treating medical/physical problems and, if possible, provide a cure, and worked with a less well defined patient group than the oncology and Macmillan nurses. The oncology nurses and the Macmillan nurses had chosen, specifically, to work with patients suffering from potentially life-limiting conditions, who were, in many instances, receiving palliative care for cancer, with the main focus on symptom relief and support. The oncology and Macmillan nurses were also more likely than the medical nurses to have completed courses relevant to this area of nursing. Both the oncology and the Macmillan nurses talked about the benefits of working in supportive teams, where they were able to discuss difficult situations with colleagues, receive support and ask for advice. They also had direct access to religious and spiritual back-up, with the Maggie's Centre and through close links with the Chaplaincy department. This kind of support and back-up was not mentioned by the medical nurses.

Lack of time and space was a problem for both medical and oncology nurses, with concerns about starting something that they might not be able to finish, being too busy to be able to spend the time that they felt patients may need and, for some of the medical nurses, patients dying or moving on to other wards very soon after admission (Box 14).

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- ‘Quite often we don’t have the same opportunities, because being an admission ward, patients have moved on, or they come in at the end stage of their illness and they die on our ward.’ (Medical Nurse 1)
- ‘I knew that we were in a situation on the ward that was very busy, so that we were not going to have the time.’ (Oncology Nurse 1)

Box 14 Lack of time and space

The Macmillan nurses were much helped by their role, which enabled them to spend time, as required, with patients, and also by having flexibility with their time and being able to go back to patients on a regular basis. The specialist palliative care team, the Macmillan services and the Maggie’s centre were utilised extensively by nurses caring for patients with cancer.

### **5.3.2. Relationships with patients**

There were some noticeable differences between the medical, oncology and Macmillan nurses in their relationships with patients, with most of the oncology nurses describing an emotional and personal involvement with patients that was not evident in interviews with the medical or Macmillan nurses. Unlike the Macmillan nurses, the oncology and medical nurses provided hands-on nursing care 24 hours a day, and some of the nurses commented that nights were a time when patients might be more anxious, and more likely to be open with their feelings. The oncology nurses often got to know patients and their families very well, and formed close and personal relationships with them during prolonged and recurrent admissions. They worked physically close to the patients, providing round the clock nursing care and carrying out various procedures, which appeared to result in the formation of more personal relationships, where the nurses chatted to patients, sharing parts of their own lives, as well as sharing emotions

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with their patients (Box 15).

- ‘We were able to attend his funeral. Kind of closure for ourselves. It is only if I have been very involved with a patient and the relatives that I would want to go to the funeral. You cannot be a robot in this kind of situation and we do get very involved.’ (Oncology Nurse 1)
- ‘We had tears together, but we also had a giggle together. We become so attached to our patients.’ (Oncology Nurse 2)
- ‘She said “come and give me a hug”. I was in tears myself, with her. It was so emotional.’ (Oncology Nurse 3)
- ‘The deaths are all expected, but it doesn’t make it any easier ... We often know the families very well, sometimes we look after these patients for years.’ (Oncology Nurse 4)
- ‘He was a lovely man and we had built up a good rapport. He’d been with us for a while, and he didn’t want to go anywhere else, not even to the Hospice or home.’ (Oncology Nurse 8).

Box 15 Oncology nurses’ more emotional relationships with patients

The medical nurses, on the other hand, often met patients briefly and knew little about them. On busy medical wards, time may be very limited and patients might die or be transferred to other areas soon after admission; however, some medical nurses did get to know patients well through longer and/or recurrent admissions. They provided nursing care for patients throughout the 24 hours, but were much less likely than the Macmillan and oncology nurses to be able to go back to their patients or their relatives, due to the fast turnover, which also resulted in the nurses having less time to build up relationships with patients. Some of the medical nurses commented on a lack of privacy in more sensitive communications with patients, as conversations could often be overheard by others. Further, patients may be very acutely ill and require immediate, urgent medical care. Responding to religious or spiritual concerns in this environment, when not

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knowing the patients or their families, or anything about their possible beliefs, could be more difficult.

The Macmillan nurses ‘dipped in’ for, at times, very intensive visits, but did not provide ‘hands-on’, round the clock, nursing care. They were able to arrange to visit patients, go back and spend time with them, as required, allowing them to build strong and trusting relationships over a longer period of time. The Macmillan nurses, as well as the medical nurses, were caring and supportive in emotional situations, but did not express the more emotional involvement of the oncology nurses.

### **5.3.3. Responses**

The Macmillan nurses were more likely than the other nurses to explore, look beyond the surface and try to establish what the patient was actually asking and why (Box 16). One particular Macmillan nurse went through a very structured ‘responding pathway’, with discussions with patients, exploration and clarifications. The medical nurses were more likely than the Macmillan and oncology nurses to experience a sense of responsibility for providing a direct answer or a resolution (Box 16).

**The Macmillan nurses tended to explore further:**

- ‘Sometimes people want facts, sometimes they want to share feelings, and it’s just to suss out what they want and how to take it.’ (Macmillan Nurse 2)
- ‘I’d just let them speak through what their own thoughts and fears are. Find out what their greatest fear is.’ (Macmillan Nurse 5)
- ‘Clarifying what the patient is actually asking, what issues are of particular concern.’ (Macmillan Nurse 6)

**The Medical nurses often felt a responsibility for providing an answer or a resolution:**

- ‘It’s just trying to reassure her, that “no, you haven’t done anything to deserve this”.’ (Medical Nurse 2)
- ‘I just went on to explain to her about what I thought.’ (Medical Nurse 5)
- ‘We just said that we couldn’t help her to die, we’re not here for that sort of thing; we’re here to help people.’ (Medical Nurse 8)

Box 16 Differences in responses between the three groups of nurses

## 5.4. Limitations

This study was limited to medical and oncology nurses from one regional hospital in Scotland, and Macmillan nurses from one region of Scotland, and results may not be transferable to nurses from other areas. The response rates and rates of consent to attend for interview were low, which resulted in those who attended being self selected.

The nurses who consented to attend for interview were more likely than the non-consenting nurses to have religious or spiritual beliefs, although the lack of consistency between information provided in the questionnaires compared to that provided in the interviews, with regards to religious faith, means that little is known about the religious or spiritual beliefs of those nurses who were not interviewed. Only one of the interviewed nurses stated a complete lack of any religious or spiritual beliefs, both in



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the questionnaire and in the interview, while most of the nurses who did not have any definite religious faith or belonging, expressed uncertainties or clearly spiritual beliefs compatible with the operational definition used in this study (Chapter 2.3) in their interviews. Therefore, it is not possible to come to any conclusions with regards to differences between those who did, and those who did not, have any religious or spiritual beliefs.

The options of 'yes', 'no', 'uncertain' in the questionnaire, to the question 'Do you regard yourself as having any religious faith', did not provide any meaningful information with regards to the nurses' actual religious faith.

Participants selected their own incidents, which may have created biases. Although they were talking about what they did in real situations, rather than what they would do in a hypothetical situation, their recollections and accounts of the situations may not have been accurate.

### **5.5. Implications for practice**

Although there is an expectation of nurses, as discussed in Chapter 1.2.5, to provide what has been termed 'spiritual care', my original idea for this study was based on practical issues that came directly from patients (Chapter 1.1), such as the patient who said that he wasn't ready to die yet, as he needed to do more good things to make up for all the bad that he had done. Chapter 2.2 showed the difficulties in trying to define

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spirituality and the different views on its role in health care. The nurses in my study described real life encounters with patients and expressed many concerns in responding to their patients; however, issues relating to the definition of spirituality did not feature as a concern to them. The nurses' own needs, in caring for their patients, related more to practical issues, rather than vocabulary or academia, as seen in previous studies (Gallison et al 2006, Kuuppelomäki 2001, Milligan 2004, Narayanasamy and Owens 2001, Ronaldson et al 2012, Ross 1994, Touhy et al 2005, Vance 2001). My conclusion is that any issues that have an impact on patients' health, or their care, must be taken into account by nurses, while providing labels for these issues may be of limited practical benefit.

The oncology and Macmillan nurses usually had easy access to support and advice, and many had attended specialist courses in oncology and palliative care. As identified in other studies (Milligan 2004, Vance 2001), a lack of training and education was a potential influence for some nurses, with the medical nurses less likely to have attended specialist courses. Some of the medical nurses commented on being able to refer to the Macmillan nurses, but gave no indication of having access to support and advice from peers or others, and a lack of support from managers and colleagues has previously been identified as a barrier (Milligan 2004). The results of my study indicate that medical nurses caring for patients with life limiting conditions would benefit from having easier access to specialist support and advice.

A good background understanding of the religions involved was helpful, while a lack of understanding sometimes caused considerable upset in the nurses. There was a tension

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between respecting and supporting patients' religious and/or spiritual beliefs and patients' rights to withhold consent. In this study, providing comfort, relieving suffering and saving lives that could be saved, took priority over patients' religious and/or spiritual beliefs when nurses negotiated the boundaries of their nursing role. This suggests that nurses would benefit from a better background understanding of the religions involved, which links up with the need for training in this area (Milligan 2004, Vance 2001). Access to a confidential forum to discuss these issues may also be of benefit.

The medical nurses were prone to feel responsible for providing answers and solving problems. The Macmillan nurses' approach would have relieved them of this burden of responsibility, and enabled them to use listening and exploration (*what is the patient actually asking, and why are they asking this?*), which would have made their work easier. Neither medical nor oncology nurses will have the same opportunities as Macmillan nurses to visit their patients and spend time with them, and it would be unrealistic to expect all nurses to acquire specialist training in palliative care. However, all nurses could benefit from some of the approaches used by the Macmillan nurses.

### **5.6 Concluding comments**

There is a need for nurses to be better prepared for their role in, so called, spiritual care, and I will end with a brief summary of conclusions of the implications for nursing practice in relation to spiritual care drawn from this study.

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Many of the skills used, particularly by the Macmillan nurses, could be used by other nurses:

- Contact with patients may be more rewarding and effective if not feeling the need to provide an answer or resolution.
- Hope is important; if one hope is taken away, try to give another.
- Encourage patients to break the situation down into more manageable 'portions' and encourage short-term goals.
- Patients with terminal diagnoses don't necessarily want to talk about this at every health care encounter:
  - They may want to talk about things that they find interesting and enjoyable.
  - 'Denial against the background knowledge' can help patients to make the most of the time that they have left.

There was tension between the role of the nurse to relieve suffering and prolong life, when possible, and the need to respect and support patients' religious and/or spiritual beliefs:

- This needs to be recognised as a nursing dilemma, and provides scope for further research.
- A better understanding of different religious/spiritual beliefs may improve nurses' ability to deal with this dilemma.
- A confidential forum where nurses can discuss sensitive and difficult issues that they encounter in their work could to increase their confidence in religious/spiritual encounters with patients.

Nurses need not only the training, preparation and support for their role in spiritual care, but also the appropriate facilities:

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- Environmental factors, such as a lack of time, suitable space and privacy, were experienced as barriers particularly by the medical nurses. This is not a new finding (see Chapter 2.5), but needs to be taken seriously by those bodies that expect nurses to provide this care.

Nurses who provided hands-on nursing care, day and night, over longer and/or repeated admissions, appeared to form more personal relationships with their patients:

- This was an interesting finding that offers scope for further research. I believe that these differences should be recognised and utilised, as different approaches may be more or less appropriate, depending on the nature of nurse/patient relationship.

As discussed in Chapter 2.2, patients and their relatives may have different views to health care professionals and academics on spirituality, and its role in health care:

- Patients' and their relatives' views should not be overlooked, and this area offers scope for further research (Chapter 2.2).

The background to this study was the needs of patients with life limiting conditions other than cancer, such as heart failure, for palliative care, including the addressing of any spiritual needs. The aims were to explore the responses, and issues that influenced these responses, of three groups of nurses (medical, oncology and Macmillan) in encounters with patients that could be considered spiritual. If medical nurses are to provide holistic care, including spiritual care, they need the support, skills, confidence, time, space and privacy to enable them to do this and would benefit from having easier access to specialist support and advice.

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PARTICIPANT INFORMATION SHEET

Study Title: Nurses' responses in spiritual encounters with patients

DEPARTMENT OF  
**NURSING AND MIDWIFERY**

University of Stirling

Highland Campus, Old Perth Road

Inverness IV2 3EG, Scotland

**Basic Invitation:** My name is Ing-Marie Logie and I work at Raigmore Hospital as a registered nurse. I am writing to you to ask you to consider taking part in a research project that I am carrying out as part of a masters degree by research.

**Purpose of the study:** The aim of this study is to identify how nurses manage issues relating to the needs of dying or seriously ill patients in relation to:

- finding meaning, purpose and fulfilment in life, suffering and death
- their need for hope and will to live
- their need for belief and faith in self, others and/or God.

**Why have I been chosen?** Because you work with patients who may be seriously ill or dying, and will be in frequent contact with patients suffering from cancer or heart failure.

**Do I have to take part:** You are entirely free to choose whether or not you wish to take part in this study, and if you do choose to take part you are entirely free to change your mind at any time.

**What happens if I decide not to take part?** You will not be disadvantaged in any way if you don't wish to take part.

**What does participating involve, and what do I have to do?** Participating in this study involves the completion of the enclosed questionnaire, which asks for basic information about your training, nursing experience, post-registration courses and demographic information. Following the questionnaire – and if you indicate that you are willing for this to happen - you may be asked to take part in an interview. The interview will involve discussing encounters that you have had with patients, relating to the purpose of the study, as above. I will ask you not to use patients' real names, in order to maintain patient confidentiality. I would expect an interview to last no longer than an hour, at most. If you decide to take part, the interview will be arranged during working hours at a time suitable to yourself and to your ward/department. The nurse manager in your ward/department has agreed to nurses completing the questionnaire and attending the interviews during working hours. Interviews will be audiotaped, subject to your agreement.

**What are the possible benefits of taking part?** You may find it interesting and helpful to discuss potentially difficult encounters that you have had with patients.

**What will happen to the results of the project?** The results of the study will be included in the thesis that I will write as part of my course. I also aim to publish the results in an appropriate professional journal, and possibly present at a meeting or conference, should that be possible. Any identifiable details will be changed in the writing-up, in order to maintain confidentiality, and in order to protect you, other participating nurses, patients, and other people who may be mentioned during the interviews.

**Who is organizing the research?** I am organising the research, supervised by my course tutor, from the University of Stirling.

**Who has reviewed this study?** The University of Stirling Departmental Research Ethics Committee for Nursing and Midwifery and Highland Local Research Ethics Committee.

If you are happy to participate in this project, I should be grateful if you would sign the enclosed consent form, complete the questionnaire, and return them both to me asap (if possible by 18 December 2006) in the addressed envelope provided. I should appreciate it if you would complete and return the questionnaire, even if not willing to take part in the interviewing part of the project.

Please contact me, as below, if you would like any further information. If you would like to discuss the any aspect of the study, with an independent healthcare professional, Tracy McGlynn, clinical psychologist, oncology, based in the Maggie Centre at Raigmore Hospital, and Iain MacRitchie, hospital chaplain at Raigmore Hospital, can also be contacted, as below.

Ing-Marie Logie  
Cardiovascular Research Nurse  
Highland Heartbeat Centre  
Raigmore Hospital  
Old Perth Road, Inverness, IV2 3 UJ  
Work Tel: 01463 705 944 (ext 5944 or bleep 7017)  
Home Tel: 01463 791 594

Tracy McGlynn  
Clinical Psychologist Oncology  
The Maggie Centre  
Raigmore Hospital  
Old Perth Road  
Inverness, IV2 3 UJ  
Tel: 01463 706 306

Iain MacRitchie  
Hospital Chaplain  
The Chaplaincy Office  
Raigmore Hospital  
Old Perth Road  
Inverness, IV2 3 UJ  
Tel: 01463 704 467



**CONSENT FORM**

**Study Title: Nurses responses in spiritual encounters with patients**

Please tick, as appropriate:

I have read the participant information leaflet and had the opportunity to ask any questions relating to this study.

I understand that my participation in this study is entirely voluntary and that I will not be disadvantaged in any way should I choose not to take part in this study or an aspect of it.

I understand that I may change my mind at any time, without giving a reason and that I will not be disadvantaged in any way for doing so.

I understand that information that I provide will be treated in confidence and that neither my name, nor any identifying information will be disclosed.

I understand that details that could potentially identify patients, their relatives or any member of staff will be changed in the writing-up.

I understand that I can contact Tracy McGlynn, Clinical Psychologist for the Oncology Department, or Iain MacRitchie, Hospital Chaplain at Raigmore Hospital (details provided in the Participant Information Sheet), for advice or support concerning any aspect of my involvement in this study.

I am happy to complete the enclosed questionnaire. I also consent to being contacted directly by the researcher (Ing-Marie Logie) and to attend an audiotaped interview.

I consent for non-identifying data to be stored on a computer and for transcripts of the recorded interview to be kept in a safe area for the duration of the study.

.....	.....	
Name of Participant	Signature of Participant	Date

.....	.....	
Name of Researcher	Signature of Researcher	Date

QUESTIONNAIRE



UNIVERSITY OF STIRLING

Study Title: Nurses responses in spiritual encounters with patients

DEPARTMENT OF NURSING AND MIDWIFERY

University of Stirling

Highland Campus, Old Perth Road

Inverness IV2 3EG Scotland

Age:

- Less than 30 years old
30 - 39 years old
40 - 49 years old
50 - 59 years old

- 60 years old or over

Sex:

- Male Female

Current ward/department:

- Macmillan Suite (Oncology) Ward 6A (Medical)
Ward 1A (Oncology) Ward 7C (Medical)
Ward 6C (Medical) Ward 11 (Medical)

Please indicate any academic qualifications that you hold:

- Certificate Degree
Diploma Post-graduate

Please give brief details: .....

Please indicate any courses that you have completed, relating to any of the following issues:

- Palliative care Oncology
Heart Failure Spirituality

Please give brief details: .....

Please indicate any courses that you are currently undertaking, relating to any of the following issues:

- Palliative care Oncology
Heart Failure Spirituality

Please give brief details: .....

Participant Code .....

Appendix III, Questionnaire, Version 1, 16 May 2005

**Do you regard yourself as having any religious faith?**

Yes                                      No                                      Uncertain

**Have you worked in your current speciality, oncology or medical nursing, for one year or more (not necessarily in your current post)?**

Yes                                      No

**How many years/months nursing experience do you have, since qualifying?**

..... Years    ..... Months

**What is your current grade?**

- C
- D
- E
- F
- G
- H

**Please tick the box, and enter your name and telephone number, if willing to take part in the interview phase of the project (see information sheet)**

Yes, I am willing to take part in the interview phase of the project

No, I am not willing to take part in the interview phase of the project

**First name** .....                                      **Surname** .....

**Telephone number** .....

Thank you for completing this questionnaire, please return together with the consent form in the enclosed stamped, addressed envelope.





## PARTICIPANT PREPARATION SHEET

### **Study Title: Nurses responses in spiritual encounters with patients**

I would like you to think of a particular situation that has arisen in the last couple of years and with a patient who is, potentially, seriously ill or dying. Here is a list of the kinds of situations I have in mind:

- A situation when a patient asked: “Why me?” or “What have I done to deserve this?”
- A time when you felt that a patient had lost their strong belief, confidence or trust (faith) in themselves, another person or in God
- When you tried to give a patient hope - for something to happen, or not to happen (for example a cure, symptom relief, dying peacefully)
- When a patient asked: “What is the point of it all?”
- A situation when a patient talked about what happens after death
- A time when you referred a patient to a chaplain or minister
- When a patient expressed feelings of despair (hopelessness)
- A situation when a patient expressed feelings of hopelessness or appeared to give up hope - for something to happen, or not to happen (for example a cure, symptom relief, dying peacefully)
- When a patient talked to you about faith (a strong belief, confidence or trust in somebody or something) or religion
- A situation when you found it difficult to care for a patient due to his/her religion

There may be only one situation you can think of that matches any of these descriptions, or there may be two or three. Between now and the interview, it would be helpful if you could jot down a few very brief notes, just to remind yourself of the circumstances in each case, so that you can tell me about it when we meet. Please remember not to use patients’ real names when making your notes, in order to maintain patient confidentiality.

Some of these questions could arise when “there is nothing more to do” (to improve prognosis) for patients. While I am allowing 45 minutes to an hour for interviews, it doesn’t *have* to take that long. You may think of a situation, but feel that there isn’t all that much to say about it and that is fine.

Participant Code .....

Appendix IV, Participant Preparation Sheet,



## **INTERVIEW SCHEDULE**

DEPARTMENT OF  
**NURSING AND MIDWIFERY**

University of Stirling  
Highland Campus, Old Perth Road  
Inverness IV2 3FG Scotland

### **Study Title: Nurses responses in spiritual encounters with patients**

Welcome and thanks for attending.

Informed consent confirmed.

Remind participant of confidentiality.

Confirm participant received trigger cues, to prepare for interview.

Tape-recording - remind participant and confirm consent.

Remind participant not use patients' real names.

May scribble down some notes while talking – mention to participant.

Tell me if you would like me to stop the recording.

- What happened?
  - What did the patient do or say?
  - How did you respond/What did you do? Address yourself, defer, refer, ignore?
  - Where any other people, including staff, involved and if so what did they do or say?
- How did those involved feel?
  - How do you think the patient felt?
  - How did you feel about the situation?
  - How do you think others involved felt about the situation?
- Why did you responded the way you did?
  - What influenced your response and actions?
  - Who, if anybody, did you talk to about this situation?
  - How do you feel about the situation now?
- What happened afterwards?
  - Was there any change in the situation?
  - Did anyone comment on it later?
  - Do you think the matter was resolved?
- Could you have managed the situation differently?
  - How?
  - What would have made a difference to how you responded?
  - Would you do anything differently if this happened again?
- Do you have any faith/religious beliefs?
- Are you aware of spirituality in your own life?
  - In what sense, and with what effects?
  - How is this relevant to you?
- Have your views on these matters been influenced by your experiences as a nurse?

Thanks for taking part in this study.



**PARTICIPANT SUPPORT INFORMATION**

DEPARTMENT OF  
**NURSING AND MIDWIFERY**

**Study Title: Nurses responses in spiritual encounters  
with patients**

University of Stirling  
Highland Campus, Old Perth Road  
Inverness IV2 3FG Scotland

**INDEPENDENT ADVISORS FOR PROJECT**

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**OTHER SUPPORT**

ICAS – Employee Support Helpline telephone number (0800 138 4389)

RCN counselling service, telephone number (0845 769 7064).

Samaritans (local number 01463 713456, national number 24 hours/day, 7 days/week  
08457 90 90 90)



2005

Address

Dear

**Re: Study Title “Nurses responses in spiritual encounters with patients**

Thank you very much for returning your completed questionnaire. I am writing to invite you to take part in the interview, mentioned in the information letter (copy enclosed, with my contact details) that you received with the questionnaire. I have also enclosed a preparation sheet for you to read, to help you think of a relevant situation that you would be happy to talk to me about.

I will contact you within the next couple of week to arrange a time, within your working hours, when we can meet for the interview that I expect will last up to 45 minutes, if you are still happy to take part in this study.

Yours sincerely

Ing-Marie Logie (Mrs)