THE RIGHT TO END-OF-LIFE SPIRITUAL CARE

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Abstract

Spiritual care has been part of end-of-life care since the beginning of the modern hospice movement. It is a core component of palliative care as specified by the World Health Organization, and both patients and their relatives consider spirituality to be an important part of end-of-life care. Spiritual care can help patients cope better with their illness and help them achieve a sense of well-being whilst improving quality of life. The understanding of what this means, however, varies considerably among different patients, resulting in a broad range of expectations. That is why healthcare providers need to assess the patient's particular needs so as to offer holistic patient-centred care. Nevertheless, spiritual care is still finding its place as a practice in healthcare. Standards of practice for spiritual care are still lacking and it is still debatable who should provide such care. Healthcare providers face various challenges when it comes to providing spiritual care. Limited training and education are considered the primary barrier to spiritual care provision. These barriers can lead to an infrequent use of spiritual care at the end of life, which can result in the presence of unmet spiritual needs. When patients' spiritual needs are not appropriately addressed, spiritual distress can occur, which can negatively influence health outcomes. The purpose of this study is to examine the legal and ethical issues involved in viewing patients as having a right to end-of-life spiritual care. This study reviews empirical evidence to examine some of the ethical issues involved in integrating spiritual care in end-of-life care. It discusses the patients' right to spiritual care from two perspectives. The first views spirituality as a dimension of health and well-being; therefore, patients can be considered to have a right to spiritual well-being as a result of their right to the highest attainable standard of health and wellbeing. The second views spiritual care as a core component of palliative care; therefore, patients can be considered to have a right to spiritual care as part of their right to receive palliative care. This study also offers practical implications on how to safeguard the patient's right to spiritual care at the end of life. It also highlights the need for bioethics to focus more on these spiritual issues as an attempt to solve the ethical dilemma related to the pivotal question: what is good care for the dying patient? Neglecting patients' spiritual dimension of care should be considered a bioethical issue, especially

when one considers the impact this may have on health outcomes and the influence it might have on the patients' satisfaction with care. Ethical and legal frameworks regarding implementation of spiritual care in Maltese healthcare settings are also considered.

Dedication

To my friend Valerie, whose fight against cancer inspired me to take on this thesis topic.

To my beloved son whose life was cut short, far too soon.

To my beautiful family, who supported me and offered unconditional love throughout my work on this thesis.

To all health care providers for their hard work, dedication and compassion.

To all those patients and their relatives who are currently experiencing a life-threatening illness and going through a difficult time in their lives.

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List of Abbreviations

SC	Spiritual Care
HCPs	Health Care Providers
WHO	World Health Organisation
AAMC	Association of American Medical Colleges
MDT	Multidisciplinary Team
JCAHO	Joint Commission on Accreditation of Healthcare Organizations
US	United States
UK	United Kingdom
UDHR	Universal Declaration on Human Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICN	International Council of Nurses
SAMOC	Sir Anthony Mamo Oncology Hospital
MDH	Mater Dei Hospital
CPR	Cardiopulmonary Resuscitation

Introduction

The dying process is usually considered a normal part of life for everyone. It is during this part of their life that people start to reflect more on the spiritual dimension and therefore their spiritual needs are more likely to emerge. In fact, evidence shows that spiritual needs and concerns are most prevalent during times of crisis and suffering.[1] When faced with a life-threatening illness, patients may experience various spiritual needs with the most frequent one being a search for meaning and purpose in life.[2] According to Clark, "caring for the patients' spiritual needs can be considered as a component of overall health care quality."[3] If spiritual needs are not addressed, patients can experience spiritual distress, which can have negative influences on the patients' health outcomes. In fact, strong evidence suggests that, when appropriate, spiritual care (SC) will help patients to meet their spiritual needs and this is linked to better health outcomes.[4]

As a result, policy-makers have started to focus more on the importance of SC and healthcare systems have started to give more attention to patients' spiritual needs. Nevertheless, at present, the World Health Organisation's (WHO) definition of health does not include the spiritual dimension. The WHO defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."[5] There is, however, an increasing need for the spiritual dimension to be incorporated in the WHO definition of health, so that spirituality can be considered part of health and not only something that can influence health outcomes.[6] In 1984, the

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1 Michelle J. Pearce *et al*., "Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients," *Supportive Care in Cancer* 20, no. 10 (2011): 2269-2276.

2 Kevin J. Flannelly, "The Relative Prevalence of Various Spiritual Needs," *Health and Social Care Chaplaincy* 9, no. 2 (2006): 25-30.

3 Paul Alexander Clark, Maxwell Drain and Mary P. Malone, "Addressing Patients' Emotional and Spiritual Needs," *Joint Commission Journal on Quality and Safety* 29, no. 12 (2004): 659-670.

4 David A. Lichter, "Studies show spiritual care linked to better health outcomes," *Health Progress* 94, no. 2 (2013): 62-66.

5 International Health Conference, "Constitution of the World Health Organisation" (2005), accessed October 5, 2018, http://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf.

6 James S. Larson, "The World Health Organization's definition of health: Social versus spiritual health," *Social Indicators Research* 38, no. 2 (1996): 181-192.

World Health Assembly accepted a resolution which included spirituality as a constituent of the WHO Member States' strategies for health; however, the WHO's health definition did not change.[7] In 1998, the WHO Regional Office for the Eastern Mediterranean Region proposed the inclusion of spirituality in the WHO's definition of health.[8] The Executive Board of the WHO also adopted a resolution suggesting that the WHO define health as "a dynamic state of complete physical, mental, spiritual and social well-being and not merely the absence of disease or infirmity."[9] The proposal to add the spiritual dimension to the health definition was, however, not taken up. In the end, no consensus was achieved because some of the executive board members believed that health "should represent the minimum standards to be met by all countries around the world."[10]

Nevertheless, in 1999 the Association of American Medical Colleges (AAMC) stated that "health is not just absence of disease, but a state of well-being that includes a sense that life has purpose and meaning."[11] In the same document the AAMC stated that "spirituality is recognized as a factor that contributes to health in many persons", especially in the context of end-of-life situations. Apart from this, many health care textbooks and articles started to include spirituality as one dimension of holistic care and well-being. Thus, when considering patients' right to the "highest attainable standard of health conducive to living life with dignity" one needs to also consider the effect of spirituality on the health and well-being of the patient.[12] National and international human rights law started to recognise the importance of the spiritual

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7 World Health Organization, "The spiritual dimension in the global strategy for health for all by the year 2000," (1984), accessed January 25, 2019, http://www.who.int/iris/handle/10665/160950.

8 Masako Nagase, "Does a Multi-Dimensional Concept of Health Include Spirituality? Analysis of Japan Health Science Council's Discussions on WHO's 'Definition of Health' (1998)," *International Journal of Applied Sociology* 2, no. 6 (2012): 71-77.

9 World Health Organisation, "Executive Board 101st Session, Resolutions and Decisions," (1998), accessed March 22, 2019, http://www.who.int/iris/handle/10665/79503.

10 Masako Nagase, "Does a Multi-Dimensional Concept of Health Include Spirituality?" 71-77.

11 Association of American Medical Colleges, "Report lll, Contemporary issues in Medicine: Communication in Medicine," (1999), accessed March 23, 2019, https://smhs.gwu.edu/gwish/sites/gwish/files/1999_MSOP_III_TF_Only.pdf.

12 Office of the High Commissioner of Human Rights, "CESR General Comment No.14: The Right to the Highest Attainable Standard of Health (Art. 12)," (2000), accessed February 17, 2019, https://www.ohchr.org/Documents/Issues/Women/WRGS/Health/GC14.pdf.

dimension of care especially when it comes to palliative care. The WHO emphasises the need for assessing and treating spiritual issues as an integral part of palliative care and, as a result, patients can be considered to have a right to SC as part of their right to palliative care.

Studies show that the majority of patients consider SC to be an important aspect of their care and recognise the need for healthcare providers (HCPs) to address their spiritual needs.[13] Studies, however, also show that many patients at the end of life have unmet spiritual needs.[14] This shows that patients' expectations and preferences are not always at the focus of end-of-life care, and this may affect the patients' satisfaction with care. Implementation of SC as part of end-of-life care faces many challenges and HCPs are experiencing a number of barriers to SC delivery. Although many patients consider the hospital chaplain as being responsible for addressing patients' spiritual needs, studies show that patients are moving away from institutional religion and tend to request SC from various members of the multidisciplinary team (MDT).[15] This, together with the inadequate number of available chaplains, means that there is a general need for all HCPs to be adequately trained and educated in addressing patients' spiritual needs. HCPs can play an important role in helping patients achieve spiritual well-being which can contribute to positive health outcomes.[16]

HCPs working in palliative care settings are increasingly acknowledging the importance of using holistic patient-centred care as part of their clinical practice. Buta and colleagues refer to the fundamental principle in bioethics, that the patient is to be considered as a whole person.[17] Health care systems need to take into account the three dimensions of the human being: the body, the mind and the spirit. It is in this context

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13 Judith Hills *et al*., "Spirituality and Distress in Palliative Care Consultations," *Journal of Palliative Medicine* 8, no. 4 (2005): 782-788.

14 Tracy A. Balboni *et al*., "Religiousness and spiritual support among advanced cancer patients and associations with end of life treatment preferences," *Journal of Clinical Oncology* 25, no. 5 (2007): 555-560.

15 Arndt Büssing *et al.,* "Are Spirituality and Religiosity Resources for Patients with Chronic Pain Conditions?" *Pain Medicine* 10, no. 2 (2009): 327-339.

16 Hung-Ru Lin and Susan Bauer-Wu, "Psycho-spiritual well-being in patients with advanced cancer: An integrative review of the literature," *Journal of Advanced Nursing* 44, no. 1 (2003): 69-80.

17 Mircea Gelu Buta, Pavel Chirilă and Adina Rebeleanu, "Bioethics and the identity of the human person," *Romanian Journal of Bioethics* 8, no. 3 (2010): 129-135.

that HCPs can understand the spiritual value of suffering and care for the patient as a whole person. Ignoring the spiritual dimension of care can have negative effects on physical and mental health of patients.[18] For this reason, lack of SC at the end-of-life need to be recognised as a bioethical issue which can have an influence on the overall health of patients. In fact, the *Universal Declaration on Bioethics and Human Rights* (2006) mentions spirituality as one of the dimensions of a person's identity and indicates the need to promote health in all aspects, including the spiritual dimension. The Declaration also emphasises that this needs to be recognised as a human right with the patient treated as a whole person.[19]

SC can help patients discover what they most value about life and prepare them to confront issues such as advanced directives and end-of-life decision making. According to Gula, patients' spirituality "will influence any weighing of benefits and burdens that lead to a moral judgment about treatment."[20] This can have an influence on the patients' choice on end-of-life care decisions, which can range from aggressive end-of-life care to palliative or hospice care. Despite the fact that one important aspect in bioethics is the ethical consideration of policies and practices involved in health care delivery and that spirituality has become an integral aspect of all healthcare practices, the connection between spirituality and bioethics is still not given enough attention.[21] Bioethics can provide HCPs with an increased awareness of ethical and legal frameworks, so as to improve end-of-life care and allows HCPs to understand all the patients' values which can influence medical decisions. Bioethics needs to also emphasise the need for HCPs to provide the most appropriate care, so as to ensure all patients' rights are being safeguarded.[22]

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18 Francesco Chirico, "Spiritual well-being in the 21st century: It's time to review the current WHO's health definition?" *Journal of Health and Social Sciences* 1, no. 1 (2016): 11-16.

19 UNESCO, *Universal Declaration on Bioethics and Human Rights* (Paris, 2006).

20 Richard M. Gula, "Spirituality and Ethics in Healthcare," *Health Progress* 81, no. 4 (2000): 17-19.

21 John Hardwing, "Spiritual Issues at the End of Life: A Call for Discussion," *The Hastings Centre Report* 30, no. 2 (2000): 28-30.

22 The Hastings Centre, "Hastings Centre Calls on Health Care Professionals and Organizations to Meet Standards for Good Care Near the End of Life," (2013), accessed March 18, 2019, https://medicalxpress.com/pdf287148911.pdf.

Personal Experience

Spirituality is considered a complex, ambiguous and subjective concept, therefore it is quite difficult for HCPs to agree on one definition of spirituality. The author of this study, however believes that although literature portrays a multifaceted use of the term, all spirituality definitions carry certain similar denominators. Having analysed various definitions of spirituality, it seems that spirituality is considered a universal concept which is based on intrinsic human dignity, thus it is considered to be present in all human beings. It involves a dynamic process, which means that spirituality can change according to life circumstances. Spirituality is usually considered to involve a search for meaning, purpose, hope and inner peace in life, and involves both existential and religious issues. It involves transcendence, an experience of moving beyond the physical level by connecting to oneself, others, nature or the environment, and/or the sacred. Kourie defines spirituality as the "raison-d'être of human existence" believing that spirituality is at the core of human existence and that it relates to the essence of every human being.[23]

Evidence shows that experiences of HCPs with spiritual distress can result in better understanding of the spiritual dimension of care, promoting SC in their practice.[24] Two important events in the present author's life bolstered this claim. Working as a healthcare profession and living a very hectic life the author suddenly found herself as a patient, in a critical condition and needing seven weeks of hospitalization. The second experience is the death of her son a few hours after his birth. The most striking thing from both these experiences, as well as her experience as a HCP, is the limited availability of SC services to both the patients and their relatives, during difficult times such as these.

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[23] Celia Kourie, "The 'turn' to spirituality," *Acta Theologica Supplement 8* 27, no. 2 (2007): 19 - 40.

[24] Helga Martins and Silvia Caldeira, "Spiritual Distress in Cancer Patients: A Synthesis of Qualitative Studies," *Religions* 9, no. 10 (2018): 285; Christina M. Puchalski, "Spirituality and the Care of Patients at the End-of-Life: An Essential Component of Care," *Journal of Death and Dying* 56, no.1 (2007): 33-46.

In the current healthcare system, SC usually consists of a chaplain referral in the last few days or even hours before the patients' death. Patients are not always informed on the available SC services unless they request it themselves. Patients deserve more than this. They deserve someone to listen to them and to dedicate enough time in helping them meet any spiritual needs that may arise when facing death. SC needs to be the role of each member of the MDT and not only the role of the hospital chaplain. Patients especially at the end of their lives, have a right for better quality SC and that is why this author chose to investigate what SC is; its importance; who should deliver SC; and the barriers in SC delivery. The main aim of this study, however, is to examine if patients have a right to SC at the end of life and whether this right is being respected and preserved in healthcare settings.

Chapter 1. Spiritual Care in Health Care

Although SC is considered an integral part of end-of-life care, HCPs still consider SC an ambiguous practice in the healthcare setting. There seems to be a lack of agreement when it comes to defining spirituality, what SC entails and who is responsible for providing such care.

As any other type of care, SC is best delivered through a team approach of HCPs caring for the patient. This team approach seems to be particularly important when it comes to palliative care settings. Although the hospital chaplain is considered a specialist in this type of care, there seems to be a need for all members of the MDT to be SC providers. The chaplain, therefore, in collaboration with other HCPs can help patients in achieving spiritual well-being, through holistic care.

Before delivering SC, chaplains and other HCPs should seek to identify the individual spiritual needs of patients, through a spiritual assessment. Spiritual assessments will help chaplains and HCPs in identifying those patients who are suffering from spiritual distress. These assessments will then facilitate an individualized SC plan for that particular patient. HCPs should acknowledge some of their limitations in delivering SC and seek assistance of someone more experienced in providing this type of care to the dying patient, such as the hospital chaplain, so as to provide meaningful SC.

1.1 Definition of Spirituality

The word spirit originates from the Latin word 'spiritus' which means breath.[1] Like breath, spirit is essential to life; it is however very difficult to define. Definitions of spirituality are extremely subjective and diverse, with each definition having several defining characteristics. When it comes to the literature there are three main approaches to defining spirituality.[2] The first approach assumes that spirituality is

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1 Walter A. Elwell, *Baker's Evangelic Dictionary of Biblical Theology* (Michigan: Baker Books, 1996).

2 Shane Sinclair, José Pereira and Shelley Raffin, "A Thematic Review of the Spirituality Literature within Palliative Care," *Journal of Palliative Medicine* 9, no. 2 (2006): 464-479.

impossible to define by words. McSherry and Cash for example, hold that a "universal definition of spirituality may be theoretically and culturally impossible."[3] The second approach is to use as broad a definition as possible, comprising all general interpretations available, while the third approach is to narrow the definition to a specific aspect of SC.

A systematic review of the literature between 1983 and 2005 found 320 definitions of spirituality, of which 74 definitions were health related.[4] After analysing these definitions the authors concluded that a definition of spirituality must incorporate four themes: (1) the meaning and purpose of life, (2) mystical phenomena, (3) religious beliefs and (4) non-religious beliefs (Appendix C.1). Instead of bringing clarity, all these different definitions add up to the confusion and disagreement. As a result, many HCPs are finding it difficult to understand what spirituality really means. This may be due to the fact that definitions of spirituality are founded on individual perspectives and interpretations rather than on established evidence.[5] This lack of a clear definition can lead to several implications. First, it can limit further progression in the knowledge involving the use of spirituality in palliative care.[6] Secondly, it will have an implication on the provision of SC in the clinical setting.[7] John Paley has also associated this lack of clarity with a lack of SC in the healthcare setting.[8] Gordon and Mitchell, however, see this lack of definition in a more positive way.[9] This lack of definition is seen as an opportunity for HCPs to develop their personal instinct and experience in their practice, which may result in a more patient-centred care that focuses on the individual.

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3 Wilfred Mcsherry and Keith Cash, "The language of spirituality: an emerging taxonomy," *International Journal of Nursing Studies* 41, no.1 (2004): 151-161.

4 Loralee Sessanna, Deborah Finnell and Mary Ann Jezewski, "Spirituality in Nursing and Health-Related Literature: A Concept Analysis," *Journal of Holistic Nursing* 25, no. 4 (2008): 252-262.

5 Shane Sinclaire, Jose Pereira and Shelley Raffin, "A thematic review of the spirituality literature within palliative care," *Journal of Palliative Medicine* 9, no. 2 (2006): 464-479.

6 Melanie Vachon, Marie Achille and Lise Fillion, "A conceptual analysis of spirituality at the end of life," *Journal of Palliative Medicine* 12, no. 1 (2009): 53-59.

7 John T. Chinball *et al.*, "Psychosocial- spiritual correlates of death distress in patients with life threatening medical conditions," *Palliative Medicine* 16, no.4 (2002): 331-39.

8 John Paley, "Spirituality and nursing: A reductionist approach," *Nursing Philosophy* 9, no. 1 (2008): 3–18.

9 Tom Gordon and David Mitchell, "A competency model for the assessment and delivery of spiritual care," *Palliative Medicine* 18, no. 7 (2004): 646-651.

Puchaski defined spirituality as a "dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred."[10] This definition, implies that spirituality is a dynamic process, changing according to life experiences and is usually triggered when the person is faced with a life threatening illness. In fact, studies show that spiritual concerns seem to become particularly important when individuals face the reality and proximity of their mortality,[11] indicating the importance of spirituality during illness and the need to address spirituality when it comes to patient's care.[12]

The Spiritual Care Taskforce of the European Association for Palliative Care also defines spirituality as:

> 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.[13]

A recent systematic review about SC in palliative care in Europe found that many of the definitions found in literature reflect elements of this definition.[14] Also a concept analysis of the empirical literature on definitions of spirituality, resulted in the discovery of eleven dimensions of spirituality (Appendix C.2).[15] Based on these dimensions the authors defined spirituality as "a developmental and conscious process characterized by two movements of transcendence either deep within the self or beyond the self." These definitions, like many others, consider spiritual issues to be universal, incorporating existential and religious perspectives. There are authors that treat these spiritual,

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10 Christina M. Puchaski *et al.,* "Improving the spiritual dimension of the whole person care: Reaching national and international consensus," *Journal of Palliative Medicine* 17, no. 6 (2014): 642-656.

11 Lauris C. Kaldjian, James F. Jekel and Gerald Friedland, "End-of-life decisions in HIV-positive patients: The role of spiritual beliefs," *AIDS* 12, no. 1 (1998): 103-107; Tracy Balboni *et al*., "Religiousness and Spiritual Support," 555–560.

12 Patricia B. Fryback and Bonita R. Reinert, "Alternative therapies and control for health in cancer and AIDS," *Clinical Nurse Specialist* 11, no.2 (1997): 64-69.

13 Steve Nolan, P. Saltmarsh and Carlo Leget, "Spiritual care in palliative care: Working towards an EAPC task force," *European Public Law* 18, no. 2 (2011): 86–89.

14 Marie-Jose H.E. Gijsberts *et al.,* "Spiritual Care in Palliative Care: A systematic Review of the recent European Literature," *Medical Science* 25, no. 7 (2019): 1-21.

15 Melanie Vachon *et al.,* "Analysis of spirituality at the end of life," 53-59.

religious and existential concepts as distinct,[16] while others consider these issues as inseparable.[17]

Although in healthcare, spirituality and religion are usually used synonymously, the term spirituality is usually considered as a wider concept than religion. Spirituality may or may not be related to religion[18] and other forms of personal coping skills may be involved.[19] Although there are some authors who do not agree that religion should play a role in the end-of-life care,[20] evidence seems to favour the notion that religious spirituality is beneficial when incorporated within patients' care.[21] Pattison and Swinton argue against this division between spirituality and religion, suggesting that spirituality has been shaped by religion through historical influence.[22] The authors suggest that separating spirituality from religion will render spirituality meaningless. Zinnbauer and colleagues also believe that although religion and spirituality seem to be two separate concepts, they are not fully independent.[23] They found that 74% of their sample population (N=346) rated themselves as religious and spiritual whereas only 19% considered themselves as spiritual but not religious.

According to Paley, the concept of spirituality as understood today is of recent origin, having become separated from religion since the 1980s.[24] For this reason, the term

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16 Shane Sinclaire and Harvey Max Chochinov, "Communicating with patients about existential and spiritual issues: SACR-D work," *Progress in Palliative Care* 20, no. 2 (2012): 72-76.

17 Patricia Boston, Anne Bruce and Rita Schreiber, "Existential suffering in the palliative care setting: an integrated review of the literature," *Journal of Pain Symptom Management* 41, no. 3 (2011): 604-618.

18 Ruth A. Tanyi, "Towards clarification of the meaning of spirituality," *Journal of Advanced Nursing* 39, no. 5 (2002): 500-509.

19 Alan Astrow, Christina M. Puchalski and Daniel P. Sulmsay, "Religion, spirituality, and health care: Social, ethical, and practical considerations," *The American Journal of Medicine* 110, no. 4 (2001): 283-287.

20 John Paley, "Spirituality and secularization: Nursing and the sociology of religion," *Journal of Clinical Nursing* 17, no. 2 (2008): 175–186; Tony Walter, "Spirituality in Palliative Care: Opportunity or Burden?" *Palliative Medicine* 16, no. 2 (2002): 133-139.

21 Timothy P. Daaleman and Larry VanCreek, "Placing religion and spirituality in end of life care," *Journal of the American Medical Association* 284, no. 19 (2000): 2514-17; Kenneth I. Pargament, Harold Koenig and Lisa M. Perez, "The many methods of religious coping: Development and initial validation of the RCOPE," *Journal of Clinical Psychology* 56, no. 4 (2000): 519-543.

22 John Swinton and Stephen Pattison, "Spirituality. Come all ye faithful," *Health Service Journal* 111, Issue 5786 (2001): 24–25.

23 Brian J. Zinnbauer *et al.,* "Religion and Spirituality: Unfuzzying the Fuzzy," *Journal for the Scientific Study of Religion* 36, no. 4 (1997): 549-564.

24 John Paley, "Spirituality and secularization," 175–186.

spirituality is considered to be still 'under construction.' Many contemporary definitions of spirituality in fact are moving from a traditionally more religious approach to a less restrictive approach, one which is more multi-cultural oriented and based on secular views. There seems to be a general acceptance that spirituality is an intrinsic element of human beings and that non-religious individuals also have spiritual concerns.[25] Walter even goes a step further, describing spirituality as "a discourse used at present time in the English- speaking world by those who wish to move beyond, or distance themselves from, institutional religion."[26]

Some definitions of spirituality have been criticized as being restrictive, suggesting that these definitions consider functional abilities and competence as necessary for developing spirituality.[27] These types of definitions exclude certain individuals, such as those with diminished mental capabilities. According to Males and Boswell, however, spirituality is a universal concept present in every individual, even those with limited functioning intellectual abilities.[28] Long explains how life's experiences may assist spiritual awareness and transformation, suggesting that everyone has the potential to undergo spiritual growth, albeit at different levels.[29]

Many authors seem to agree on the fact that spirituality is a personal concept: every individual can create his or her own definition of spirituality.[30] This can raise objections to the general application of spirituality used in some definitions. HCPs should recognize the patients' spiritual beliefs if present, by taking a spiritual history and incorporating these beliefs in the patient's care. In the healthcare setting, it is common that patients' spiritual beliefs differ from those of the HCP. Conflicts are best avoided if HCPs have sufficient self-awareness on their own spirituality and understand the fact that each individual will have his own understanding of spirituality.[31] In the healthcare setting,

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25 Ruth Tanyi, "Clarification of spirituality," 500-509.
26 Tony Walter, "Spirituality in Palliative Care," 133-39.
27 Wilfred Mcsherry and Keith Cash, "The language of spirituality," 151-161.
28 J. Males and C. Boswell, "Spiritual needs of people with mental handicap," *Nursing Standard* 48, no. 4 (1990): 35-37.
29 Ann Long, "Nursing: A spiritual perspective," *Nursing Ethics* 4, no. 6 (1997): 496–510.
30 Wilfred McSherry and Keith Cash, "The language of spirituality," 151-161.
31 Bart Cusveller, "Cut from the right wood: Spiritual and ethical pluralism in professional nursing practice," *Journal of Advanced Nursing* 28, no. 2 (1998): 266–273.

there should be a consensus and understanding that it is normal to have different definitions of the term spirituality.

1.2 Spiritual Distress

Individuals suffering from terminal illness usually associate their illness with spiritual distress.[32] Spiritual distress in the healthcare setting refers to suffering related to the spiritual dimension of the patient and may include both existential as well as religious concerns.[33] Suffering can be defined as the "state of severe distress associated with events that threaten the intactness of the person."[34] In 1964, Dame Cicely Saunders developed the idea of 'total pain' experienced by patients at the end of life (Appendix A.1).[35] In this concept, suffering includes a combination of physical, psychological, social and spiritual struggles. Sometimes HCPs seem to be too preoccupied with the science of medicine, focusing on the physical aspect of the patient and neglecting the patients' psychological, social and spiritual struggles, which may also contribute to patients' suffering. There seems to be a debate in the literature whether the focus of medicine should be to cure the disease or to relieve suffering.[36]

When it comes to the literature one of the most common causes leading to spiritual distress at the end of life is the feeling of guilt which can re-emerge during the dying process.[37] This can result in significant distress, and is mostly present in individuals with strong religious backgrounds. Other potential causes of spiritual distress may include

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[32] Alan B. Astrow *et al.,* "Is failure to meet spiritual needs associated with cancer patients' perceptions of quality of care and their satisfaction with care?" *Journal of Clinical Oncology* 25, no. 36 (2007): 5753-7.

[33] Lucy Selman *et al.,* "Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries," *Palliative Medicine* 32, no. 1 (2017): 1-15.

[34] Eric J. Cassell, "The Nature of Suffering and the Goals of Medicine," *New England Journal of Medicine* 306, no. 11 (1982): 639-645.

[35] Anita Mehta and Lisa S. Chan, "Understanding of the Concept of ''Total Pain," *Journal of Hospice and Palliative Nursing* 10, no. 1 (2008): 26-32.

[36] Eric J. Cassell, "Suffering and Medicine," 639-645; Michael J. Balboni, Christina M. Puchalski and John R. Peteet, "The Relationship between Medicine, Spirituality and Religion: Three Models for Integration," *Journal of Religion and Health* 53, no. 5 (2014): 1586-1598.

[37] Bei-Hung Chang *et al*., "End-of-life spiritual care at a VA medical centre: Chaplains' perspectives," *Palliative and Support Care* 10, no.4 (2012): 1-6.

the loneliness of dying,[38] threats to personal meaning and purpose,[39] lack of forgiveness and reconciliation with others or some higher power.[40] Religious and cultural interpretations related to the illness can also sometimes result in spiritual distress. Studies show that religious beliefs strongly influence the individuals' perception on the cause of an illness, such as negative religious coping, where the illness is perceived as a punishment from God leading to, a higher incidence of distress.[41] Interestingly, although negative religious coping was linked with higher incidence of distress and depression, positive religious coping, for example getting closer to one's faith due to medical crisis, was not associated with distress.[42] This may be due to the fact that positive religious coping could be associated with more beneficial outcomes such as well-being and improved psychosocial or physical functioning. In their study, Pargament and colleagues found that in elderly ill patients, spiritual discontent and negative religious coping are associated with an increased risk of death.[43] These studies suggest that there is a link between spiritual distress and health outcomes. Other studies also link spiritual distress with decreased patients' quality of life,[44] increased desire for hastened death,[45] end-of-life despair,[46] dissatisfaction with care,[47] loss of dignity,[48] increased incidence of

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38 Barbara Carroll, "A phenomenological exploration of the nature of spirituality and spiritual care," *Mortality* 6, no. 1 (2001): 81-98.

39 Daniel B. Hinshaw, "The spiritual needs of the dying patient," *Journal of American College of Surgeons* 195, no. 4 (2002): 565-568.

40 Margaret Holloway *et al.,* "Spiritual care at the end of life: A systematic review of the literature," *Universities of Hull, Staffordshire and Aberdeen* (2010), accessed October 1, 2018, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215798/dh_123804.pdf.

41 Judith Hills *et al*., "Spirituality and distress in palliative care consultation," 782-788.

42 Allen Sherman *et al*., "Religious Struggle and Religious Comfort in Response to Illness: Health Outcomes among Stem Cell Transplant Patients," *Journal of Behavioural Medicine* 28, no. 4 (2005): 359-367.

43 Kenneth I. Pargament *et al*., "Religious struggle as a predictor of mortality among medically ill elderly patients: A 2-year longitudinal study," *Archives of International Medicine* 161, no. 15 (2001): 1881–5.

44 Tracy Balboni *et al*., "Religiousness and Spiritual Support," 555-560.

45 William Breitbart *et al.,* "Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients with Cancer," *The Journal of the American Medical Association* 284, no. 22 (2000): 2907-11.

46 Colleen S. McClain, Barry Rosenfeld and William Breitbart, "Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patient," *The Lancet* 361, Issue 9369 (2003): 1603-7.

47 Alan Astrow, "Failure to Meet Spiritual Needs," 5753-7.

48 Harvey Max Chochinov *et al*., "The landscape of distress in the terminally ill," *Journal of Pain and Symptom Management* 38, no. 5 (2009): 641-649.

depression,[49] poorer physical functioning and increased hospitalization, which can result in increased healthcare costs.[50]

A recent study found that 40.8% of cancer patients (N=170) undergoing chemotherapy were diagnosed as suffering from spiritual distress.[51] Similar findings are found in another study where spiritual distress was reported to be present in 44% of the sample population (N= 113).[52] Another study however, has reported the occurrence of spiritual distress at the end of life, to be as high as 96% (N=57).[53] Such findings resulted in the development of a consensus project; 'Improving the Quality of Spiritual Care as a Dimension of Palliative Care' which highlights the importance of routine assessment by HCPs for spiritual distress.[54] In this way, spiritual concerns can be tackled appropriately and further health complications can be prevented.

1.3 Spiritual Assessment

Spiritual assessment is defined as "the process of gathering and organizing spiritually based data into a coherent format that provides the basis for interventions."[55] The goal of spiritual assessments should be to increase the HCP's understanding of the patient's spiritual beliefs and practices so that they can provide individualised, effective and culturally sensitive SC. Spiritual assessments will also help HCPs in identifying those

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49 Christian J. Nelson et al., "Spirituality, Religion, and Depression in the Terminally Ill," *Psychosomatics* 43, no. 3 (2002): 213-220.

50 Crystal L. Park, Wortmann Harlow, and Jennifer Donald Edmondson, "Religious Struggle as a Predictor of Subsequent Mental and Physical Well-Being in Advanced Heart Failure Patients," *The Journal of Behavioural Medicine* 34, no. 6 (2009): 426-436.

51 Sílvia Caldeira *et al.,* "Clinical Validation of the Nursing Diagnosis Spiritual Distress in Cancer Patients Undergoing Chemotherapy," *International Journal of Nursing Knowledge* 28, no. 1 (2017): 44–52.

52 David Hui *et al*., "The Frequency and Correlates of Spiritual Distress Among Patients with Advanced Cancer Admitted to an Acute Palliative Care Unit," *American Journal of Hospice & Palliative Medicine* 28, no. 4 (2011): 264-270.

53 Caterina Mako, Kathleen Galek and Shannon Poppito, "Spiritual Pain among Patients with Advanced Cancer in Palliative Care," *Journal of Palliative Medicine* 9, no. 5 (2006): 1106-13.

54 Christina Puchalski, "Improving Quality of Spiritual Care," 885-904.

55 David R. Hodge and Crystal Holtrop, "Spiritual assessment: A review of complementary assessment models," in *Spiritual Assessment: Handbook for Helping Professionals*, ed. David Hodge (Botsford: North American Association of Christians in Social Work, 2003), 167-192.

patients suffering from spiritual distress and who would therefore require additional spiritual support.[56]

Nowadays, spiritual assessments are required in various settings, including hospitals, home care organizations and long-term care facilities.[57] The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) for example, requires an initial brief spiritual assessment upon the patient's hospital admission.[58] The aim of this brief assessment is to determine the patient's denomination and the presence of any significant spiritual beliefs and practices. This assessment may however indicate the need for a more comprehensive assessment. The JCAHO does not state what should be included in the assessment, leaving it to hospital organizations to define the content and details of spiritual assessments and the qualifications of the HCPs carrying out the assessment. It does however, provide a list of questions directed to patients and their relatives, as a guide (Appendix C.3).

A similar concept is adopted by the Trent Hospice Audit Group where spiritual assessment is categorised into three stages.[59] The first stage is routine assessment for all hospital patients on their admission, including only general information. The second stage is the multidisciplinary stage, where members of the MDT assess the patient's spiritual concerns through the patient's physical, psychological and social aspects. The third stage is the specialist assessment which is usually done by the hospital chaplain for those patients who are suffering from more complex spiritual issues, and therefore require more specialised knowledge and competencies.

Spiritual assessment can be done through both extrinsic and intrinsic means. The former include formal assessment tools and techniques whereas the latter include the HCPs'

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56 Fiona Timmins and Sílvia Caldeira, "Assessing the Spiritual Needs of Patients," *Nursing Standard* 31, no. 29 (2017): 47-53.

57 David R. Hodge, "A Template for Spiritual Assessment: A Review of the JCAHO Requirements and Guidelines for Implementation," *Social Work* 51, no. 4 (2006): 317-326.

58 The Joint Commission on Accreditation of Healthcare Organizations, "Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centred Care: A Roadmap for Hospitals," (2010), accessed November 13, 2018, https://www.jointcommission.org/roadmap_for_hospitals/.

59 John Hunt *et al*., "The quality of spiritual care-developing a standard," *International Journal of Palliative Nursing* 9, no. 5 (2003): 208-215.

qualities, attitudes and experiences.[60] Spiritual assessments will help HCPs to initiate a spiritual dialogue with the patient and identify any spiritual and cultural practices, beliefs and values.[61] Formal spiritual assessment tools can be used when spiritual concerns are unclear and when the HCP lacks specific guidance about what type of SC they should provide.[62] Four of the most widely used formal assessment tools are HOPE, SPIRITual, FAITH and FICA (Appendix B.1-4).[63] Using these assessment tools will help HCPs in overcoming barriers to SC provision and enhance communication between the patient and the HCP.[64] Some authors however, believe that it is more appropriate to assess the patients' spiritual needs informally through open questions, believing that spiritual assessment should be a more explorative rather than a standardised process.[65]

Usually, they are the patients themselves or their relatives who will request SC or ask to see a hospital chaplain.[66] Fitchett and colleagues, however found that only 35% of hospitalized patients requested some sort of spiritual service from the hospital chaplain and this was greatly associated with the length of hospital stay.[67] Other authors, report even lower rates, with approximately 20% of patients requesting SC in Switzerland.[68] As the primary providers of SC, hospital chaplains usually rely on a nurse referral which usually involves basic information from the initial assessment of patient's spiritual concerns.[69] Yet, while the patients' denomination is often included in HCPs' assessment

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60 Shane Sinclair and Harvey Max, "Patients' existential and spiritual issues," 72-76.

61 Ruth Tanyi, "Clarification of Spirituality," 500-509.

62 Fiona Timmins, "Assessing Spiritual Needs," 47–53.

63 Michael Blaber, June Jones and Derek Willis, "Spiritual care: Which is the best assessment tool for palliative settings?" *International Journal of Palliative Nursing* 21, no. 9 (2015): 430-438.

64 Joann Hungelmann *et al.,* "Focus on spiritual well-being: harmonious interconnectedness of mind-body-spirit – use of the JAREL spiritual well-being scale," *Geriatric Nursing* 17, no. 6 (1996): 262–266; LeBron J. McBride, Lloyd Pilkington and Gary L. Arthur, "Development of brief pictorial instruments for assessing spirituality in primary care," *Journal of Ambulatory Care Management* 21, no. 4 (1998): 53–61.

65 Fiona Timmins, "Assessing Spiritual Needs," 47–53.

66 George Fitchett, Peter M. Meye and Laurel Arthur Burton, "Spiritual Care in the Hospital: Who Requests It? Who Needs It?" *The Journal of Pastoral Care* 54, no. 2 (2000): 173-186.

67 *Ibid.*

68 Urs Winter-Pfändler and Christoph Morgenthaler, "Who Needs Chaplain's Visitation in General Hospitals? Assessing Patients with Psychosocial and Religious Needs," *The Journal of Pastoral Care and Counselling* 65, no. 2 (2001): 1-9.

69 Kevin J. Flannelly, Kathleen Galek and George F. Handzo, "To what extent are the spiritual needs of hospital patients being met?" *The International Journal of Psychiatry in Medicine* 35, no. 3 (2005): 319-323.

sheets on hospital admission, many HCPs frequently ignore this section.[70] It seems that many HCPs do not feel comfortable in assessing and documenting patients' spiritual needs. Sometimes they find it difficult to isolate spiritual concerns from other more overt concerns such as psychological, physical and social concerns.[71]

Physicians, for example, were found to be reluctant to assess the spiritual needs of their patients, due to lack of training, time constraints and the worry that they would surpass ethical boundaries.[72] Dein and Stygall give three reasons why HCPs and patients themselves show a lack of interest in discussing religious and spiritual concerns.[73] The first reason is that religion and spirituality are considered personal issues and when discussed these may lead to some level of discomfort. Secondly, in many people's minds, spirituality and religion can be associated with more negative matters, such as superstition and persecution. Thirdly, when these issues are discussed this might be interpreted to mean that the patients are approaching their end, the underlying assumption being that these issues are discussed only when everything else has failed.

Based on the findings of the spiritual assessment, hospital chaplains and HCPs can discover an individualized SC plan, which includes appropriate interventions that can help the patient achieve spiritual well-being.

1.4 Spiritual Well-Being

The inter-professional model of SC (Appendix A.2)[74] together with the biopsychosocial-spiritual model (Appendix A.4.3)[75] indicate the importance of a holistic approach to patients' care, and that all HCPs have an ethical obligation to provide this type of care.

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70 Fiona Timmins, "Nurses' Views of Spirituality and Spiritual Care in the Republic of Ireland," *Journal for the Study of Spirituality* 3, no. 2 (2013): 123-139.

71 Barbara Carroll, "Nature of spiritual care," 81-98.

72 Harold G. Koenig, "Religion, Spirituality, and Medicine: Research Findings and Implications for Clinical Practice," *Holistic Nursing Practice* 19, no. 2 (2005): 62-69.

73 S. Dein and J. Stygall, "Does being religious help or hinder coping with chronic illness? A critical literature review," *Palliative Medicine* 11, no. 4 (1997): 291-298.

74 Christina Puchalski *et al.,* "Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference," *Journal of Palliative Medicine* 12, no. 10 (2009): 885-904.

75 Daniel P. Sulmasy, "A biopsychosocial-spiritual model for care of patients at the end of life," *The Gerontologist* 42, no. 3 (2002): 24-33.

Like spirituality, well-being is usually considered a complicated concept, one difficult to define. Well-being is usually not considered a global concept.[76] That is, an individual could experience well-being in one particular aspect of his life while lacking well-being in another aspect. HCPs need to understand this specific and non-global nature of the concept of well-being. When speaking of spiritual well-being therefore, one needs to understand that this is only one part of the person's overall well-being.

Spiritual well-being is defined as:

> A sense of harmonious interconnectedness between self, others/nature, and Ultimate Other which exists throughout and beyond time and space. It is achieved through a dynamic and integrative growth process which leads to a realization of the ultimate purpose and meaning of life.[77]

From this definition, one can observe that the term 'spiritual well-being' is inevitably dependant on the definition of spirituality which, as already discussed, is very subjective. Spiritual well-being is therefore also considered an individualized concept.

There is a common conception that as a disease progresses quality of life and general well-being decrease. Although an assumption that physical status declines as the disease progresses is reasonable, one cannot assume that all terminally ill patients have poor quality of life since, as already mentioned, there are other determinants of well-being.[78] There are studies which investigate these associations between spiritual well-being and health. Dreyer found a strong relationship between a lifestyle that is health promoting in nature and the level of spiritual well-being.[79] Spiritual well-being is also linked to

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[76] Margaret Holloway *et al.,* "Spiritual care at the end of life," 1-105.

[77] Joann Hungelmann *et al*., "Spiritual well- being in older adults: Harmonious interconnectedness," *Journal of Religion Health* 24, no. 2 (1985): 152.

[78] Robin S. Cohen *et al*., "The McGill Quality of Life Questionnaire: A measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability," *Palliative Medicine* 9, no. 3 (1995): 207-219.

[79] Lukas Dreyer and Sonja Dreyer, "Spiritual well-being and Health," *Journal for Physical Health Education, Recreation and Dance* 7, no. 1 (2001): 142-152.

improved quality of life,[80] increased life-satisfaction,[81] promoting mental health,[82] and decreased emotional instability and mood disorders.[83] In fact, evidence shows that spiritual well-being can improve quality of life more than physical and emotional well-being, emphasising the importance of SC.[84] Apart from this, a systematic review has also found a positive association between spiritual well-being and physical symptoms such as decreased pain intensity, fatigue and drowsiness.[85]

Evaluation tools assess spiritual outcomes after SC interventions have been used. These are different from spiritual assessment tools, used by HCPs to assess the spiritual needs of patients. Although evidence on external measure tools for spiritual well-being is lacking, the most commonly used tool seems to be the 'Functional Assessment of Chronic Illness Therapy- Spiritual Well-being Scale' (FACIT-Sp) by Paloutzian and Ellison in 1982 (Appendix B.5).[86] In fact, a systematic review on evaluation tools for spiritual well-being at the end of life found that the FACIT-Sp together with the 'McGill Quality of Life Questionnaire' (Appendix B.6) are the most widely used tools in the literature.[87] The FACIT-Sp showed strong internal consistency, reliability, a substantial association with quality of life and simultaneous validity with other measures of spirituality.[88]

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80 Mei Bai and Mark Lazenby, "A Systematic Review of Associations between Spiritual Well-Being and Quality of Life at the Scale and Factor Levels in Studies among Patients with Cancer," *Journal of Palliative Medicine* 18, no.3 (2014): 1-13.

81 Jo Kim *et al.,* "Spirituality, Quality of Life, and Functional Recovery after Medical Rehabilitation," *Rehabilitation Psychology* 45, no. 4 (2000): 365-368.

82 Esa Jafaria Gholam *et al.,* "Spiritual well-being and mental health in university students," *Procedia Social and Behavioural Sciences* 5, no.1 (2010) 1477–81.

83 Mark M. Leach and Russell Lark, "Does spirituality add to personality in the study of trait forgiveness?" *Personality and Individual Differences* 37, no. 1 (2004): 147-156.

84 Mei Bai *et al.,* "Exploring the relationship between spiritual well-being and quality of life among patients newly diagnosed with advanced cancer," *Palliative and Supportive Care* 13, no. 4 (2014): 1-9.

85 Carla Ripamonti *et al.,* "Spiritual Care in Cancer Patient: A need or an option?" *Current Opinion in Oncology* 30, no. 4 (2018): 1-7.

86 Ruth Tanyi, "Clarification of spirituality," 500-509.

87 Oliver Amparo, Enric Benito and Laura Galiana, "Evaluation tools for spiritual support in end of life care: increasing evidence for their clinical application," *Current Opinion in Supportive and Palliative* care 9, no. 4 (2015): 357-360.

88 Amy H. Peterman *et al*., "Measuring spiritual well-being in people with cancer: The Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being scale (FACIT-Sp)," *Annals of Behavioural Medicine* 24, no. 1 (2002): 49-58.

1.5 Delivering Spiritual Care: Whose Role is it?

Addressing spiritual issues is generally considered a standard practice of holistic palliative care, and therefore all HCPs working with patients at the end of their life are usually considered responsible for providing such care.[89] The literature however seems to present a debate about who from the MDT is best suited for such a job. Together with clinicians, hospital chaplains, counsellors and community clergy are usually considered responsible for providing SC. According to Sinclair, determining who should address the patient's spiritual needs depends on HCPs' capabilities and comfort, availability of resources and patient's individual needs.[90] Similarly, Selman and colleagues suggest that the most suitable person to provide SC depends on the individual patient, the type and severity of the spiritual distress and the competency of the SC provider.[91]

Gordon and Mitchell underline the importance of professional competencies when it comes to SC.[92] In fact, they have developed a competency model for the assessment and delivery of SC (Appendix A.4.5), focusing on the knowledge, skills and actions of the individual HCP. These competencies allow hospices and palliative care units to show the level of SC being offered. Puchalski and colleagues have also developed a role based model of SC focusing on professional competencies, where the chaplain is the primary spiritual caregiver, but other HCPs have also specific responsibilities in providing SC (Appendix A.4.8).[93] Similarly, Chochinov has developed the 'ABCDs of Dignity Conserving Care' which presents a set of attitudes, behaviours and other competencies, necessary for all HCPs to respond to spiritual needs (Appendix A.3).[94]

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89 Christina Puchalski *et al*., "Improving Quality of Spiritual Care," 885-904.
90 Shane Sinclair and Harvey Max, "Patients' existential and spiritual issues," 72-76.
91 Lucy Selman *et al*., "Patients' and caregivers' needs in spiritual care," 1-15.
92 Tom Gordon and David Mitchell, "Model of Assessment and Delivery of Spiritual Care," 646-651.
93 Christina M. Puchalski *et al*., "Interdisciplinary Spiritual Care for Seriously Ill and Dying Patients: A Collaborative Model," *The Cancer Journal* 12, no. 5 (2006): 398-413.
94 Harvey Max Chochinov, "Dignity and the Essence of Medicine: The A, B, C, and D of Dignity Conserving Care," *British Medical Journal* 335, no. 7612 (2007): 184-187.

1.5.1 Health Care Professionals and Spiritual Care

Clinicians present in a palliative care setting may include physicians, consultants, nurses, occupational therapists, psychologists, social workers, physiotherapists and speech-language pathologists. Yet, literature seems to focus mainly on the nursing profession when it comes to SC. This can be due the general assumption that nurses spend most of the time with the patient and therefore spiritual assessment and care were frequently considered to be the nurse's role.[95] For example, in the UK, a study about physiotherapists' perceptions on SC found that there were no other available studies which investigated SC provision in this particular profession.[96]

In general, it is assumed that hospital chaplains have the main role in providing SC; however, HCPs are nowadays assuming greater responsibility. Walter states that this new responsibility for HCPs may sometimes turn out to be an 'unwelcome burden'.[97] The author suggests that one should not assume that all HCPs can offer SC to any patient, due to differences between and among patients and HCPs themselves. This highlights the importance of a MDT approach in the palliative care setting, so if one member of the team is not suitable to deliver SC to a particular patient, another member of the team can assume this responsibility.

Evidence regarding whether each and every HCP should provide SC seems to be controversial. Some authors believe that SC may be efficiently and interchangeably provided by all members of the MDT.[98] Singh and Ajinkya also emphasize the importance of medical professionals to address patients' needs, desires and perspectives on spirituality, within the clinical setting.[99] Other authors, however perceive the role of physicians in assessing and addressing spiritual issues as inappropriate, arguing that

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95 Barbara Carroll, "Nature of Spiritual Care," 81-98.

96 Helen Turner and Christopher C. H. Cook, "Perceptions of Physiotherapists in Relation to Spiritual Care," *Journal for the Study of Spirituality* 6, no. 1 (2016): 58–77.

97 Tony Walter, "Spirituality in Palliative Care," 133-40.

98 Timothy P. Daaleman *et al*., "An Exploratory Study of Spiritual Care at the End of Life," *The Annals of Family Medicine* 6, no. 5 (2008): 406-411.

99 Darpan Kaur, Mohinder Gingh and Shaunak Ajnya, "Spirituality and Religion in Modern Medicine," *Indian Journal of Psychological Medicine* 34, no. 4 (2012): 399-402.

religion and medicine are two separate and very different areas.[100] They also argue that having physicians discuss spirituality is not a solution for resolving the body and mind division. Poole and Cook also discuss whether physicians who pray with their patient or disclose their religious beliefs would be breaching their professional boundaries.[101]

Sloan and colleagues discuss the various ethical issues that may result when a physician attempts to address spiritual issues.[102] The first ethical issue constitutes an invasion of the patient's privacy, where the physician is departing from his area of expertise possibly increasing the risk of doing harm. Another ethical consideration is the fact that although spiritual issues can have health implications, there are many other factors, such as socioeconomic and marital status, which can also have health implications but which seem to not be given the right importance for the physician. According to these authors, those physicians who link spirituality and medicine do this in such a way that is not determined by the utilitarian expectations of better health. Even if there is enough evidence which link spirituality to better health outcomes, the authors believe that before all these ethical issues are resolved, physicians need to be careful in dealing with patients' spiritual issues.

Research however, indicates that many patients want their HCPs, apart from clergy, to address spiritual concerns as part of their care.[103] A sample of 103 patients and family caregivers were asked who they considered to be their spiritual caregiver in their palliative care setting, and only 17% identified a cleric, while 29% identified other HCPs.[104] Hart and colleagues however, found that usually patients do not expect

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[100] Raymond J. Lawrence, "The Witches' Brew of Spirituality and Medicine," *The Society of Behavioural Medicine* 24, no. 1 (2002): 74-76.

[101] Rob Poole and Christopher C. Cook, "Praying with a patient constitutes a breach of professional boundaries in psychiatric practice," *British Journal of Psychiatry* 199, no. 2 (2011): 94-8.

[102] Richard P. Sloan, Emilia Bagiella and Tia Powell, "Religion, Spirituality, and Medicine," *The Lancet* 353, no. 9153 (1999): 664-667.

[103] Andrea C. Phelps *et al*., "Addressing spirituality within the care of patients at the end of life: Perspectives of patients with advanced cancer, oncologists, and oncology nurses," *Journal of Clinical Oncology* 30, no. 20 (2012): 2538–44; Scott Murray *et al.,* "Exploring the spiritual needs of people dying of lung cancer or heart failure: A prospective qualitative interview study of patients and their carers," *Palliative Medicine* 18, no. 1 (2004): 39-45.

[104] Timothy Daaleman *et al*., "Study on End of Life Spiritual Care," 406-11.

physicians and other HCPs to be their primary spiritual caregivers.[105] All the same, patients think that HCPs should be able to discuss spiritual issues with them especially near the end of their life.

Although many HCPs consider SC as an important aspect of end-of-life care, SC seems to be infrequently provided by HCPs due to a number of perceived barriers,[106] which shall be discussed in the next chapter. Studies for example show that nurses in general are good in determining spiritual needs but they are not sure on how to provide SC.[107] Nurses were also found to have difficulty in defining SC although they did recognize that they have an important role in SC.[108] Rodin and colleagues studied HCPs' role perceptions in providing SC, and how this is related to the provision of SC.[109] They found that nurses are more likely than physicians to perceive that they have an important role in SC provision. Physicians' role perceptions were more influenced by their religion and/or spirituality and these perceptions were found to be more predictive of actual SC provision.

Palliative care guidelines seem to recognize the importance of a multidisciplinary approach to spirituality in end-of-life care, where HCPs have a shared responsibility in the provision of such care.[110] All HCPs working in a palliative care setting should have a basic level of competency in SC, especially when it comes to the initial spiritual assessment, done on admission and throughout the patients' hospital stay.[111] Following the assessment findings, HCPs can refer patients to a more specialised SC provider.[112]

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105 Alton Hart *et al.*, "Hospice patients' attitudes regarding spiritual discussions with their doctors," *American Journal of Hospice and Palliative Medicine* 20, no. 2 (2003): 135-139.

106 Michael Balboni *et al.,* "Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and physicians and the role of training," *Journal of Clinical Oncology* 31, no. 4 (2013): 461–467.

107 Wilfred McSherry, "Nurses' perceptions of spirituality and spiritual care," *Nursing Standards* 13, no. 4 (1998): 36–41.

108 Tony Bush and Nina Bruni, "Spiritual care as a dimension of holistic care: A relational interpretation," *International Journal of Palliative Nursing* 14, no. 11 (2008): 539-545.

109 Danielle Rodin *et al*., "*Whose role? Oncology practitioners' perceptions of their role in providing spiritual care to advanced cancer patients,*" *Journal of Pain and Symptom Management* 49, no. 2 (2015).

110 Christina Puchalski *et al.,* "Improving quality of Spiritual Care," 885–904.

111 Lucy Selman *et al.,* "Patients' and Caregivers' needs in spiritual care," 1-15.

112 Christina Puchalski *et al.,* "Improving quality of Spiritual Care," 885–904.

1.5.2 The Role of Spiritual Care Specialists

In the literature there seems to be a replacement of the term 'chaplain' to a 'spiritual care provider' or 'spiritual care specialist' highlighting the need to distance this profession from institutional religion.[113] SC specialists or providers offer specialist SC to every patient and do not represent only a particular faith or religious tradition. Their role is evolving more into a health related profession, integrating more with the hospital MDT and focusing more on evidence-based practice.[114] In fact, Parameshwaran described the chaplain's SC process as an 'evidence-based clinical method of care,' which includes the neuro-physiological principles of mindfulness and empathy.[115]

Evidence-based practice for chaplains can only be possible by ongoing training and education. Attard emphasizes the importance of pastoral supervision, peer study groups and ongoing training for hospital chaplains to determine more efficient ways of treating patients and their relatives.[116] There seems to be an increasing importance for further qualifications in this profession. Some healthcare organizations require chaplains to have an accredited master's degree in religion or divinity and a number of units of Clinical Pastoral Care education while others may actually need their chaplains to earn a doctoral degree.[117]

Mowat and colleagues have described how hospital chaplains engage in "an active process of finding people who need spiritual care, identifying the nature of the need and responding to the need through theological reflection and the sharing of spiritual practices."[118] This definition of the role of the hospital chaplain highlights the importance of assessing and screening those patients who would benefit from their

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113 Tony Walter, "Spirituality in Palliative Care," 133-140.

114 John Swinton, "Rediscovering Mystery and Wonder: Toward a Narrative-Based Perspective on Chaplaincy," *Journal of Health Care Chaplaincy* 13, no. 1 (2002): 223-236.

115 Ramakrishnan Parameshwaran, "Theory and practice of chaplain's spiritual care process: A psychiatrist's experiences of chaplaincy and conceptualizing trans-personal model of mindfulness," *Indian Journal of Psychiatry* 57, no. 1 (2015): 21-29.

116 Mario Attard, "The Role of the Hospital Chaplain," in *Spirituality: The Human Dimension in Care,* ed. by Donia Baldacchino and Linda Ross (Malta: University of Malta, 2008), 54-59.

117 "Becoming a Healthcare Chaplain," Pastoral Counselling Organization, accessed November 30, 2018, https://www.pastoralcounseling.org/career/healthcare-chaplain.

118 Harriet Mowat *et al.*, *What do Chaplains do? The Role of the Chaplain in Meeting the Spiritual Needs of Patients* (Aberdeen: Mowat Research, 2007), 29-50.

service. Hospital chaplains can use different screening tools which can help them to identify those patients who need their service and how urgently they need it. One of these tools is the 'Clinical and Coping Score' developed by Ledbetter (Appendix B.7).[119] It is a computerised screening tool based on two factors: the medical situation of the patient and the patient's coping resources. Referral by family or other HCPs together with patient's request are considered.

Hospital chaplains have also other responsibilities apart from providing SC. These may include participation in healthcare ethics committees, performing religious ceremonies and other rituals, training and supporting other HCPs and patients' relatives,[120] liaising with other religious leaders as well as offering bereavement support to relatives.[121] A recent study about the perspectives of nurses, physicians and social workers on the role of chaplains, found that although the majority reported that they understood what chaplains do, only a small proportion of these HCPs knew about specific duties of the chaplain, such as providing spiritual support for HCPs and assisting in treatment decision-making.[122] HCPs' lack of understanding of the chaplain's role can lead to a missed opportunity to consult a chaplain when it is needed.

Hospitals are increasingly recognizing the importance of providing chaplaincy service to the patients. Studies show that patients who received visits from a chaplain evaluated these visits as beneficial and were more likely to be satisfied with the services during their hospital stay.[123] Similarly, another study found that the majority of patients who had been visited by a chaplain confessed that their spiritual needs had been addressed.[124] In fact, since 2000 the JCAHO has recommended hospitals to have a

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119 Timothy J. Ledbetter, "Screening for Pastoral Visitations Using the Clinical and Coping Score," *Journal of Pastoral Care and Counselling* 62, no. 4 (2008): 367-374.

120 Larry VandeCreek and Laurel Burton, "Professional Chaplaincy: Its Role and Importance in Healthcare," *The Journal of Pastoral Care* 55, no. 1 (2001): 81-97.

121 Michael C. Wright, "Chaplaincy in hospice and hospital: Findings from a survey in England and Wales," *Palliative Medicine* 15, no. 3 (2001): 229-242.

122 Annelieke Damen *et al.*, "What Do Chaplains Do: The Views of Palliative Care Physicians, Nurses, and Social Workers," *American Journal of Hospice & Palliative Medicine* 2, no. 1 (2018): 1-6.

123 Larry Vandecreek *et al.,* "Patient and family perceptions of hospital chaplains," *Hospital & Health Services Administration* 36, no. 3 (1991): 455-467.

124 George W. Kernohan *et al.,* "An evidence base for a palliative care chaplaincy service in Northern Ireland," *Palliative Medicine* 21, no. 6 (2007): 519-525.

qualified chaplain as part of the healthcare team, and has issued a number of policies and procedures for hospital chaplains.[125] Issues such as spiritual assessment, documentation in medical records, education and training are included in the JCAHO standards. In response to this, in 2003 the Association of Hospice and Palliative Care Chaplains developed standards of practice for chaplains working with patients at the end of life.[126]

Literature emphasises the need for all HCPs to share responsibility in providing SC. The hospital chaplain, however, can be considered as a specialist SC provider.[127] HCPs should therefore collaborate with hospital chaplains and work together as a team to address patient's spiritual needs through times of suffering. Thus, when HCPs feel not competent, uncomfortable or do not have enough time to address these issues, they should ask for support from the hospital chaplain.[128]

Finally, it may be concluded that there is still ambiguity when it comes to defining SC and who should be responsible for such care. HCPs still find it difficult to understand what SC entails and how to approach patients' spiritual concerns. SC, as any other type of care is best delivered within a team approach, where all members of the MDT together with the hospital chaplain will be able to assess patients for spiritual needs. If not appropriately addressed spiritual needs can lead to spiritual distress and this can have an influence on the patients' health outcomes. Thus the aim of SC, is to promote spiritual well-being and improve patients' health outcomes, even at the end of life. The next chapter examines SC in the context of end-of-life care within palliative and hospice settings and discusses the use of spiritual interventions. It also focuses on the frequency

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125 Joint Commission Standard, "Joint Commission Review Crosswalk for Chaplain Services," *The Joint Commission* (2011), accessed November 11, 2018, http://www.healthcarechaplaincy.org/userimages/Joint%20Commission%20Review%20Crosswalk%20for%20Chaplain%20Services%20by%20APC.pdf.

126 David Mitchell, *Standards for Hospice and Palliative Care Chaplaincy*, (London: Association of Hospice and Palliative Care Chaplains, 2006), 1-23.

127 Shane Sinclaire and Harvey Max Chochinov, "Communicating with patients about spiritual issues," 72-76.

128 Emily McClung, Daniel H. Grossoehme and Ann Jacobson, "Collaborating with Chaplains to Meet Spiritual Needs," *Medsurg Nursing: Official Journal of the Academy of Medical-Surgical Nurses* 15, no. 3 (2006): 147-156.

of SC at the end of life, examining some of the barriers to SC provision. Finally, it will examine the perceived importance of SC from both patients and HCPs perspectives.

Chapter 2. End-of-life Spiritual Care

Although there is growing evidence that SC is an important part of the end-of-life care and that many patients want HCPs to provide this type of care, in practice patients' spiritual needs are not always being met. One reason for this could be the presence of a number of barriers which can limit SC provision, with the most prominent barrier being lack of HCPs' SC training and education.

HCPs face many ethical concerns related to treatment decisions and these concerns have been the focus of bioethics. Nevertheless, these are not the issues that mostly trouble patients and their relatives at the end of life. For many patients, treatment decisions at the end of life are considered irrelevant.[1] Thus apart from focusing on issues such as advanced directives and proxy consents, bioethics also needs to focus on the spiritual dimension of patients' care at the end of life.

2.1. Spirituality in Palliative and Hospice Care

The WHO defines palliative care as:

> An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[2]

This definition incorporates the use of SC as an integral part of palliative care. In fact, SC has been an integral part of end-of-life care since the beginning of modern hospice movement developed by the late Dame Cicely Saunders. SC at the end of life includes helping patients to recognise and develop their spiritual perspective and respecting their choices and decisions. This definition also includes patients' relatives who may also benefit from SC, by helping them deal with their loss and grief during the illness and bereavement process. Holyoke and Stephenson discuss how SC should not be

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1 John Hardwing, "Spiritual Issues at the End of Life: A Call for Discussion," 28-30.

2 World Health Organization, "National cancer control programmes: Policies and Managerial Guidelines," (2002), accessed February 18, 2019, http://www.who.int/cancer/media/en/408.pdf.

considered a particular field of palliative care but rather a fundamental quality which constitutes palliative care.[3]

Usually it is quite difficult to distinguish when palliative care should begin. Masso and colleagues classify the phases of palliative care into five stages: the stable, unstable, deteriorating, terminal and bereavement stages.[4] In contrast, Jeffrey discusses a conventional model for treating patients with terminal illness, which is divided into three stages of care.[5] The first stage is the curative stage of care, where the main aim is survival and where the physical aspect of the disease is given greatest importance. The second stage is the palliative stage, where the main aim is to improve the patient's quality of life by considering social, emotional and spiritual aspects of the patient apart from their physical needs. The last stage of care is the terminal stage, where the main aim is to help the patient die with dignity. The boundaries and transitions between these phases are not always clear, and Jeffrey believes that respect for patient's autonomy will usually help HCPs in deciding when it is time to switch from one phase to another. Communication between members of the MDT, understanding individual and family processes and time for acceptance were also found to help in the transition from one phase of care to another.[6]

A problem found today in many healthcare settings is the assumption that palliative and terminal care are the same. Although it is widely accepted that SC should be an integral part of palliative care, HCPs are sometimes delaying or even skipping this stage of care and going from the curative to the terminal stage of care. When palliative care is delayed until the last few weeks or even days of life, there is a missed opportunity to provide patients with the necessary care they require. One of the greatest barriers to early palliative care is the lack of well-timed identification of those patients who may benefit

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3 Paul Holyoke and Barry Stephenson, "Organization-level principles and practices to support spiritual care at the end of life: A qualitative study," *BMC Palliative care* 16, no. 24 (2017): 1-19.

4 Malcom Masso *et al*., "Palliative care phase: inter-rater reliability and acceptability in a national study," *Palliative Medicine* 29, no. 1 (2015): 22-30.

5 David Jeffrey, "Appropriate palliative care: when does it begin?" *European Journal of Cancer Care* 4, no. 3 (2007): 122-126.

6 Margaret H. Crighton *et al.,* "Transitioning to End-of-Life Care in the Intensive Care Unit," *Cancer Nursing* 31, no. 6 (2008): 478-484.

from such care. HCPs, therefore, should screen patients to discover those who would benefit from early palliative care, taking into account some of the trigger factors such as decline in general health, poorly controlled symptoms and decreased patient's independence.[7]

Another limiting factor in providing palliative care is the fact that many patients associate the word 'palliative' with imminent death and therefore are reluctant to receive such care. In fact, Zimmermann and colleagues studied patients' and HCPs' perceptions of palliative care and found that there is a negative stigma associated with death, which tends to provoke fear and avoidance.[8] This negative perception can be linked to the limited public knowledge on palliative care. Hirai and colleagues found that approximately 63% of their study participants (N= 3984) had no knowledge of palliative care services.[9] A similar result was found in a survey involving one thousand people, where only 24% were found to be familiar with the term palliative care.[10] In contrast, 86% were familiar with the term hospice care. These findings highlight the need for health promotion on palliative care to improve public knowledge and enhance the quality of end-of-life care through the use of early onset appropriate palliative care.[11]

Murtagh and colleagues studied the need for palliative care in a national population using death registration data.[12] The authors looked who among those who died were able to benefit from palliative care using a professionally defined perspective, and they found that up to 80% would have benefited from palliative care early in the course of illness. In fact, in 2014, the WHO indicated the importance of early palliative care from

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7 Scott Murray *et al*., "Palliative care from diagnosis to death," *BMJ Clinical Research* 356 (2017): 1-5.

8 Camilla Zimmermann *et al*., "Perceptions of palliative care among patients with advanced cancer and their caregivers," *Canadian Medical Association Journal* 188, no. 10 (2016): 1-11.

9 Kei Hirai *et al.,* "Public Awareness, Knowledge of Availability, and Readiness for Cancer Palliative Care Services: A Population-Based Survey across Four Regions in Japan," *Journal of Palliative Medicine* 14, no. 8 (2011): 918-922.

10 "Living well at the end of life: A national conversation," The Regence Foundation (2011), accessed January 3, 2019, www.syndication.nationaljournal.com/communications/NationalJournalRegence Toplines.pdf.

11 Sonya Mcilfatrick *et al*., "Exploring public awareness and perceptions of palliative care: A qualitative study," *Palliative Medicine* 28, no. 3 (2013): 273-280.

12 Fliss E.M. Murtagh *et al.,* "How many people need palliative care? A study developing and comparing methods for population-based estimates," *Palliative Medicine* 28, no. 1 (2014): 49-58.

diagnosis onwards and that this should be included in the care of patients with any life threatening illness.[13] Studies had linked early palliative care with patients' improved quality of life and mood.[14] Apart from these effects, Temel and colleagues also found that early palliative care can result in longer survival even though patients use less aggressive care approach.[15] There seems to be an emphasis on the importance of starting SC as part of palliative care as early as possible, usually from around the time the patient is given the diagnosis. Palliative care when started early on can also include curative therapies at the same time and if the condition improves palliative care can be discontinued. Starting palliative care early on will help eliminate missed opportunities for those patients who die earlier than predicted.

A systematic review found that most patients prefer to receive palliative care and die at home, for various reasons which shall be discussed in the next chapter.[16] Palliative care at home is usually provided through hospice care; however, for the patient to receive such care, there is usually a need for a physician to certify a prognosis of six months or less.[17] In certain chronic and terminal illnesses apart from cancer, however, it is difficult to provide an exact prognosis.[18] This leaves a good amount of patients who die before getting access to this care, although hospice care studies show great benefits for patients and their relatives. When comparing hospice patients to other conventional care patients, hospice patients showed better pain and symptom control and were more likely to die at home with their relatives.[19] Hospice patients are more likely to die in a

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13 World Health Organisation, "Strengthening of palliative care as a component of integrated treatment within the continuum of care," *World Health Assembly* (2014), accessed January 5, 2019, http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_R7-en.pdf.

14 M. Bakitas *et al.,* "Effects of palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial," *Journal of American Medical Association* 302, no. 1 (2009): 741–749.

15 Jennifer S. Temel *et al*., "Early palliative care for patients with metastatic non-small-cell-lung cancer," *New England Journal of Medicine* 363, no. 8 (2010): 733–742.

16 Barbara Gomes *et al.,* "Heterogeneity and changes in preferences for dying at home: A systematic review," *BMC Palliative Care* 12, no. 7 (2013): 1-13.

17 Cara Wallace, "Hospice Eligibility and Election: Does Policy Prepare Us to Meet the Need?" *Journal of Aging and Social Policy* 27, no. 4 (2015): 364- 380.

18 Ellen Fox *et al.,* "Evaluation of Prognostic Criteria for Determining Hospice Eligibility in Patients with Advanced Lung, Heart, or Liver Disease," *The Journal of the American Medical Association* 282, no. 17 (1999): 1638-45.

19 David S. Greer *et al.,* "An alternative in terminal care: Results of the National Hospice Study," *Journal of Chronic Diseases* 39, no. 1 (1986): 9-26.

way that fulfil their last wishes and together with their relatives are more satisfied with the care provided.[20]

Studies show how terminally ill patients tend to report stronger spiritual perspectives than healthy or non-terminally ill patients.[21] Providing SC for terminally ill patients involves building meaningful connections, respecting their decisions regarding the dying process, and understanding their individual spiritual needs through discussions regarding their life experiences and accomplishments.[22] SC in terminally ill patients can be viewed as a coping mechanism helping patients to achieve well-being and die with dignity in spite of their illness. Spiritual well-being can also be achieved through self-actualization, understanding the meaning of the disease experience and accepting death.[23]

2.1.1 Spirituality and Death

In palliative care, dying is considered a normal part of life for every individual; however, literature shows that the concept of a 'good death' is extremely subjective.[24] For Jones and Willis, a 'good death' is "one that is pain free, dignified and one in which active resuscitation never occurs."[25] They argue, however, that this is not what all patients want. HCPs therefore need to have the appropriate skills and resources to discover how patients want to die, without being paternalistic. Walter discusses how patients who are facing their own mortality can face death either as an end in itself or a beginning to something more important.[26] This depends on the patients' belief system and their

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20 Norma Jean Dawson, "Need satisfaction in terminal care settings," *Social Science and Medicine* 32, no. 1 (1991): 83-87.

21 Pamela G. Reed, "Preferences for spirituality-related nursing interventions among terminally ill and non-terminally ill hospitalized adults and well adults," *Applied Nursing Research* 4, no. 3 (1991): 122-128.

22 Pam Stephenson, Claire Draucker and Donna S. Martsolf, "The Experience of Spirituality in the Lives of Hospice Patients," *Journal of Hospice and Palliative Nursing* 5, no. 1 (2003): 51-58.

23 P.B. Fryback and B.R. Reinert, "Spirituality and people with potentially fatal diagnoses," *Nursing Forum* 34, no. 1 (1999): 13-22.

24 Ira R. Byock, "Where do we go from here? A palliative care perspective," *Critical Care Medicine* 34, no. 11 (2006): 416-420.

25 June Jones and Derek Willis, "In search of a good death: What is a good death?" *British Medical Journal (online)* 327, no. 7408 (2003): 224.

26 Tony Walter, "Spirituality in palliative care," 133-139.

expression through institutionalized religious traditions. Facing the issue of getting closer to one's mortality can also result in more spiritual reflections which can lead to the development of spiritual concerns and needs.[27] Broadhurst and Harrington studied the transcendence phenomenon commonly experienced by patients before dying.[28] The authors highlight the importance for HCPs to accept this phenomenon as a spiritual experience, which can lead to a peaceful death. Similarly, Narayanasamy mentioned how this transcendence phenomenon experienced by patients will help them in finding peace no matter how severe their illness is.[29]

Steinhauser and colleagues studied what factors are considered important at end of life for patients, relatives and HCPs.[30] They found that pain and symptom management, communication with HCPs, preparation for death and an occasion to accomplish a sense of completion where factors that patients, relatives and HCP all considered important. Stephenson and colleagues studied the experience of spirituality in patients receiving hospice care.[31] All patients in their study described dying the way they lived and that all the beliefs, values, and spiritual experiences that were significant to them during life were also significant while dying. Talking to patients about their life experiences, therefore, can enable HCPs to discover what is important for them during the dying process.

Decisions on when to stop treating the disease and let the patient die have been the focus of bioethics since the development of new medical technologies which gave growing power to HCPs.[32] Singer argues how patients have the same power as physicians

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27 Ira R. Byock, "The Meaning and Value of Death," *Journal of Palliative Medicine* 5, no.2 (2002): 279-288.

28 Kathleen Broadhurst and Ann Harrington, "A Thematic Literature Review: The Importance of Providing Spiritual Care for End-of-Life Patients Who Have Experienced Transcendence Phenomena," *The American Journal of Hospice and Palliative Care* 33, no. 9 (2015): 1-13.

29 Aru Narayanasamy, "Spiritual coping mechanisms in chronically ill patients," *British Journal of Nursing* 11, no. 22 (2002): 159-175.

30 Karen E. Steinhauser *et al.,* "Factors considered important at the end of life by patients, family, physicians, and other care providers," *The Journal of the American Medical Association* 284, no. 19 (2000): 2476-82.

31 Pamela Stephenson *et al*., "Spirituality in Hospice Patients," 51-58.

32 Benjamin Noys, "Bioethics and Death," in *The Culture of Death*, ed. by Benjamnin Noys (New York: Bloomsbury Academic, 2005), 77-99.

when it comes to ethical decisions such as refusing medical treatment.[33] Conversely, Agamben, a philosopher, considers these medical decisions about death as bio-political rather than biological decisions, which must therefore be tackled politically.[34] Others seem to disagree with this, arguing that when problems arise in the health care setting, there is a shift from a philosophical or political view to a more medical or biological view and, although both seem to be interrelated, this shift seems to be necessary.[35]

Health systems and medical progress are delaying death and maintaining the population alive for longer periods of time. In fact, individuals seem to have more control in deciding when death will happen. According to Mitchell, doing so, only delays the inevitable, so more emphasis should be placed on end-of-life care and how to maintain quality of life as death approaches, and not only focusing on prolonging life.[36] Field also discusses the concept of the 'medicalization of death' where death is perceived less as an inevitable part of life and more as a failure of medical treatment.[37] Linked to this concept is the institutionalization of death where the care of the dying patient has been increasingly associated with the role of HCPs, especially physicians and nurses. This has been related to family lifestyle changes and the inability of modern families to take responsibility in caring for their dying relative. Terminally ill patients, therefore, are increasingly being cared for and dying in hospitals or in inpatients hospice centres, with consequently, less patients dying at home, even though the preferred place of death is at home, as shall be discussed in the next chapter.

A problem found today in healthcare settings is the fact that HCPs tend to look at death as a failure and in doing so they are often unable to identify those patients who are

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33 Peter Singer, "A dubious distinction," *The Guardian*, accessed January 23, 2019, https://www.theguardian.com/commentisfree/2007/jan/17/comment.health.

34 Giorgio Agamben, *Homo Sacer: Sovereign Power and Bare Life* (Stanford: Stanford University Press, 1998), 126-136.

35 Andrew Weis, "Matters of Life and Death Through Agamben: From Bare Life to Forms-of-Life," *University of Toronto*, Canada (2009), accessed January 26, 2019, https://www.academia.edu/1161898/Matters_of_Life_and_Death_Through_Agamben_From_Bare_Life_to_Forms-of-Life.

36 Geoffrey Mitchell, "Rapidly increasing end-of-life care needs: A timely warning," *BMC Medicine* 15, no. 126 (2017): 1-2.

37 David Field, "Palliative medicine and the medicalization of death," *European Journal of Cancer Care* 3, no. 2 (1994): 58-62.

actually dying. A solution to this can be to offer the best available care for every patient, not only for cancer patients or patients under the care of a specialist palliative care team.[38] This seems especially important in elderly patients who seem to comprise a high proportion of palliative care beds. Some authors even suggest that due to a natural higher risk of death, all elderly hospitalized patients should be provided with SC, without it being imposed.[39]

2.1.2 Spiritual Interventions

Literature seems to present an unclear picture of SC at the end of life,[40] and most HCPs seem to poorly understand what such care includes.[41] SC involves both assessment to identify spiritual needs as discussed in the previous chapter (chapter 1.3) and spiritual interventions to meet these needs. There are some authors, however, who seem to disagree with the idea of SC interventions. A systematic review on the role of SC at the end of life, for example, found evidence supporting the notion that SC is not about interventions but an approach in which care, including physical care, is given through relationships.[42] Similarly, Williams and colleagues agree that SC is provided mainly through an environment of accepted human values, dignity and shared decision making, and not through spiritual interventions.[43]

In spite of this, a systematic review on SC found 28 articles mentioning the term SC intervention, 90% of which were within the nursing field.[44] The authors grouped these mentioned interventions into ten categories: religious, spiritual, counselling, emotional support, advocacy, presence, respect, communication, adjunct therapy and other care.

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38 John Ellershaw and Chris Ward, "Care of the dying patient: The last hours or days of life," *BMJ (online)* 326, issue 7379 (2003): 30-34.

39 Tony Walter, "Spirituality in palliative care," 133-139.

40 Shane Sinclair *et al.,* "A thematic review of the spirituality literature," 464-479.

41 Susann Strang, Peter Strang and Britt-Marie Ternestedt, "Spiritual needs as defined by Swedish nursing staff," *Journal of Clinical Nursing* 11, no. 1 (2002): 48-57.

42 Adrian Gwyn Edwards, "The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: A meta-study of qualitative research," *Palliative Medicine* 24, no. 8 (2010): 753-770.

43 Sharon W. Williams, Laura Hanson and Jim Rawlings, "An Exploratory Study of Spiritual Care at the End of life," *The Annals of Family Medicine* 6, no. 5 (2008): 406-411.

44 Leonard Hummel *et al*., "Defining Spiritual Care: An Exploratory Study," *Journal of Health Care Chaplaincy* 15, no. 1 (2008): 40–51.

Only a few of these categories, however, include a clear description of what spiritual interventions involve. There were also some spiritual interventions that did not fall under one particular category; for example, active listening, which is a universally used intervention can be present in a number of categories. Another finding from this study was that chaplains and nurses tend to agree on specific SC interventions.

Another systematic review found that there are two types of spiritual interventions in the literature: scoping and improvement interventions.[45] Scoping interventions offer knowledge to HCPs and help them develop an evidence-based practice, while improvement interventions aim at improving the delivery and practice of SC. The same review identified nine SC models in the palliative setting (Appendix A.4.1-4.9). The main aim of these models is to promote awareness, development and integration of spirituality within HCPs' practice. Findings from this review showed that evidence in supporting the effectiveness of individual SC interventions is limited. Evidence, however, seems to favour a multidisciplinary and interdisciplinary approach to the provision of SC. Oliver and colleagues also highlight the difficulty in standardizing complex spiritual interventions and the lack of evaluation tools in studying the effects of these interventions on health outcomes.[46] Similarly, Hunt and colleagues found that SC lacks quality standards of practice, which can act as a guidance for HCPs.[47] In view of this need the authors developed a quality standard to provide a consistent approach during assessment, delivery and evaluation of SC.

Caldeira and Timmins also developed the 'ABCDE components of SC' (Appendix A.5) as a guide for nurses and other HCPs, to be used with their clinical reasoning skills to plan further SC interventions.[48] Apart from this, HCPs should also follow their profession's ethical standards or codes of ethics. Wright discusses how HCPs have an ethical obligation to provide SC and how the ethical principles of beneficence, non-maleficence,

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45 Margaret Holloway *et al.,* "Spiritual care at the end of life," 1-105.
46 Oliver Amparo *et al.*, "Evaluation tools for spiritual support in end of life care," 357-360.
47 John Hunt *et al.*, "The quality of spiritual care," 208-215.
48 Sílvia Caldeira and Fiona Timmins, "Implementing spiritual care interventions," *Nursing standard: Official Newspaper of the Royal College of Nursing* 31, no. 34 (2017): 54-60.

autonomy and advocacy are also applicable to SC.[49] The Maltese nursing code of ethics specifies that "the patient has to be treated in his/her totality as a person and consideration has to be given to his/her physical, psychological, social and spiritual needs."[50] It also highlights the need for HCPs to respect the patients' various rights, including that of autonomy and self-determination. Respecting patients' autonomy also applies in those cases where the patients do not want to discuss any spiritual issues. In fact, informed consent (not necessarily written) is usually considered necessary before spiritual assessments and referrals to spiritual care specialists.[51] Puchalski and colleagues also describe the important role of HCPs in carefully describing and documenting each spiritual intervention used, in patients' medical records together with its outcome.[52]

Gulherme discusses some nursing interventions that are considered adequate in helping patients overcome spiritual distress.[53] These include music therapy, guided imaging, therapeutic touch, progressive muscle relaxation, distant intercessory prayer, reminiscence therapy, affective support group and meditation. Emblen and Halstead found that patients, nurses and chaplains tend to associate prayer, reading scripture, presence, listening and referral to a chaplain as the main nursing SC interventions.[54] Similarly Stranahan found that HCPs consider prayer and referral to clergy as the most frequently used spiritual interventions.[55] Other spiritual interventions mentioned in literature are fulfilling dying wishes, talking to relatives regarding end-of-life decisions,[56]

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49 Kathy B. Wright, "Professional, ethical, and legal implications for spiritual care in nursing," *Image: Journal of Nursing Scholarship* 30, no. 1 (1998): 81-83.

50 Nursing and Midwifery Board, "*Maltese Code of Ethics for Nurses and Midwives,*" accessed January 28, 2019, https://deputyprimeminister.gov.mt/en/phc/pdu/documents/maltese_code_of_ ethics_ nurses.pdf.

51 Elizabeth Johnston Taylor, "Spiritual Care: Evangelism by the bedside?" *Journal of Christian Nursing* 28, no. 4 (2011): 194-202.

52 Christina Puchalski *et al*., "Improving the quality of spiritual care," 885-904.

53 Caroline Gulherme, "Spiritual distress in cancer patients: Nursing interventions," *Revista de Enfermagem UFPE on-line* 5, no. 2 (2011): 290-294.

54 J.D. Emblen and L. Halstead, "Spiritual needs and interventions: Comparing the views of patients, nurses, and chaplains," *Clinical Nurse Specialist* 7, no. 4 (1993): 175-182.

55 Susan Stranahan, "Spiritual Perception, Attitudes about Spiritual Care, and Spiritual Care Practices among Nurse Practitioners," *Western Journal of Nursing Research* 23, no. 1 (2001): 90-104.

56 Theris A. Touhy, Cynthia Brown and Carol J. Smith, "Spiritual Caring: End of Life in a Nursing Home," *Journal of Gerontological Nursing* 31, no. 9 (2005): 27-35.

providing worship services, providing longer and more frequent family visits,[57] helping in funeral arrangements, and even attending to physical needs.[58]

Studies show that patients and HCPs are associating SC more with assessing and supporting spiritual needs,[59] and coping with illness,[60] rather than religious forms of interventions. Balboni and colleagues found that although the majority of patients and HCPs perceive prayer as spiritually supportive this is not always considered appropriate especially when initiated by HCPs and not by patients themselves.[61] Baldacchino and Draper discuss the importance for HCPs to be familiar with the various spiritual coping strategies that can be used in both religious and non-religious patients.[62] They discuss two specific strategies, the stress-coping strategies developed by Folkman and Lazarus in 1984,[63] and the numinous experience developed by Otto in 1950,[64] which can help both religious and non-religious patients achieve spiritual well-being through self-empowering.

A systematic review found that there are only a small number of studies which include patients' perception to SC interventions.[65] This is quite worrying because it means that SC interventions are being developed without the opinion of patients themselves when they are the main service users. One of these studies found that patients describe a set of interpersonal attitudes necessary in providing effective SC, including openness,

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57 Nasser Abu-El-Noor, "ICU Nurses perceptions and practice of spiritual care at the end of life: Implications for policy changes," *Online Journal of Issues in Nursing* 21, no. 1 (2016): 1-6.

58 Joan Thomas and Andrew Retsa, "Transacting self-preservation: a grounded theory of the spiritual dimensions of people with terminal cancer," *International Journal of Nursing Studies* 36, no. 3 (1999) 191-201.

59 Andrea Phelps *et al*., "Addressing Spirituality at the end of life," 2538-44.

60 Laura Hanson *et al*., "Providers and Types of Spiritual Care during Serious Illness," *Journal of Palliative Medicine* 11, no. 6 (2008): 907-914.

61 Micheal J. Balboni *et al.,* ""It Depends": Viewpoints of Patients, Physicians, and Nurses on Patient-Practitioner Prayer in the Setting of Advanced Cancer," *Journal of Pain and Symptom Management* 41, no. 5 (2011): 836-847.

62 Donia Baldacchino and Peter Draper, "Spiritual coping strategies: A review of the nursing research literature," *Journal of Advanced Nursing* 34, no. 6 (2001): 833 – 841.

63 S. Folkman and R.S. Lazarus, *Stress, Appraisal and Coping*, 1984, quoted in Donia Baldacchino and Peter Draper, "Spiritual coping strategies," 833 – 841.

64 R. Otto, *The Idea of the Holy: An Inquiry into the Non-Rational Factor in the Idea of the Divine and its Relation to the Rational*, 1950, quoted in Donia Baldacchino and Peter Draper, "Spiritual coping strategies," 833-841.

65 Margaret Holloway *et al*., "Spiritual care at the end of life," 1-105.

respect, genuineness, non-judgment, hopefulness, honesty, empathy, kindness and being spiritually aware.[66] Similarly, another study, this time involving HCPs' perceptions, identified five basic skills necessary for SC, including hearing, sight, speech, touch and presence (Appendix C.4).[67] These skills, together with other qualities of HCPs such as spiritual beliefs, seem to be more important for achieving spiritual well-being rather than more technical skills or evidence-based knowledge. In fact, Puchalski discusses how "spirituality may not be amenable entirely to strict evidence-base criteria," unlike other types of care used in the healthcare settings where evidence based practice is considered crucial.[68]

Although there is limited evidence demonstrating the effectiveness of specific SC interventions,[69] a consensus is emerging in the literature that some evidence exists to support the provision of SC in healthcare settings.[70] In summary, literature is presenting an increasing evidence regarding the importance of a patient-centred approach to SC within an interdisciplinary model where all HCPs contribute to patient's care.[71] Apart from this, most of the interventions present in meeting patient's spiritual needs adopt a therapeutic communication approach.[72] In fact, active listening together with compassion and presence are considered essential characteristics for HCPs in order to provide good quality SC.[73] Presence is considered as the essence of SC by both patients[74] and HCPs.[75] SC is also considered relational, given through relationships between patients and HCPs. These positive relationships were found to support patients in meeting their own spiritual needs.[76] Another study found that for both patients and

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66 Lucy Selman *et al.,* "Patients' and Caregivers' needs in spiritual care," 1-15.
67 Shane Sinclair *et al*., "Spiritual care: How to do it," *Supportive and Palliative Care* 2, no. 4 (2012): 319-327.
68 Christina M. Puchalski, "Spirituality and the Care of Patients at the End-of-Life," 33-46.
69 Margaret Holloway *et al*., "Spiritual care at the end of life," 1-105.
70 Peter Speck, "The evidence base for spiritual care," *Nursing Management* 12, no. 6 (2005): 28-31.
71 Christina M. Puchalski *et al.,* "Interdisciplinary Spiritual Care for Patients," 398-413.
72 Christina M. Puchalski *et al.,* "Improving the quality of spiritual care," 885-904.
73 Christina M. Puchalski, "Spirituality and the Care of Patients at the End-of-Life," 33-46.
74 Timothy P. Daaleman *et al*., "An Exploratory Study of Spiritual Care at the End of Life," 406-411.
75 Shane Sinclair *et al*., "Spiritual care: How to do it," 319-327.
76 Adrian Gwyn Edwards, "The understanding of spirituality and spiritual care," 753-770.

HCPs ideal SC seems to be described as individualised, voluntary, includes chaplains, and involves the assessment and support of patients' own spirituality.[77]

2.2 Frequency of Spiritual Care at the End of Life

Although the JCAHO has required that SC be provided to all patients in hospital settings and although the importance of SC is highlighted across palliative care guidelines and policies, literature seems to portray a different reality when it comes to clinical practice, where SC seems to be limited or of not enough quality.[78] Studies show how despite the evidence-based importance of SC, which shall be discussed shortly, many patients in palliative care settings are not being spiritually assessed and supported. For example, Balboni and colleagues found that out of 230 patients, 47% reported unmet spiritual needs by their religious communities and 72% by their medical HCPs.[79] Selman and colleagues also found that majority of patients and relatives (N=145) feel that they did not receive sufficient SC.[80]

Similarly, Astrow and colleagues found that from a sample of 369 patients, only 6% reported that a HCP had asked about their spiritual needs while 18% reported that their spiritual needs were not being met.[81] Of these patients the majority were less satisfied with the quality of care given. Another study found similar findings, were out of 75 patients with advanced cancer, 87% mentioned never having received any form of SC from their nurses and 94% from their physicians.[82] The same study also showed that only 31% of nurses and 24% of physicians reported providing SC to their patients. Phelps and colleagues also found that out of 75 patients with advanced cancer only 25% had previously received some type of SC.[83] Another study, this time involving 174 Muslim

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77 Andrea Phelps *et al.,* "Addressing spirituality at the end of life," 2538–44.
78 Danielle Rodin *et al.,* "Practitioners' perceptions of their role in providing spiritual care," 1-8.
79 Tracy A. Balboni *et al.,* "Religiousness and Spiritual Support," 555-560.
80 Lucy Selman *et al.,* "Patients' and Caregivers' needs in spiritual care," 1-15.
81 Alan B. Astrow *et al.,* "Patients' perceptions of quality of care and satisfaction with care," 5753–57.
82 Michael Balboni *et al.*, "Why is spiritual care infrequent at the end of life?" 461–467.
83 Phelps *et al.*, "Addressing Spirituality at the End of Life," 2538-44.

patients in palliative care hospitals, found that although the rate of SC provision was high it was not enough to meet the spiritual needs of patients.[84]

Interestingly, Fitchett and colleagues found that older, more religious patients, suffering from more serious illness which require longer hospitalizations, tend to request SC the most.[85] The authors discuss how in reality this should not necessarily mean that these are the ones who mostly need it. Usually, patients who have the most spiritual needs are the ones who have the least religious resources and are the ones who less likely request SC. Similarly, Kennedy and Cheston found that patients who were not formerly religious and seem least likely to request SC may be the ones who mostly benefit from appropriate SC.[86] That's why HCPs, together with the hospital chaplain, should identify these patients through spiritual assessments, so as to provide the necessary support, always if the patient is willing to discuss such issues. Evidence shows that the majority of patients would have no objection to discuss their spiritual needs with their HCP.[87]

This infrequent provision of SC in healthcare settings does not appear to be caused by a lack of perceived importance of SC in end-of-life care, since studies show that both patients and HCPs in end-of-life care settings agree that SC is important and that it is the role of HCPs to provide such care.[88] Treloar believes that one reason why SC is infrequently integrated in healthcare is the fact that modern medicine tends to focus on pragmatism, making use only of tangible and measurable methods of care which are quite incompatible with spirituality.[89] Also, the cause for this limited provision of SC despite the perceived importance of such care, seems to be linked with a number of barriers, which will be described shortly.

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84 Anong Phibal and Urai Hatthakit, "The Spiritual Care Needs and Spiritual Care Received," *Supportive and Palliative Care* 3, no. 2 (2013): 248-249.

85 George Fitchett *et al*., "Spiritual Care in the Hospital," 173-186.

86 Christine Kennedy and Sharon E. Cheston, "Spiritual distress at life's end: Finding meaning in the maelstrom," *Journal of Pastoral Care and Counselling* 57, no. 2 (2003): 131–141.

87 George Fitchett *et al*., "Spiritual Care in the Hospital," 173-186.

88 Adrian Phelps *et al.,* "Addressing spirituality at the end of life," 2538–44.

89 Linda L. Treloar, "Integration of spirituality into healthcare practice by nurse practitioners," *Journal of the American Academy of Nurse Practitioners* 12, no. 7 (2000): 280-285.

A study investigating physicians' perceptions of their role in providing SC at the end of life found that less than 50% of physicians perceived themselves as adequately attending to their patients' spiritual needs.[90] Kuuppelomaki similarly found that the majority of nurses working in palliative care settings are unwilling to provide SC to their patients for several reasons.[91] One main reason seemed to be their lack of knowledge and skills in providing support to dying patients. Other limiting factors seem to be related to the difficulties patients may experience in expressing their spiritual needs and the limited availability of hospital chaplaincy service. This study showed that out of 328 nurses, half reported they only rarely offered spiritual support and over one third were not willing to provide such care. In contrast, Balboni and colleagues found that the majority of nurses (74%) and physicians (60%) are willing to provide SC, although they reported that a number of these nurses (39%) and physicians (41%) in practice are providing SC less often than desired (Appendix C.5).[92]

2.2.1 Barriers to Spiritual Care

To improve the frequency of SC provision and its quality, an understanding of the barriers HCPs are facing in their clinical setting is required. Studying these barriers will help in the identification of solutions to overcome them and increase the provision of SC to patients at the end of their lives. In the healthcare setting, barriers that prevent spiritual needs from being met may develop within HCPs, patients or the setting in which SC is provided and these may include personal, cultural or institutional factors.[93] The literature studying such barriers, however, seems to be limited and many studies do not examine the direct link between these barriers and actual SC provision.[94]

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90 Neil J. Faber *et al.,* "Frequency and perceived competence in providing palliative care to terminally ill patients: a survey of primary care physicians," *Journal of Pain and Symptom Management* 28, no. 4 (2004): 364-372.

91 Merja Kuuppelomaki, "Spiritual support for terminally ill patients: Nursing staff assessments," *Journal of Clinical Nursing* 10, no. 5 (2001): 660–670.

92 Michael J. Balboni *et al.,* "Nurse and Physician Barriers to Spiritual Care Provision at the End of Life," *Journal of Pain and Symptom Management* 48, no. 3 (2014): 400–410.

93 Adrian Gwyn Edwards, "The understanding of spirituality and spiritual care," 753-770.

94 Michael Balboni *et al.,* "Barriers to Spiritual Care Provision," 400–410.

One barrier to the provision of SC is the difficulty in understanding the meaning of spirituality and ones' role in providing SC.[95] Although SC is being increasingly recognized as an important aspect of patients' care, it still seems difficult to agree on what it is because of its highly subjective nature. Draper and McSherry explain that "we are a long way from having a universal agreement about what it means."[96] The fact that spirituality has different meanings and interpretations has implications on the way HCPs should be educated and trained on spirituality. This can also have implications on policy makers and other regulatory entities that should be careful not to draw any definite conclusions on what constitutes spirituality, especially when it comes to policies and guidelines on SC.[97] This lack of definition may result in lack of knowledge in the area of spirituality that may lead to a sense of ambiguity both for the patient and the HCP. In HCPs this can lead to a lack of confidence when it comes to providing SC and in patients this may interfere with the awareness of the concept of spiritual need or the inability to recognize that HCPs, apart from chaplains, are also responsible for SC provision.[98] Studies have reported that HCPs show lack of confidence in addressing spiritual needs which may be a direct result of the lack of knowledge.[99]

Apart from a lack of confidence in providing SC, HCPs face other barriers which limit them in addressing the spiritual needs of patients. Studies also mention a reluctance by HCPs to provide SC to their patients.[100] The reasons cited for this reluctance have included lack of education in SC, lack of time, lack of private space,[101] fear of invading a patient's privacy, a general lack of awareness of one's own spirituality,[102] secularization

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95 Lucy Rushton, "What are the barriers to spiritual care in a hospital setting?" *British Journal of Nursing* 23, no. 7 (2014): 370-374.

96 Peter Draper and Wilfred McSherry, "A critical view of spirituality and spiritual assessment," *Journal of Advanced Nursing* 39, no. 1 (2002): 1-2.

97 Wilfred McSherry, Keith Cash and Linda Ross, "Meaning of Spirituality: Implications for Nursing Practice," *Journal of Clinical Nursing* 13, no. 8 (2004): 934-941.

98 "Barriers influencing the provision of spiritual care," NurseKey, accessed January 28, 2019, https://nursekey.com/barriers-influencing-the-provision-of-spiritual-care/.

99 Michael Balboni *et al.,* "Why is spiritual care infrequent at the end of life?" 461–467.

100 Chris James Swift, Sara Calcutawalla and Rosie Elliot, "Nursing attitudes towards recording of religious and spiritual data," *British Journal of Nursing* 16, no. 20 (2007): 1279–82.

101 Michael Balboni *et al*., "Barriers to Spiritual Care Provision," 400–410.

102 Margaret Holloway *et al.,* "Spiritual care at the end of life," 1-105.

of modern society[103] and a lack of appreciation of the role of spirituality in the care of patients.[104] Rodin and colleagues found a direct link between the perceived importance of HCPs' role in SC and actual SC provision to patients.[105] Balboni and colleagues also discuss how HCPs' perception that SC is better delivered by others can act as a barrier to SC provision.[106] Similarly, other studies show that SC provision can also be impeded by some nurses considering SC to be a religious or pastoral matter and should therefore be addressed by hospital chaplains.[107]

Another barrier to SC is the belief that spiritual needs cannot be addressed if the HCP and the patient have different belief systems.[108] Hodge discusses how patients' spiritual beliefs and practices can sometimes function as a barrier to SC provision.[109] This can be prevented by properly assessing patients' needs and beliefs which can then be matched with appropriate interventions. When HCPs perceive a patient's belief system as different from their own, they may avoid the spiritual aspect of care and consider other aspects of care as more important.[110] This can lead HCPs to prefer treating patient's physical symptoms rather than taking the time to hold patients' hands and listen to their suffering. This is especially so when there are other issues involved, such as financial burdens, lack of staff, high turnover rates, and the pressure to be firmly evidence based and time effective. [111]

McSherry has grouped all the barriers to SC provision mentioned in the literature and classified them into five categories: economic, educational, environmental, ambiguous and sensitivity.[112] Economic barriers include issues such as lack of time, staff shortage

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103 Donia R. Baldacchino, "Teaching on spiritual care: The perceived impact on qualified nurses," *Nurse Education in Practice* 11, no. 1 (2011): 47-53.
104 Christina Puchalski *et al.,* "Interdisciplinary Spiritual Care," 398-416.
105 Danielle Rodin *et al.,* "Practitioners' perceptions of their role in providing spiritual care," 1-8.
106 Michael Balboni *et al.,* "Barriers to Spiritual Care Provision," 400–410.
107 Aru Narayanasamy and Jan Owens, "A critical incident study of nurses' responses to the spiritual needs of their patients," *Journal of Advanced Nursing* 33, no. 4 (2001): 446–455.
108 Helga Martins and Sílvia Caldeira, "Spiritual Distress in Cancer Patients," 1-17.
109 David Hodge, "A Template for Spiritual Assessment," 317-326.
110 Lay Hwa Tiew *et al*., "Hospice Nurses' Perspectives of Spirituality," *Journal of Clinical Nursing* 22, no. 19-20 (2013): 2923–33.
111 Christina Puchalski, "Spirituality and the care of patients," 33-46.
112 Wilfred McSherry, "Nurses' perceptions of spirituality and spiritual care," 36-40.

and lack of resources. Educational barriers involve the lack of training and knowledge which shall be discussed shorty. Environmental factors include lack of a private place where to discuss spiritual issues. Ambiguous factors include issues related to lack of understanding of what spirituality entails and lack of one's spiritual awareness. Sensitivity factors include issues related to HCPs perceiving spirituality as a private issue and therefore not considering it their role to discuss such private issues with the patient.

2.2.2 Spiritual Care Training

Some of the barriers to SC most mentioned in the literature seems to be related to insufficient academic training in spirituality,[113] end of life communication skills, and spiritual awareness.[114] Research indicates that most HCPs have received very limited or even no training on spirituality during their graduate training. Balboni and colleagues, for example, found that only 12 to 14% of HCPs (N=339) had received SC training.[115] Another study by Balboni and colleagues found that the majority of nurses (88%) and physicians (86%) (N= 339) claimed to have never received SC training.[116] McSherry also noted that 71.8% out of 559 qualified nurses felt that they did not receive adequate training, for them to be prepared in addressing spiritual issues.[117] The author also suggests that there is a strong possibility that the limited knowledge and skills that nurses have in SC decrease both their ability and willingness to provide SC. There are other studies in fact, which found that majority of HCPs desire to learn more about how to assess spirituality.[118] Balboni and colleagues found that 79% of nurses and 51% of physicians, desire to learn more on SC.[119]

Evidence shows that the strongest predictor of an actual SC provision is spiritual training and education.[120] Narayanasamy suggests that there is a link between inclusion of SC

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113 Aru Narayanasamy, "Nurses' awareness and educational preparation in meeting their patients' spiritual needs," *Nurse Education Today* 13, no. 3 (1993): 196-201.
114 Christina Puchalski, "Spirituality and the care of patients," 33-46.
115 Michael Balboni *et al.,* "Why is spiritual care infrequent at the end of life?" 461–467.
116 Michael Balboni *et al*., "Barriers to Spiritual Care Provision," 400–410.
117 Wilfred McSherry, "Nurses' perceptions of spirituality and spiritual care," 36-40.
118 David R. Hodge, "Why Conduct a Spiritual Assessment? A Theoretical Foundation for Assessment," *Advances in Social Work* 5, no. 2 (2004): 183-196.
119 Michael Balboni *et al.,* "Barriers to Spiritual Care Provision," 400–410.
120 *Ibid.*

education and an increase in nurses' knowledge and understanding of spiritual issues which in turn can result in increased provision of SC.[121] SC training can result in HCPs becoming more confident and competent in providing SC, by learning how to offer compassionate caregiving, moving from a disease-centred model of care to a patient-centred model of care, appropriately assessing patients' spiritual needs, identifying the importance of spirituality in healthcare and the role of hospital chaplains, learning necessary communication skills, exploring their own spirituality and learning about various religious and cultural traditions.[122] Robinson and colleagues also studied the effectiveness of SC training in 115 HCPs from various disciplines and found that participation in a one day spiritual generalist workshop was effective enough to teach HCPs general SC skills and to collaborate more with the hospital chaplain.[123] All these studies have focused on how SC training had an effect on HCPs outcomes, such as increased knowledge and competency. Focusing the effect of SC training on patients' outcomes, Yang and colleagues found a link between SC training and improved patients' quality of life.[124]

In 1992, Puchalski observed how medical students received very limited SC training, with only 3 medical schools incorporating spirituality courses in their curricula.[125] She therefore introduced an elective course on spirituality at the George Washington University School of Medicine. In 1996, this course became part of the compulsory curriculum and since then over 75% of medical schools in the US are requiring students to study courses in spirituality related to health. The author discusses how more work needs to be done in spite of this improvement. In fact, Rasinksi and colleagues found

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121 Aru Narayanasamy, "Nurses' awareness and educational preparation in spiritual care," 196-201.

122 Christina Puchalski and D.B. Larson, "Developing curricula in spirituality and medicine," *Academic Medicine* 73, no. 9 (1998): 970-974.

123 Mary Robinson *et al.,* "Efficacy of Training Interprofessional Spiritual Care Generalists," *Journal of Palliative Medicine* 19, no. 8 (2016): 814-821.

124 Grace M. Yang *et al*., "Effect of a spiritual care training program for staff on patient outcomes," *Palliative and Supportive Care* 15, no. 4 (2016): 1-10.

125 Christina Puchalski, "Spirituality and Medicine: Curricula in Medical Education," *Journal of Cancer Education* 21, no. 1 (2006): 14-18.

that in 2003, only 23% of practicing physicians in the US reported receiving formal SC training.[126]

Similarly, in 1985 Carson and Gerardi introduced a course called 'Spirituality in Nursing Practice' within a nursing school in the US.[127] After its success, more schools started to incorporate spirituality courses as part of the nursing curricula. Studies show that in the UK there are still less medical schools teaching spirituality when compared to the US with rates ranging from 31% to 59% of medical schools.[128] In 1999, the UK Commission for Education in Nursing and Midwifery tried to address this educational need with the 'Fitness for Practice'.[129] One of the competencies listed in this document is the need for nurses to identify spiritual needs of their patients. Also, in some EU countries such as Portugal, HCPs have study units on spirituality only as part of a Masters' or postgraduate palliative course.[130]

In Malta, a study unit entitled 'The spiritual dimension in care' was introduced in 2002 as part of the diploma nursing course at the University of Malta.[131] Apart from this, another study unit entitled 'Spiritual coping in illness and care' was introduced as part of the continuous professional development (CPD) of qualified nurses.[132] Evaluation data on the study unit found that nurses who have undertaken the study unit showed increased knowledge on the spiritual dimension to care and improved self-awareness of their role in SC.[133] Due to the positive impact this study unit has had on nurses, Baldacchino recommends that other members of the MDT apart from nurses participate in these study units. Apart from this, educators from Malta together with other

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126 Kenneth A. Rasinski *et al.,* "An assessment of US physicians' training in religion, spirituality, and medicine," *Medical Teacher* 33, no. 11 (2011): 944-945.

127 Verna Benner Carson and Ruth Gerardi*,* "Spirituality for credit: Finding a place in the secular curriculum. 1985," *Journal of Christian Nursing* 30, no. 1 (2013): 34-37.

128 David Neely and Eunice J. Minford, "Current status of teaching on spirituality in UK medical schools," *Medical Education* 42, no. 2 (2008): 176–182.

129 P.L. Bradshaw, "Fitness for Practice," *Journal of Nursing Management* 8, no. 1 (2001):1–2.

130 Sílvia Caldeira, Sara Pinto and Manuel Luís Capelas*,*" Implementing spiritual care at the end of life: Portugal," *European Journal of Palliative Care* 24, no. 4 (2017): 175-176.

131 Donia R. Baldacchino, "Teaching on the spiritual dimension in care to undergraduate nursing students: The content and teaching methods," *Nurse Education Today* 28, no. 5 (2008): 550–562.

132 Donia R. Baldacchino, "Teaching on spiritual care," 47-53.

133 Donia R. Baldacchino, "Spiritual Care Education of Health Care Professionals," *Religions* 6 (2015): 594-613.

educators from Netherlands, Norway and the UK, are taking part in the Enhancing Nurses' and Midwives' Competence in Providing Spiritual Care through Innovative Education and Compassionate Care (EPICC) project, which aims at enhancing HCPs' SC training.[134] At present, however, there are no official study units on spirituality in HCPs' curricula at degree level, except for midwifery, who have a compulsory study unit entitled 'Spirituality in Midwifery' in their third year of studies. Apart from this, Bugeja discusses the need for the curriculum in specialists' training in family medicine for Malta, to include competency skills in assessing and dealing with spiritual issues especially when dealing with palliative care patients.[135]

McSherry and Draper discuss some of the intrinsic and extrinsic barriers that limit the introduction of spirituality courses in nursing curricula.[136] Intrinsic barriers can include political and socioeconomic factors within the institution itself, while extrinsic barriers may include social, cultural or religious factors of the individuals involved or of the society in general. Another barrier in SC training mentioned in the literature is the lack of uniformity in SC education. Neely and Minford found that there is lack of uniformity when it comes to the content, structure, quantity or type of staff member providing the training.[137] According to Lloyd-Williams and Field, nurses' curricula are not only lacking spiritual training but also basic palliative care training.[138] This type of training is limited to fewer hours when compared to medical students' curricula and it usually involves only the theoretical aspect. Yardley and colleagues also studied palliative patients' perspectives on SC training, and concluded that their perspective is important in the understanding of how SC training should include learning through experience and reflection.[139] The authors conclude that there is a need for more formal evaluation to

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134 "EPPIC Project," European Union's Erasmus+ Programme, accessed January 30, 2019, http://blogs.staffs.ac.uk/epicc/.

135 Anton Bugeja, "Spirituality in General Practice," *Maltese Family Doctor* 19, no. 1 (2010): 26-31.

136 Wilfred McSherry and Peter Draper, "The spiritual dimension: Why the absence within nursing curricula?" *Nurse Education Today* 17, no. 5 (1997): 413-417.

137 David Neely and Eunice Minford, "Current status of teaching on spirituality in UK," 176–182.

138 Mari Lloyd-Williams and David Field, "Are undergraduate nurses taught palliative care during their training?" *Nurse Education Today* 22, no. 7 (2002): 589-592.

139 Sarah Yardley, Catherine E. Walshe and A. Parr, "Improving training in spiritual care: A qualitative study exploring patient perceptions of professional educational requirements," *Palliative Medicine* 23, no. 7 (2009): 601-617.

assess the effectiveness of training in the clinical setting and also recommended further research to investigate who is the most competent to teach the SC educators themselves.

Even though SC education alone is not considered enough to provide good quality SC,[140] evidence shows that SC training is the strongest predictor of SC provision.[141] Spiritual training and education should therefore, form part of HCPs' curricula.[142] Although there are studies which support the concept that spirituality can be taught to HCPs,[143] there are other authors who argue that since spirituality is developed through life experiences, it is something that could not be formally taught.[144] Another debate present in the literature is whether HCPs' own spiritual awareness has an influence on SC provision. Some authors suggests that HCPs first need to evaluate and understand their own spirituality through SC training, before delivering SC to patients,[145] while others believe that SC provision does not depend upon the HCPs' understanding of their own spirituality.[146] For example, Walter believes that SC provision does not depend on HCPs' own spirituality, arguing that SC can be provided by anyone and for anyone.[147] There seems to be an agreement, however, that the main goal of SC training is always to improve patients' care by providing patient-centred holistic care.[148]

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140 Edwards Adrian Gwyn, "The understanding of spirituality," 753-770.

141 Michael Balboni, "Why is spiritual care infrequent at the end of life?" 461-467.

142 John Hunt *et al.,* "The quality of spiritual care," 208-215.

143 Pamela J. Meredith *et al.,* "Can spirituality be taught to health care professionals?" *Journal of Religion and Health* 51, no. 3 (2012): 879-889.

144 Ann Bradshow, "Teaching spiritual care to nurses: An alternative approach," *International Journal of Palliative Nursing* 3, no. 1 (1997): 51-57.

145 Ian Govier, "Spiritual care in nursing: A systematic approach," *Nursing Standard* 14, no. 17 (2000): 32-36.

146 Verna Benner Carson, "Application of nursing theory to spiritual needs," in *Spiritual Dimensions of Nursing Practice*, ed. V.B. Carson and H.G. Koeing (Philadelphia: Templeton Press, 2008), 148–179.

147 Tony Walter, "The ideology and organization of spiritual care," *Palliative Medicine* 11, no. 1 (1997) 21-30.

148 Christina Puchalski, "Spirituality and Medicine," 14-18.

2.3 The Importance of Spiritual Care at the End of Life

Evidence is favouring the concept of a psychosomatic approach in healthcare, which offers a more holistic view of patients.[149] This approach, highlights the importance of connecting the mind and body which are considered to be in interaction with each other. Nowadays, the terms body, mind and spirit are becoming more frequently used when it comes to holistic care, therefore SC should be considered an important aspect of patients' care.[150] In fact, studies show that through spiritual well-being patients' psychological and physical symptoms can be improved.[151] A systematic review found over 300 studies investigating the importance of spirituality in health.[152] Although it is difficult to study the effectiveness of SC, due to its multi-dimensional nature, the majority of these studies found a positive relationship between spirituality and health. A recent systematic review on SC in palliative care in Europe, however, found that despite this growing evidence there is not enough documentation to support its importance, concluding that "SC remains the least developed and most neglected dimension of palliative care."[153]

Puchalski describes how research studying the effects of spirituality on health usually focus on three aspects: mortality, coping and recovery.[154] Studies show how SC can stimulate an adjustment in patients to cope better with their illness and suffering.[155] This can be achieved through the effect it has on existential concerns such as promoting

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[149] Aggie Casey *et al.,* "A Model for Integrating a Mind/Body Approach to Cardiac Rehabilitation: Outcomes and correlators," *Journal of Cardiopulmonary Rehabilitation and Prevention* 29, no. 4 (2009): 230–238.

[150] Cecilia Chan, Petula Sik Ying Ho, and Esther Chow, "A Body-Mind-Spirit Model in Health," *Social Work in Health Care* 34, no. 3-4 (2002): 261-282.

[151] James Carmodya *et al.,* "Mindfulness, spirituality, and health-related symptoms," *Journal of Psychosomatic Research* 64, no.4 (2008): 393-403; Bei-Hung Chang *et al.,* "Relaxation response and spirituality: Pathways to improve psychological outcomes in cardiac rehabilitation," *Journal of Psychosomatic Research* 69, no. 2 (2010): 93–100.

[152] Carl E. Thoresen, "Spirituality and health: Is there a relationship?" *Journal of Health Psychology* 4, no. 3 (1999): 291-300.

[153] Marie-Jose Gijsberts *et al.,* "Spiritual care in palliative care," 1-21.

[154] Christina M. Puchalski, "The role of spirituality in health care," *Proceedings (Baylor University Medical Centre* 14, no. 4 (2001): 352-357.

[155] Richard A. Jenkins and Kenneth Pargament, "Religion and Spirituality as Resources for Coping with Cancer," *Journal of Psychosocial Oncology* 13, no. 1-2 (1995): 51-7.

hope and meaning of life and death.[156] Gall and Cornblat also discuss how patients who face a terminal illness will usually cope with the stress through religious or spiritual strategies.[157] The authors also propose a cognitive model of adjustment (Appendix A.6) to describe the link between spiritual and religious resources and aspects of well-being. In their study, Phelps and colleagues also found that SC can promote patient's emotional well-being and help strengthen the relationship between HCPs and patients.[158] Puchalski believes that this relationship can have a placebo effect, which can sometimes influence health outcomes.[159] Narayanasamy and Owens also believe that when the relationship between patient and HCP is built on trust, HCPs tend to be more satisfied with the experience of giving SC.[160] According to these authors, SC can therefore promote a sense of well-being in HCPs and act as a valuable part of holistic patient care.

There are a number of studies which show that higher levels of spiritual support may promote patients' well-being. Higher levels of spiritual well-being can then be linked to decreased levels of anxiety and depression,[161] increased self-actualization[162] and better control of pain and suffering.[163] Other studies have linked spiritual support with improved quality of life and dignity,[164] increased hospice use, decreased levels of aggressive treatment at end of life[165] and decreased medical costs.[166] As already mentioned (Chapter 1.2), however, there are studies which have linked spirituality with

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156 Alyson Moadel *et al*., "Seeking meaning and hope: Self-reported spiritual and existential needs among an ethnically-diverse cancer patient population," *Psycho-Oncology* 8, no. 5 (1999): 378–385.

157 Terry Lynn Gall and Mark W. Cornblat, "Breast cancer survivors give voice: A qualitative analysis of spiritual factors in long-term adjustment," *Psycho-Oncology* 11, no. 6 (2002): 524–535.

158 Andrea Phelps *et al.,* "Addressing Spirituality at the End of Life," 2538-44.

159 Christina Puchalski*,* "The role of spirituality in health care," 352-357.

160 Narayanasamy Aru and Owens Jan "Nurses' responses to the spiritual needs," 446-455.

161 M.O. Delgado-Guay, *et al*., "Spirituality, religiosity, and spiritual pain in advanced cancer patients," *Journal of Pain & Symptom Management* 41, no. 6 (2011) 986-994.

162 Joseph Tloczynski, Christa Knoll and Andrew Fitch, "The relationship among Spirituality, Religious Ideology, and Personality," Journal of Psychology and Theology 25, no. 2 (1997): 208-213. abstract

163 McBride J. LeBron *et al.,* "The relationship between a patient's spirituality and health experiences," *Family Medicine* 30, no. 2 (1998): 122-126.

164 Ana Luisa González-Celis and Juana Gómez-Benito, "Spirituality and Quality of Life and Its Effect on Depression in Older Adults in Mexico," *Psychology* 4, no. 3 (2013): 178-182.

165 Tracy Balboni *et al*., "Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death," *Journal of Clinical Oncology* 28, no. 3 (2010): 445–452.

166 Tracy Balboni *et al*., "Support of cancer patients' spiritual needs and associations with medical care costs at the end of life," *Cancer* 117, no. 23 (2011): 5383–91.

negative religious coping which can have an adverse effect on patients' health.[167] Some authors have also linked religiosity with more frequent use of aggressive treatment to prolong life.[168] Sulmasy, for example, discusses how certain religious patients with advanced cancer will desire to continue receiving aggressive treatments due to a belief in miracles.[169]

A good understanding of patients' and their relatives' perspectives, together with HCPs' perceptions on what is important at the end of life, is essential to achieve a successful improvement in end-of-life care. Singer and colleagues studied patients' perspectives on quality end-of-life care and found five aspects as being the most important.[170] These include pain and symptom relief, preventing unnecessary prolongation of dying process, accomplishing a sense of control, alleviating burden and improving family relationships. This study also shows that patients tend to agree on the importance of addressing spiritual issues at end of life. Similarly, Clark and colleagues found that patients consider meeting their spiritual needs as an important aspect of care while in hospital.[171]

MacLean and colleagues studied patients' perceptions on the importance of SC and found that this depends on the severity of the disease.[172] For example, from a sample of 456 patients, 19% perceived SC as important during physician's office visits, while 50% considered SC as important near death. Similar findings were found in the study by McCord and colleagues where patients perceived SC as most appropriate in the presence of a life-threatening illnesses or a serious medical condition.[173] Another study involving 230 patients diagnosed with advanced cancer found that as much as 88% perceived religion and spirituality as an important aspect of end-of-life care.[174] Similar

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167 Judith Hills *et al*., "Spirituality and distress in palliative care consultation," 782-788.

168 Tracy Balboni, "Religiousness and Spiritual Support," 555-560.

169 Daniel P. Sulmasy, "Spiritual Issues in the Care of Dying Patients ". . . It's Okay Between Me and God,"" *Journal of American Medical Association* 296, no. 11 (2006): 1385-92.

170 Peter A. Singer, Douglas K. Martin and Merrijoy Kelner, "Quality End-of-Life Care: Patients' Perspectives," *The Journal of the American Medical Association* 281, no. 2 (1999): 163-168.

171 Paul Alexander Clark *et al.,* "Addressing Patients' Emotional and Spiritual Needs," 659-670.

172 Charles D. MacLean *et al.,* "Patient Preference for Physician Discussion and Practice of Spirituality," *Journal of General Internal Medicine* 18, no. 1 (2003): 38-43.

173 Gary McCord *et al*., "Discussing spirituality with patients: A rational and ethical approach," *The Annals of Family Medicine* 2, no. 4 (2004): 356-361.

174 Tracy Balboni *et al.,* "Religiousness and Spiritual Support," 555-560.

findings were found in a study by Pearce and colleagues were 85% of advanced cancer patients (N=150) perceived spirituality as playing a very important role in their overall health and recovery.[175] Likewise Winkelman and colleagues found that 86% of advanced cancer patients(N= 69) believe that HCPs should address their spiritual needs within a healthcare setting.[176] Murray and colleagues also found that independent of any religious beliefs, spiritual concerns are important for patients with terminal cancer as early as from diagnosis.[177] Edwin and Bushwick also found similar findings and concluded that although many patients desire this type of care from their HCPs, spiritual issues were rarely discussed by HCPs.[178] In contrast, Yeung and colleagues found that although terminally ill patients perceived SC as effective they rated its importance relatively low.[179] In fact, Phelps and colleagues emphasize that there is an important minority of patients who believe that SC can be harmful, for a number of reasons, including privacy issues.[180]

This time, studying not only patients' perspectives but also HCPs' perspectives, Phelps and colleagues also found that almost 78% of 75 patients with advanced cancer, 71.6% of 204 physicians and 85.1% of 114 nurses believed that routine SC would have a positive impact on patients' well-being and the patient-provider relationship.[181] Similarly, Balboni and colleagues found that the majority of both patients and HCPs view SC as having a positive impact on patients' health.[182] Findings from the study, however, show that patients rated this impact of SC more positive than HCPs. One reason for this may be due to the fact that patients with terminal illness seem to be more religious or spiritual then HCPs. In fact, the authors concluded that religious and spiritual characteristics of HCPs tend to influence both the perceived importance of SC and actual

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175 Michelle Pearce *et al.,* "Unmet spiritual care needs impact spiritual well-being," 2269–76.

176 William D. Winkelman *et al*., "The Relationship of Spiritual Concerns to the Quality of Life of Advanced Cancer Patients: Preliminary Findings," *Journal of Palliative Medicine* 14, no. 9 (2011): 1-7.

177 Scott Murray *et al.,* "Exploring spiritual needs of people dying of cancer," 39 –45.

178 Dana Edwin and King B. Bushwick, "Beliefs and Attitudes of Hospital Inpatients about Faith Healing and Prayer," *The Journal of Family Practice* 39, no. 4 (1994): 349-352.

179 Ellen Wai Fong, Yeung Peter French and Anna Oi Sang Leung, "The impact of hospice inpatient care on the quality of life of patients terminally ill with cancer," *Cancer Nursing* 22, no. 5 (1999): 350-357.

180 Andrea Phelps *et al.,* "Addressing spirituality at the end of life," 2538–44.

181 *Ibid.*

182 Michael Balboni, "Why is spiritual care infrequent at the end of life?" 461-467.

SC provision. Similarly, Holmes and colleagues found that majority of seriously ill patients (62% of 65 patients) and majority of physicians (68% of 67 physicians) considered spirituality as an important aspect of care.[183] Chang and colleagues also found that the majority of HCPs consider SC as necessary for a peaceful death.[184] Turner and Cook studied physiotherapists' perception on SC and also found that, although the majority of physiotherapists consider SC as an important aspect of care, there is still a lack of training and ambiguity when it comes to their role in providing SC.[185] Similarly, McSherry found that although most nurses consider SC as an important aspect of patient's care, they still feel unsure about the effectiveness of SC.[186] In fact, Kostak and Celikkalp linked midwives and nurses' perception of the importance of SC with their knowledge on SC and training they received.[187] Saguil and Phelps also discuss how this perceived importance of spirituality in health is usually shaped through various medical literature, hospital policies, and clinical practice guidelines.[188]

In summary, it seems that although most HCPs recognise the importance of SC, especially in palliative care settings, and agree on their role in providing SC together with the hospital chaplain, they still do not provide enough SC to meet patients' spiritual needs. The discussion in the next chapter will therefore focus on the moral and legal rights of patients with regards to SC as part of end-of-life care. Practical issues related to the implementation of SC will also be discussed, with the ultimate aim to find solutions on how to preserve the patient's right to SC. It includes a discussion on the cultural influences with regards to SC provision, the consequences of neglecting

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183 Seth M. Holmes, Micheal W. Rabow and Suzanne L. Dibble, "Screening soul: Communication regarding spiritual concerns among primary care physicians and seriously ill patients approaching the end of life," *American Journal of Hospice and Palliative Medicine* 23, no. 1 (2006) 25-33.

184 Sung O.K. Chang *et al*., "Identifying perceptions of health professional regarding deathbed visions and spiritual care in end-of –life care: A delphi consensus study," *Journal of Hospice Palliative Nursing* 19, no. 2 (2017): 177-184.

185 Helen Turner and Christopher C.H. Cook, "Perceptions of Physiotherapists in Relation to Spiritual Care," *Journal for the Study of Spirituality* 6, no. 1 (2016): 58-77.

186 Wilfred McSherry, "Nurses' perceptions of spirituality," 36-40.

187 Melahat Akgun Kosta and Ulfiye Celikkal, "Nurses and Midwives Opinions about Spirituality and Spiritual Care," *International Journal of Caring Sciences* 9, no. 3 (2016): 975- 984.

188 Aaron Saguil and Karen Phelps, "The Spiritual Assessment," *American Family Physician* 86, no. 6 (2012): 546-550.

patients' spiritual needs, patients' satisfaction with overall care, the patients' preferred place for end-of-life care and the quality of SC being provided.

Chapter 3. The Patient's Right for Spiritual Care

Bioethics deals with ethical problems in healthcare, taking into consideration the rights of patients and the laws that safeguard these rights. In his critical view, Benatar discusses the relationship between 'bioethics' and 'health and human rights'.[1] The philosopher explains that although both fields involve issues on human rights, bioethics involves more than that. The author also describes how both legal and moral rights are linked with correlative duties. Thus, if patients are considered as having a right to receive SC, then someone has a duty to provide such care. In the previous chapter, the problem of infrequent SC provision was discussed. Studies showed that HCPs are not providing enough SC, even during the end-of-life stage where spiritual issues seem to become most relevant. This is leading to inadequate patients' holistic care and creating an ethical dilemma on whether HCPs are respecting their patients' rights and fulfilling their own duties. In dealing with this ethical dilemma one needs to understand whether patients have a right to such care and investigate whether there are any existing laws and policies regarding this issue.

3.1 The Legal Aspect of Spiritual Care

The socio-economic right to health and well-being was first mentioned in 1948 in the *Universal Declaration on Human Rights* (UDHR)[2] and then in the *International Covenant on Economic, Social and Cultural Rights* (ICESCR) (1966).[3] A growing interest in defining this right to health resulted in the ICESCR and the *Convention on the Rights of the Child* (1989) defining health as the "highest attainable standard of physical and mental

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1 David Benatar, "Bioethics and health and human rights: A critical view," *Journal of Medical Ethics* 32, no. 1 (2006): 17–20.

2 United Nations, *Universal Declaration of Human Rights* (1948).

3 United Nations, *International Covenant on Economic, Social and Cultural Rights* (1966).

health."[4] As already mentioned, although spirituality is not directly mentioned in the WHO's definition of health, it has been incorporated in the WHO's health strategies and is considered as one important dimension of health and well-being. This increased interest in the spiritual dimension to health and well-being has also led to the development of specific regulatory bodies, such as the WHO and the Human Rights Council, to incorporate SC as part of the patients' right to health and well-being. Also, apart from these international human rights treaties, there are several regional instruments and more than 115 national constitutions that mention this right to health care.[5] All these human rights conventions seem to focus on the importance of respecting human dignity, a fundamental value of every human being.[6] In fact Article 1 of the UDHR mentions that "all human beings are born free and equal in dignity and rights" and the preamble of the ICESCR states that "these rights derive from the inherent dignity of the human person."

Andorno studied the relationship between human dignity and human rights from a bioethical point of view.[7] He speaks about the 'inherent or intrinsic human dignity' which unlike 'moral dignity' should be the focus of bioethics and human rights systems. The author defines this intrinsic human dignity as 'an ultimate source of all rights' and talks about the obligation of states to respect these rights and provide justice for every individual. Respecting human rights usually is safeguarded by the states' legal recognition of such rights. Andorno however points out that a legal system may not always consider the concept of human dignity as a theory for human rights, but may view human dignity as a necessary basis for the welfare of society in general. That is why the *Declaration on the Promotion of Patients' Rights in Europe* considers patients' rights as individual rights not as social rights. The same declaration states that patients have

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4 United Nations, *International Covenant on Economic, Social and Cultural Rights* (1966), Article 12; United Nations, *Convention on the Rights of the Child* (1989), Article 24.

5 Office of the United Nations High Commissioner for Human Rights and World Health Organization, "The Right to Health" (2008), accessed February 18, 2019, https://www.ohchr.org/Documents/Publications/Factsheet31.pd

6 Mette LeBech, "What is Human Dignity?" *Maynooth Philosophical Papers*, accessed February 19, 2019, http://mural.maynoothuniversity.ie/392/1/Human_Dignity.pdf.

7 Roberto Andorno, "Human Dignity and Human Rights," in *Handbook of Global Bioethics*, ed. Henk A.M.J. ten Have and Bert Gordijn (Dordrecht: Springer, 2014), 45- 57.

the right to "receive spiritual support and guidance at all times" and "the right to humane terminal care and to die with dignity".[8]

Chochinov and colleagues studied the perception of dignity among fifty patients with advanced cancer.[9] After analysing their findings, they developed the Dignity-Conserving Model of Care (Appendix A.7). Although patients in this study found it difficult to express themselves because of the complexity and ambiguous nature of the term, they managed to describe a number of concerns, feelings and activities related to dignity. These were summarised into three categories: illness-related concerns, dignity conserving repertoire and social dignity inventory. From these three categories, the authors concluded that dignity not only consists of internal components (inner feelings, spiritual resources and issues related to illness) but there are also external components involved (environmental influences and one's perception of worthiness by others). Due to the fact that loss of dignity is associated with a decreased desire to continue living, this model can help HCPs in finding ways to preserve the dying patients' dignity. One way this can be achieved is by helping patients find inner spiritual resources through SC.[10]

In the early 1990's Mann started working on a conceptual framework and theory which linked together health, ethics and human rights.[11] He viewed health and human rights as complementary approaches, necessary for achieving well-being. Mann and colleagues proposed a fundamental relationship between health, human rights and dignity which can have practical implications when it comes to accomplishing human well-being.[12] They emphasized the importance for HCPs to protect against violations to patients' rights which can have health implications. Similarly, the WHO believes that "promoting and protecting health and respecting, protecting and fulfilling human rights

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8 World Health Organisation, *A Declaration on the Promotion of Patients in Europe* (1994), Articles 5.9 and 5.11.

9 Harvey Max Chochinov *et al*., "Dignity in the terminally ill: A developing empirical model," *Social Science and Medicine* 54, no. 3 (2002): 433–443.

10 Harvey Max Chochinov, "Dignity conserving care: A new model for palliative care," *Journal of American Medical Association* 287, no. 17 (2002): 2253–60.

11 Jonathan Mann, "Health and Human Rights: If Not Now, When?" *Health and Human Rights* 2, no. 3 (1997): 113-120.

12 Jonathan Mann *et al.,* "Health and human rights," *Health and Human Rights* 1, no. 1 (1994): 6–93.

are inextricably linked."[13] In the same document, examples were given of such connections between health and human rights (Appendix C.6).

In 1998 the JCAHO included assessment for spiritual needs and the provision of SC as part of the patient rights standards and stated that "patients have a fundamental right to considerate care that safeguards their personal dignity and respects their cultural, psychosocial and spiritual values."[14] The JCAHO recognized the importance of respecting the patient's right to access spiritual services and started requiring hospitals to address patients' spiritual needs while providing end-of-life care.[15] In response to this, healthcare organizations started creating institutional guidelines which include issues related to the spiritual needs of patients, their relatives and HCPs.[16] Also, in 1999 the Council of Europe issued the *Protection of the Human Rights and Dignity of the Terminally Ill and Dying* declaring that at the end of life the fundamental rights of patients which are derived from their intrinsic dignity, can be violated if there is insufficient access to palliative care and if their spiritual needs are not properly addressed.[17] Moreover, in 2005, the *Universal Declaration on Bioethics and Human Rights* was developed to protect human dignity and rights, and to protect the well-being of individuals over the interest of science and society in general.[18] This declaration mentions the spiritual dimension together with biological, psychological, social and cultural dimensions to describe a person's identity. It also indicates the need for governments to promote health in all these dimensions including spiritual well-being.

The *International Council of Nurses* (ICN) Code of Ethics also specifies the nurse's role of promoting "an environment in which the human rights, values, customs and spiritual

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13 "Linkages between health and human rights," World Health Organization, accessed February 27, 2019, http://www.who.int/hhr/HHR%20linkages.pdf.

14 Lawrence L. La Pierre, "JCAHO safeguards spiritual care," H*olistic Nursing Practice* 17, no. 4 (2003): 219.

15 John Ehman, "References to Spirituality, Religion, Beliefs, and Cultural Diversity," *The Joint Commission's Comprehensive Accreditation Manual for Hospitals (*2008), accessed February 20, 2019, http://www.acper esearch.net/JCAHO_Spirit_refs_2015_HOSPITAL.pdf.

16 Paul Alexander Clark *et al.,* "Addressing Patients' Emotional and Spiritual Needs," 659-670.

17 Parliamentary Assembly Council of Europe, *Protection of the Human Rights and Dignity of the Terminally Ill and Dying* (1999), Article 7.

18 UNESCO, Universal Declaration on Bioethics and Human Rights (2006).

beliefs of the individual, family and community are respected."[19] The ICN views human rights in healthcare as involving both the recipients and the providers, implying that both patients and HCPs should be treated with dignity. Among the different patients' rights mentioned, one can find the right to die with dignity,[20] and the nurses' responsibility to provide high quality end-of-life care which can lead to a dignified death.[21] In the *Maltese Code of Ethics for Nurses and Midwives*, there are two instances where patients' rights are mentioned, emphasising the importance for nurses to respect their patients' rights, and to support patients in all their needs including their spiritual needs.[22]

Recent statistics show that health problems related to the circulatory system and cancer are the two leading causes of death in European Union countries, including Malta.[23] These data show that chronic illness, as opposed to acute illness and injury, are becoming the most frequent cause of death. This leads to a higher demand and more prolonged use of healthcare services, which therefore increase the states' obligation in providing such services including palliative care services.[24] In fact, a recent systematic review found that between the years 1983 and 2016 there had been thirty-four palliative care declarations published, some national and others international (Appendix C.7).[25] Although these declarations, are not legally binding they picture palliative care as a basic human right which is fundamental to health and human dignity. These

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19 "*The ICN Code of Ethics for Nurse* (2012)," International Council of Nurses, accessed January 24, 2019, https://www.icn. ch/sites/default/files/inline-files/2012_ICN_Codeofethicsfornurses_%20eng.pdf.

20 "Nurses and Human Rights (2011)," International Council of Nurses, accessed February 27, 2019, https://www.icn.ch/sites/ default/files/inline-files/E10_Nurses_Human_Rights%281%29.pdf.

21 "Nurses' role in providing care to dying patients and their families," International Council of Nurses, accessed February 15, 2019, https://www.icn.ch/sites/default/files/inlinefiles/A12_Nurses_Role_Care_Dying_ Patients.pdf.

22 Nursing and Midwifery Board, "Maltese Code of Ethics for Nurses and Midwives (1997)," accessed January 28, 2019, https://deputyprimeminister.gov.mt/en/phc/pdu/documents/maltese_code_of_ethics_nurses.pdf.

23 "Causes of Death Statistics," Eurostat Statistics Explained, accessed January 27, 2019, https://ec.europa.eu/eurostat/statistics-explained/index.php/Causes_of_death_statistics#Main_ findings.

24 Agnes Binagwaho *et al.,* "Extending the Right to Health to the Moment of Death: End of Life Care and the Right to Palliation in Rwanda," *Health and Human Rights* 17, no.2 (2015), accessed January 30, 2019, https://www.hhrjournal.org/2015/12/extending-the-right-to-health-to-the-moment-of-death-end-of-life-care-and-the-right-to-palliation-in-rwanda/.

25 Hamilton Inbadas *et al.,* "Palliative Care Declarations: Mapping a New Form of Intervention," *Journal of Pain and Symptom Management* 52, no. 3 (2016): 7-15.

declarations also emphasise the importance for this right to be respected by governments and international organizations as early as from diagnosis.

One can note therefore, that although SC is not often mentioned directly as a patients' right, there are a number of both international and national human rights declarations that recognize palliative care as a human right. As already mentioned in the previous chapter (Chapter 2.1), SC is an integral part of palliative care, with WHO emphasising the need for palliative care to include psychological, social and spiritual aspects of patient care.[26] Respecting a patient's right to palliative care therefore involves the need to offer holistic care and to support patients' needs, including spiritual needs. For example, the *National Consensus Project for Quality Palliative Care* which is comprised of sixteen national organizations, regards SC as one of the eight domains necessary for quality palliative care.[27] Similarly, as discussed above, SC is included in a number of other national and international palliative care guidelines. For example, the WHO guideline booklet for HCPs mentions providing psychosocial and spiritual support as part of end-of-life care.[28]

The United Nations' Committee on Economic, Social and Cultural Rights states that "it is critical to provide attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity"[29] and mentions that states are "obligated to respect the right to health and must not deny or limit equal access to preventive, curative, or palliative health services."[30] The United Nations' Committee on the Rights of the Child also mentions palliative care and states that "children are entitled

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[26] World Health Organization, "WHO Definition of Palliative," accessed January 17, 2019, www.who.int/cancer/palliative/definition/en/.

[27] National Coalition for Hospice and Palliative Care, "Clinical Practice Guidelines for Quality Palliative Care in Clinical Practice Guidelines for Quality Palliative Care (2018)," accessed January 20, 2019, https://www.nationalcoalitionhpc.org/wpcontent/uploads/2018/10/NCHPCNCPGuidelines_4thED_web_FINAL.pdf.

[28] World Health Organization, "Palliative care: Symptom management and end-of-life care. Integrated management of adolescent and adult illness (2004)," accessed January 23, 2019, https://www.who.int/hiv/pub/imai/genericpalliativecare082004.pdf?ua=1.

[29] United Nations Committee on Economic, Social and Cultural Rights, "The right to the highest attainable standard of health, General Comment No. 14 (2000)," paragraph 25, accessed February 3, 2019, http://www.escr-net.org/docs/i/425238.

[30] *Ibid*., paragraph 34.

to quality health services, including prevention, promotion, treatment, rehabilitation and palliative care services."[31] In 2013, the European Association for Palliative Care together with three other international organizations, released the *Prague Charter Palliative Care: A Human Right* to promote access to palliative care as a human right.[32] It explains how access to palliative care should be considered a legal obligation by governments worldwide and describes palliative care as "the most basic concept of care-that of providing for the individual needs of the patient," including also the patients' spiritual needs.

Furthermore, in 2014 the World Health Assembly issued an international resolution on palliative care, emphasising the need for WHO and member states to provide palliative care to patients diagnosed with life-threatening illness.[33] It also states that healthcare settings should help these patients in relieving their suffering through proper "assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual." It points out that it is the ethical responsibility of HCPs to alleviate spiritual suffering and provide good quality end-of-life care through an inter-disciplinary team approach, which shall include a spiritual support provider. The resolution also highlights the importance of HCPs' continuing education and training on how to address patients' spiritual needs. Also, in 2015, the *Inter-American Convention on Protecting the Human Rights of Older Persons* was adopted as a regional instrument by the General Assembly of the Organization of American States.[34] Article 6 of the Convention says that:

> States parties shall take steps to ensure that public and private institutions offer older persons access without discrimination to comprehensive care, including palliative care, avoid isolation; appropriately manage problems related to the fear of death of the

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31 Committee on the Rights of the Child, *General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24)*.

32 "The Prague Charter- Palliative Care: A human right (2009)" European Association for Palliative Care, accessed February 23, 2019, https://www.eapcnet.eu/events/previous-eapc-events/prague-charter.

33 World Health Assembly, "Strengthening of palliative care as a component of comprehensive care throughout the life course (2014)," accessed January 28, 2019, http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf.

34 Organization of American States, "Inter-American Convention on Protecting the Human Rights of Older Persons (2015)," accessed February 14, 2019, http://www.oas.org/en/sla/dil/docs/inter_american_treaties_A-70_human_rights_older_persons.pdf.

> terminally ill and pain; and prevent unnecessary suffering, and futile and useless procedures.

The same Convention mentions that social, psychological, and spiritual problems of the elderly are necessary elements of palliative care.

In 2016, the Maltese Ministry for Health published the *Patient Charter* to highlight patients' rights and responsibilities within healthcare settings.[35] Principle 6 of this charter describes how patients have a right "to request spiritual and/or religious support when admitted into a healthcare establishment." This implies that all patients receiving care have a right to SC, and not only those receiving end-of-life care. The same document also refers to the patients' right to "expect an end-of-life care that is dignified, comforting and supporting relief from any unnecessary suffering." Here the document is specifying the patients' right to SC in an end-of -life setting where patient's well-being is of outmost importance.

Despite all these national and international human rights laws which focus on palliative care as a human right, Brennan has pointed out that there are many countries around the world that do not meet these international basic guidelines to the provision of palliative care.[36] The author describes the difficulties present when talking about palliative care as a human right, the difficulty to isolate this right from other basic rights, difficulties in understanding what this right really constitutes and difficulties related to adherence and enforcement. Nevertheless, there is a general agreement regarding the importance for governments to use all the available resources to safeguard the patients' rights to end-of-life SC as part of their right to palliative care. This should be provided to everyone without discrimination. Quality SC is an integral part of palliative care, where patients' individualised needs and cultural beliefs are taken into consideration. So as to

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35 Malta Parliamentary Secretariat for Health, *Patient Charter* (2016), accessed January 29, 2019, https://meae.gov.mt/en/public_consultations/mehhealth/documents/patient%20charter%20%28in%20english%29.pdf.

36 Frank Brennan, "Palliative Care as an International Human Right," *Journal of Pain and Symptom Management* 33, no. 5 (2007): 494-499.

be able to provide quality SC, governments also need to ensure sufficient budget allocation, adequate staff training and education and appropriate hospital resources.[37]

3.2 End-of-Life Care in Malta

Palliative Care in Malta is offered either though Hospice Malta, a registered non-governmental organization or through government services at Sir Anthony Mamo Oncology Centre (SAMOC) or Mater Dei Hospital (MDH).

The Malta Hospice Movement was established in 1989 following the work of Dame Cicely Saunders. Hospice MDT consists of approximately twelve nurses, a chaplain (specialized in SC), a psychologist, two physiotherapists and two social workers working on a full-time basis, as well as three physicians, specialized in palliative care working on a part time basis. The whole MDT meet once a week to discuss particular cases and review new referrals. Patients' self-referrals or referrals from the patients' family general practitioners or any other physician from public service are accepted together with the application. Currently, on average, there is one patient referral every day. During the patient's first visit, the patient is assessed by various members of the MDT. Patient assessment is recorded digitally through a computerised system and includes a spiritual assessment which is usually done by a nurse, who will then refer to the chaplain if spiritual needs emerge. The chaplain will discuss spiritual issues with patients and accompany them though their journey. He will listen their concerns, help them with any unfinished business, pray with them and guide family meetings on end-of-life decisions. The chaplain however rarely administers the last rites to patients because these are usually administered by community clergy chosen by patients or their relatives. He usually provides SC for patients of different religious faiths, but sometimes on a patient's request he will liaise with other religious leaders and ask for their service. The chaplain can organize joint visits with other members of the MDT, and usually holds a visit once a week or once every fortnight, either at the patients' home or at hospital. Apart from these visits, those patients who are physically fit enough can attend sessions at the Day

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[37] Liz Gwyther, Frank Brennan and Richard Harding, "Advancing Palliative care as a Human Right," *Journal of Pain and Symptom Management* 38, no. 5 (2009): 767-774.

Therapy Unit which include spiritual discussions amongst other activities. Hospice also offers bereavement services to relatives, where two spiritual events are also organized: a memorial mass and a spiritual day. The memorial mass is held once every month and the spiritual day once a year. Both these activities are done to help relatives achieve spiritual healing. Apart from this, in 2021 the Hospice movement is expected to start offering also inpatient and respite palliative care services in the St Michael's Hospice complex.[38]

SAMOC was opened in 2013, providing both in-patients and out-patients services to cancer patients. It has a Palliative Care Unit, which approximately includes sixteen beds. Apart from the medical team, the hospital has two chaplains working alternately on a weekly basis. Medical staff here use a pink document, where patients are asked for their religious denomination. This is the only document in the patient's file which is filled by the chaplain. Here, the chaplain writes a note on whether last rites were administered and after the patient's death this is signed by a physician. The chaplain is also responsible for inputting death rate statistics. Referrals to the hospital chaplain are usually done on patients' request. Also, similar to what happens in Hospice, the chaplain will provide SC to patients with different religious faiths and when necessary, liaise with other religious leaders. Nevertheless, patients can also bring their own spiritual director from outside the hospital. Apart from patients' visits, the chaplain at SAMOC is also responsible for administering holy communion to patients daily, administering other sacraments such as confession when requested, and celebrating a daily mass. Apart from delivering SC to patients and relatives the chaplain will also provide spiritual support to other members of the MDT. There are also instances when other members of the MDT will ask for the presence of the chaplain to offer support to patients and relatives when taking end-of-life decisions. In contrast to Hospice the chaplain at SAMOC usually administers the last rites, and offers spiritual support to relatives after the patient's death. Here relatives can also make use of bereavement counselling provided by social workers and psychologists.[39]

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[38] Fr Alfred Vassallo, personal communication, November 18, 2018.

[39] Fr Vincent Buhagiar, personal communication, November 29, 2018.

Another place where patients can receive end-of-life care is at MDH. In this general government hospital there are five chaplains in total, working a twelve-hour shift on a roster basis, and one reliever who changes every six months. Referrals are usually done by other MDT members on a patient's request. Apart from this, the chaplain here is also part of the cardiopulmonary resuscitation (CPR) team, and in emergency situations the chaplain is called to administer the last rites. Chaplains also administer last rites to patients who are undergoing major operations. Similar to SAMOC, chaplains at MDH are also responsible for administering sacraments such as holy communion with the help of the Eucharistic Ministers. Chaplains at MDH offer visits to patients in the wards, liaise with other religious leaders according to patients' requests and offer spiritual support to other staff and to patients' relatives. Sometimes chaplains will refer to other members of MDT, such as social workers, counsellors and psychologists, who work together in meeting specific needs of patients. Similar to SAMOC, chaplains at MDH do not input any data in patients' files, but only fill the pink document regarding the administration of last rites.[40]

Limiting factors faced by chaplains at MDH and SAMOC include lack of private space in the ward; a limited number of chaplains; no continuation of care (patients are only seen for short periods of time); lack of training and education, especially in the area of paediatrics; and absence of formal regular communication between individual chaplains. Apart from these limitations, there are also chaplains who are facing limitations related to their old age or due to other commitments. In view of these limiting factors, hospital chaplains meet once a year where they have training sessions on Pastoral Health Care by a SC specialist. In fact, evidence highlights the importance of chaplains being both clinically and theologically trained so as to provide cultural oriented SC independent of patients' faith.[41]

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40 Fr Bertrand Vella, personal communication, December 2, 2018.

41 Arthur M. Lucas, "Introduction to the discipline for pastoral care giving," in *The Discipline for Pastoral Care Giving: Foundations for Outcome Oriented Chaplaincy*, ed. Larry VandeCreek and Arthur M. Lucas (New York: Routledge, 2001), 1-35.

3.3 Meeting Patients' Spiritual Needs at the End of Life

Spiritual needs are usually defined as human expectations on finding meaning, purpose and value in life, which can either be related to one's personal religious beliefs or not.[42] Puchalski and colleagues discuss the difficulty experienced by HCPs in assessing patients' spiritual needs due to the complex nature of spirituality and the difficulty in differentiating spiritual needs from other related needs.[43] Similarly, Büssing and Koeing discuss the complexity and multidimensional nature of spiritual needs.[44] They mention how in theory one can differentiate between existential, psychosocial, religious and spiritual needs however all these needs are clinically interconnected to each other. Nevertheless, evidence shows that only by obtaining better understanding of patient's spiritual needs can HCPs provide individualised SC.[45] In response to the lack of existing evidence when it comes to the definition and measurement of spiritual needs, Sharma and colleagues have developed the *Spiritual Needs Assessment for Patients* which is considered a valid and reliable instrument in helping HCPs assess spiritual needs among culturally diverse patients (Appendix B.8).[46] Similarly, Galek and colleagues constructed a 29-item spiritual need survey which helps HCPs explore patients' spiritual needs, among patients with different religious beliefs (Appendix B.9).[47]

El Nawawi and colleagues talk about the high prevalence of spiritual needs in patients suffering from a life threatening illness.[48] The same authors also found that spiritual needs can be present in patients who do not consider themselves as spiritual or religious

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42 Scott Murray *et al*., "Exploring the spiritual needs of dying people," 39-45.

43 Christina M. Puchalski *et al*., "A systematic review of spiritual and religious variables in Palliative Medicine, American Journal of Hospice and Palliative Care, Hospice Journal, Journal of Palliative Care and Journal of Pain and Symptom Management," *Palliative and Supportive Care* 1, no. 1 (2003): 7–13.

44 Arndt Büssing and Harold Koenig, "Spiritual Needs of Patients with Chronic Diseases," *Religions* 1, no. 1 (2010): 18-27.

45 Kathleen Galek *et al.,* "Assessing a Patient's Spiritual Needs: A Comprehensive Instrument," *Holistic Nursing Practice* 19, no. 2 (2005): 62-69.

46 Rashmi K. Sharma *et al.,* "The Spiritual Needs Assessment for Patients (SNAP): Development and validation of a comprehensive instrument to assess unmet spiritual needs," *Journal of Pain and Symptom Management* 44, no. 1 (2012): 44-51.

47 Kathleen Galek *et al.,* "Assessing a Patient's Spiritual Needs," 62-9.

48 Norma M. El Nawawi, Michael Balboni and Tracy A. Balboni, "Palliative care and spiritual care: The crucial role of spiritual care in the care of patients with advanced illness," *Current Opinion in Supportive and Palliative Care* 6, no. 2 (2012): 269-74.

and are frequently present in ethnic minorities. Moadel and colleagues for example studied spiritual needs in an ethnically diverse population of patients suffering from cancer.[49] They found that 75% of patients (N=248) reported at least one spiritual need with an average of two spiritual needs per patient. Also in her study, Hermann identified twenty-nine different spiritual needs among elderly patients with terminal cancer.[50] The author grouped these spiritual needs into six categories which include the need for religion, companionship, positive outlook, involvement and control, to finish business, and to experience nature. Similarly, Finocchiaro described spiritual needs of dying patients as a search for meaning and hope, giving and receiving forgiveness, completing unfinished business and dying peacefully.[51] In another study investigating spiritual needs among ethnically diverse patients diagnosed with cancer, the need to overcome fears was perceived as the most common spiritual need, followed by the need to find hope, peace of mind, meaning in life and spiritual resources.[52] Similarly Grant and colleagues also found that spiritual needs of patients with advanced illness are generally associated with fear of dying and loss of self-identity.[53] Taylor also found that family caregivers tend to experience spiritual needs similar to those of patients in their care.[54]

HCPs together with chaplains need to work together in screening patients for spiritual needs. According to Fitchett and colleagues most patients find no objection in discussing such needs with their HCPs.[55] In contrast, other studies show that spiritual needs are usually not explicitly stated by patients, and that only a positive caring relationship between HCP and a patient, can help patients open up and discuss their spiritual needs, which can then be met through SC.[56] Apart from this, health policy makers should also

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49 Alyson Moadel *et al.,* "Seeking meaning and hope," 378–385.

50 Carla Herman, "Spiritual needs of dying patients: A qualitative study," *Oncology Nursing Forum* 28, no. 1 (2001): 67-72.

51 Darlene N. Finocchiaro, "Supporting the patient's spiritual needs at the end of life," 32-36.

52 Alyson Moadel *et al.,* "Seeking meaning and hope," 378–385.

53 Elisabeth Grant *et al*., "Spiritual issues and needs: Perspectives from patients with advanced cancer and non-malignant disease. A qualitative study," *Palliative and Supportive Care* 2, no. 4 (2005): 371-378.

54 Elizabeth Johnston Taylor, "Spiritual needs of patients with cancer and family caregivers," *Cancer Nursing* 26, no. 4 (2003): 260-266.

55 George Fitchett *et al*., "Spiritual Care in the Hospital," 173-186.

56 Lisbeth Fagerström, Katie Eriksson and Ingegerd Bergbom, "The patient's perceived caring needs: Measuring the unmeasurable," *International Journal of Nursing Practice* 5, no. 4 (2000): 199-208.

acknowledge the importance in supporting patients' spiritual needs.[57] Only after identifying patients' spiritual needs, can HCPs discover SC interventions to meet these needs, but HCPs should also take into consideration any cultural influences and the context where end-of-life care is taking place.

3.3.1. Spiritual Care for Patients with Different Cultural Beliefs

Unlike most other European countries, the Constitution of Malta recognizes the "Roman Catholic apostolic religion" as the state religion.[58] The Constitution also states, however, that "every person in Malta shall have full freedom of conscience and enjoy the free exercises of their respective mode of religious worship."[59] Although, in 2016, Catholics in Malta including foreigners, were estimated to represent 84.4% of population, Malta is nowadays considered to include a multi-cultural and ethnically diverse society.[60] In 2014, in fact, there were 23, 643 reported foreigners living in Malta from 151 different countries.[61] A survey carried out by the Archdiocese of Malta in 2017 found that around 95% of Maltese citizens believe in God and 61% considered religion important for their lives.[62] A similar result was achieved in a survey by Eurobarometer Poll in 2005, where 95% of people living in Malta declared to believing in God, 3% believing in some sort of spirit or life force, and 1% were non-believers.[63] Interestingly, Malta ranked as one of four countries with the least rate of non-believers. The same survey studied spiritual beliefs, and 52% of Maltese citizens reported that they frequently think about the meaning and purpose of life. In other countries, such as Austria and Hungary, only 26% and 27% respectively responded to think often about meaning and purpose of life

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57 Khadijeh Hatamipour *et al.,* "Spiritual Needs of Cancer Patients: A Qualitative Study," *Indian Journal of Palliative Care* 21, no. 1 (2015): 61-67.

58 Government of Malta, *Constitution of Malta* (1964), Chapter I, Article 2, Paragraph 1.

59 *Ibid,* Chapter IV, Article 40, Paragraph 1.

60 Claire Caruana, "Mass attendance set to collapse in the years to come," *Times of Malta*, accessed January 27, 2019, https://www.timesofmalta.com/articles/view/20190127/local/mass-attendance-set-to-collapse-in-the-years-to-come.700305.

61 Neil Camilleri, "23,000 foreign nationals from 151 countries living in Malta," *Malta Independent*, accessed February 23, 2019, https://www.mccv.org.au/23000-foreign-nationals-from-151-countries-living-in-malta/.

62 Claire Caruana, "Mass attendance".

63 European Commission, "Eurobarometer Social values, Science and Technology (2005)," accessed February 25, 2019, https://web.archive.org/web/20070406155642/http://ec.europa.eu/public_opinion/archives/ebs/ebs_225_report_en.pdf.

(Appendix C.8). Similarly, a study on the provision of SC in Ireland found that this is still mainly focused within a Roman Catholic religion framework, unlike the UK's SC which is more multi-faith oriented.[64] These socio-demographic factors will have an effect when it comes to delivering SC, because HCPs need to understand existing cultural differences and how this may affect SC provision.[65]

In healthcare, culture includes but is not limited to "age or generation, gender, sexual orientation, occupation and socio-economic status, ethnic origin and migrant experience, religious or spiritual belief and disability."[66] Fawcett and Noble discuss the effects of socio-political constraints and how delivery of SC is influenced by the social and ideological background of both patients and HCPs.[67] The importance of cultural influences on spiritual needs of patients during end-of-life care has been recognized for some time now.[68] The *International Convention on the Elimination of All Forms of Racial Discrimination* (1965) emphasises the need for governments to respect a person's social and cultural rights with regards to healthcare access without racial discrimination.[69] Martsolf describes three ways on how culture and spirituality could be related.[70] Spirituality could be either directly related to cultural norms, or in opposition to these norms or there could be a balance between these cultural norms and the individual's own life experience. The author also talks about the importance for HCPs to perform a self-assessment of their own spirituality before performing patients' spiritual assessments and delivering SC. Self-assessment will help HCPs determine how their own

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64 Health Service Executive, "A Question of Faith: The Relevance of Faith and Spirituality in Health Care Dublin: Health Service Executive (2011)," accessed February 28, 2019, http://www.hse.ie/eng/services/publications/corporate/Your_Service,_Your_Say_Consumer_Affairs/Reports/questionoffaith.pdf.

65 Michael Schultz *et al*., "From pastoral care to spiritual care- Transforming the conception of the role of the spiritual care provider," *Harefuah* 156, no. 11 (2017): 735-739.

66 Karen Holland, "Cultural Care: Knowledge and skills for implementation in practice," in *Cultural Awareness in Nursing and Health Care,* ed. Karen Holland and Christine Hogg (United States of America: Routledge, 2010), 58- 77.

67 Tonks N. Fawcett and Amy Noble, "The challenge of spiritual care in a multi-faith society experienced as a Christian nurse," *Journal of Clinical Nursing* 13, no. 2 (2004): 136-142.

68 David Lukoff, Francis Lu and Robert Turner, "Cultural considerations in the assessment and treatment of religious and spiritual problems," *Psychiatric Clinics of North America* 18, no. 3 (1995): 467-485.

69 United Nations, International Convention on the Elimination of All Forms of Racial Discrimination (1965), Article 5.

70 Donna S. Martsolf, "Cultural aspects of spirituality in cancer care," *Seminars in Oncology Nursing* 13, no. 4 (1997): 231–236.

cultural background is affecting their spirituality and this can help to avoid imposing one's own cultural beliefs on patients while delivering SC. Culturally appropriate SC consists in HCPs helping patients achieve spiritual well-being by using the patient's own values, beliefs, norms and life practices in the process.

Recognition of the importance of 'cultural competence' is considered central to SC delivery and training.[71] According to Selman and colleagues, cultural competence in SC should involve an ongoing evaluation of the process of care delivery and an awareness of the influences of cultural beliefs on SC delivery.[72] HCPs should understand that learning about different cultures is not enough. They need to understand the importance of getting to know the patient's cultural demands, how these can influence the patients' spiritual needs and how to cater SC to those particular needs. Nevertheless, a systematic review on end-of-life care services to ethnic minorities in the UK found that not only is access to the service limited but the quality of service is also lacking.[73] Ethnic minorities tend to perceive end-of-life services as culturally inappropriate which can lead to higher rates of patients' dissatisfaction with the service. Another recent systematic review also found that there is limited evidence about culturally and spiritually sensitive interventions used in end-of-life care.[74] The authors explain how Western bioethics focuses on spirituality, religion and culture as important aspects that can influence end-of-life care delivery and decision making, putting special emphasis on particular beliefs among ethnic minorities.

The necessity for HCPs to meet spiritual needs of an ethnically diverse population should also reflect the design and delivery of educational programmes and training.[75] Price and

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71 Yasmin Gunaratnam, "Intercultural palliative care: Do we need cultural competence?" *International Journal of Palliative Nursing* 13, no. 10 (2007): 470-477.

72 Lucy Selman *et al.,* "Improving confidence and competence of healthcare professionals in end-of-life care: An evaluation of the 'Transforming End of Life Care' course at an acute hospital trust," *BMJ Supportive and Palliative Care* 6, no. 2 (2016): 231–236.

73 Natalie Evans *et al.,* "Systematic Review of the Primary Research on Minority Ethnic Groups and End-of-Life Care from the United Kingdom," *Journal of Pain and Symptom Management* 43, no. 2 (2012): 261-286.

74 Mei Lan Fang *et al.,* "A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: Findings from a scoping review," *BMC Geriatrics* 16, no. 107 (2016): 1-14.

75 Kate Gerrish, "Preparation of nurses to meet the needs of an ethnically diverse society: Educational implications," *Nurse Education Today* 17, no. 5 (1997): 359-365.

Sodeke discuss the need for HCPs to be trained in cultural competency but also underline the need for basic knowledge on humanities.[76] This is congruent with the ethics of HCPs who are oath bound to respect their professional code of ethics. In fact, the Maltese Code of Ethics for Nurses and Midwives stresses the importance for care to be adapted to the unique needs of the patient, including their spiritual needs. It also states that HCPs should "not discriminate amongst patients/clients on grounds of age, nationality, race, sex, gender orientation, religious beliefs, personal attributes, nature or origin of their health problem or any other factor."[77]

Although socio-demographic and religious factors seem to have the biggest effect on patients' spiritual needs, other factors such as education and marital status can also influence patients' spiritual needs.[78] HCPs need to respond to the changes in society so as to be able to provide culturally sensitive SC without stereotypical assumptions.[79] Schultz and colleagues discuss the challenges experienced by HCPs when it comes to providing SC for patients with different religious beliefs.[80] They mention how HCPs have shifted their care from religious to spiritual well-being, and with this shift they are able to provide care for patients of any religious faith. The authors in this study also recommend that SC would not be directly linked to religious leaders because this may limit the service to only certain patients. Similarly, MacLaren explains the difficulty HCPs experience when addressing patients with different religious needs, and the need for HCPs to put their own personal beliefs to one side, so as to be able to focus on the patients' spiritual needs.[81] The author in this study also discusses the problem of separating spirituality from religion especially when the HCP has strong personal beliefs and describes the development of secular SC, as one solution that helps HCPs deliver SC

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76 Connie C. Price and Stephen Sodeke, "Letter to the Editor: End-of-Life Care and Racial Disparities: All Social and Health Care Sectors Must Respond!" *The American Journal of Bioethics* 6, no. 5 (2006): 33-34.

77 Nursing and Midwifery Board, "Maltese Code of Ethics for Nurses and Midwives."

78 Alyson Moadel *et al.,* "Seeking meaning and hope," 378-385.

79 Wilfred Mcsherry and Keith Cash, "The language of spirituality," 151-161.

80 Michael Schultz, "From pastoral care to spiritual care," 735-739.

81 Jessica MacLaren, "A kaleidoscope of understandings: Spiritual nursing in a multi-faith society," Journal *of Advanced Nursing* 45, no. 5 (2004): 457-464.

to patients with different religious faiths. This can help HCPs appreciate the concept of pluralism and to treat every patient in a multi-faith society.

3.3.2 Consequences of Unmet Spiritual Needs

Although evidence shows that SC can help patients cope with their illness[82] and the effects of hospitalization,[83] evidence also shows that patients' spiritual needs are not always being met. In a study investigating the spiritual needs of an ethnically diverse population of cancer patients (N=194) the rate of unmet spiritual needs as perceived by patients ranged from 25% to 51%.[84] Pearce and colleagues found that approximately 28% of advanced cancer patients (N=150) reported having received less overall SC than they desired from HCPs, the religious community and chaplains.[85] Interestingly, they perceived receiving the least SC from hospital chaplains, with 40% of patients stating that they have received less SC than desired from the hospital chaplain. Study findings also show that patients who received less overall SC than desired reported more symptoms of depression and lower levels of spiritual well-being. These findings are consistent with other studies which found a link between unmet spiritual needs and poorer health outcomes. For example, Winkelman and colleagues found that unmet spiritual needs can lead to worse psychological quality of life especially in younger patients.[86] Nelson and colleagues also found a negative association between spiritual well-being and depression, but no association between religiosity and depression.[87] The authors thus concluded that the beneficial effects of religion could be the results of improved spiritual well-being and not merely due to the religious practices used. Furthermore, Buck and McMillan studied the frequency of unmet spiritual needs of

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82 Cheryl Westlake and Kathleen Dracup, "Role of spirituality in adjustment of patients with advanced heart failure," *Progress in Cardiovascular Nursing* 16, no. 3 (2001): 119-125.

83 Robert A. Schnoll, Lisa Harlow and Lisa Brower, "Spirituality, demographic and disease factors, and adjustment to cancer," *Cancer Practice* 8, no. 6 (2000): 298-304.

84 Alyson Moadel *et al.,* "Seeking meaning and hope," 378-385.

85 Michelle J. Pearce *et al.,* "Unmet spiritual care needs impact spiritual well-being," 2269–76.

86 William D. Winkelman *et al.,* "The relationship of spiritual concerns to the quality of life," 1022-8.

87 Christian J. Nelson *et al.,* "Spirituality, religion, and depression in the terminally ill," 213–220.

patients' caregivers and also found a positive association between unmet spiritual needs and depression.[88]

Similarly, O'Connor and colleagues found an association between meeting patients' spiritual needs and spiritual well-being, which together with a fighting spirit proved to improve patients' quality of life.[89] Grant and colleagues suggested that unmet spiritual needs may lead to spiritual distress and that this could lead to more physical and psychosocial problems such as anxiety, sleeplessness and despair.[90] The authors found that sometimes patients will express spiritual distress through physical symptoms and that HCPs tend to treat the physical symptoms without treating the underlying cause, which is the spiritual distress caused from unmet spiritual needs. Unmet spiritual needs therefore, may result in a vicious cycle which can lead to more hospitalisations and inability to receive end-of-life care at home. In another study, patients with life threatening illness also reported how sometimes HCPs can unintentionally cause spiritual distress by ignoring the patients' sense of identity and self-worth.[91]

Astrow and colleagues found that patients who reported unmet spiritual needs were less satisfied with the quality of their overall care, when compared to patients who had their spiritual needs met.[92] Sulmasy believes that a solution to this problem is the 'biopsychosocial- spiritual model' of care which can be used by HCPs to treat patients holistically.[93] A holistic patient-centred approach to end-of-life care can prevent spiritual needs from becoming spiritual distress, which can have various health consequences. This can be achieved by a positive relationship between HCPs and patients, where HCPs help patients to respond to their own spiritual needs.[94]

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88 Harleah G. Buck and Susan C. McMillan, "The Unmet Spiritual Needs of Caregivers of Patients with Advanced Cancer," *Journal of Hospice and Palliative Nursing* 10, no. 2 (2008): 91-99.

89 Moira O'Connor *et al.,* "Relationships between quality of life, spiritual well-being, and psychological adjustment styles for people living with leukaemia: An exploratory study," *Mental Health Religion and Culture* 10, no. 6 (2007): 631–664.

90 Elisabeth Grant *et al.,* "Spiritual issues and needs," 371–378.

91 Scott Murray *et al.,* "Exploring the spiritual needs of people dying," 39-45.

92 Alan Astrow *et al.,* "Failure to Meet Spiritual Needs and Patients' Perceptions," 5753-7.

93 Daniel Sulmasy, "A Biopsychosocial-Spiritual Model for the Care," 24-33.

94 Elisabeth Grant *et al.*, "Spiritual issues and needs," 371–378.

3.4 The Dying Experience at Home or in Institutional Settings

The location of death is an important aspect of end-of-life care. It gives an idea of where that person had received care at the very end of his life and how that care could be improved.[95] Death statistics show that the majority of people are dying at hospital or other health care facilities. Broad and colleagues studied the place of death of patients in 36 nations between 2001 to 2010, and found that 54% of deaths occurred at hospitals, 12% at elderly nursing homes, and 32% elsewhere.[96] Similar results can be found in the UK were in 2016 about 46.9% of deaths occurred in hospitals, 21.8% in residential care home, 23.5% at home and about 5.7% in hospices.[97] In Malta, the Annual Mortality Report shows that in 2015, approximately 68.9% of deaths occurred in hospitals while approximately 14% died at their own home. Deaths in residential homes differed depending on the age group: 18.5% in people above 65 years and only 1.9% in people under 65 years (Appendix C.9).[98]

Nakamura and colleagues found that among factors influencing whether a person dies at home or in hospital, it was the opinion of relatives that had the greatest influence.[99] Thus, when relatives of a terminally ill patient wanted to care for the patient at home that patient had a higher chance of actually dying at home. Costa and colleagues have also studied the factors that influence place of death among terminally ill patients.[100] They found a number of factors which can influence where the patient dies, these

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95 James Flory *et al*., "Place of death: U.S. trends since 1980," *Health Affairs* 23, no. 3 (2004): 194-200.

96 Joanna B. Broad *et al.,* "Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics," *International Journal of Public Health* 58, no. 2 (2013): 257–267.

97 Government of United Kingdom, "Public Health England Statistical commentary: End of Life Care Profiles (2018)," accessed March 1, 2019, https://www.gov.uk/government/publications/end-of-life-care-profiles-february-2018-update/statistical-commentary-end-of-life-care-profiles-february-2018-update.

98 Kathleen England, "Annual Mortality Report (2015)," *Maltese Department of Health Information and Research,* accessed March 2, 2019, https://deputyprimeminister.gov.mt/en/dhir/Documents/Deaths/Annual%20Mortality%20Report%202015.pdf.

99 Shunsuke Nakamura *et al.,* "Factors influencing death at home in terminally ill cancer patients," *Geriatrics and Gerontology International* 10, no. 2 (2010): 154-160.

100 Vania Costa *et al.,* "The determinants of home and nursing home death: A systematic review and meta-analysis," *BMC Palliative Care* 15, no. 1 (2016): 1-15.

include: early referral to palliative care, the availability of home palliative care services, the patients' own preference, age, gender, diagnosis, the patients' support at home and the caring skills of patient's relatives. Flory and colleagues, for example, found an ethnical difference in place of death, with African-American people more likely to die in hospital when compared to Caucasians.[101] One possible reason for this could be the lack of hospice or home care available among this ethnic group of patients. Furthermore, a study on family perspectives on the quality of end-of-life care found that those patients who received more than three days hospice service had more likely died in their preferred place.[102]

Although death rates at hospital or other institutions seem to be higher than death rates at home, there is evidence supporting a recent shift, with more deaths occurring at home and less at hospital. In fact, Billingham and colleagues talk about a reversal of the 'institutionalisation of death', reporting that since 2004 there has been a trend for patients, especially those diagnosed with cancer, to actually die at home.[103] This trend has also been noted in Canada where statistics show that in 2013 about 62.8% of people died at hospital, but this rate started to decrease slowly every year, with a reported 59.9% dying at hospital in 2017.[104] A similar trend has been observed in the UK, where between 2004 to 2016 there has been a decrease of 11% of deaths in hospital and an increase of 5.1% of home deaths and 5.3% of residential home deaths.[105]

Nevertheless, evidence shows that there is a big difference between the actual place of death and the preferred place of death. A systematic review found that the majority of patients with advanced cancer would prefer to receive end-of-life care and die at their

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101 James Flory *et al.,* "Place of death: U.S. trends since 1980," 194-200.

102 Alexi Anne Wright *et al.,* "Family Perspectives on Aggressive Cancer Care Near the End of Life," *The Journal of the American Medical Association* 315, no. 3 (2016): 284-292.

103 Matthew James Billingham and Sarah Jane Billingham, "Congruence between preferred and actual place of death according to the presence of malignant or non-malignant disease: A systematic review and meta-analysis," *Supportive and Palliative Care* 3, no. 2 (2013): 144-154.

104 Canadian National Statistics Department, "Deaths, by place of death (hospital or non-hospital)," *Statistics Canada* (2017), accessed March 3, 2019, https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310071501.

105 Government of United Kingdom, "Statistical commentary: End of Life Care Profiles."

home, while choosing in-patient hospice care as their second option.[106] In the UK, for example, about 67% of people chose to die at home; however, only 25% actually had the opportunity to do so, while the others died in an institution.[107] Similar results were found in Australia where 70% of people chose to prefer dying at home but only 14% actually died there.[108] Another systematic review by Gomes and colleagues found that between 31% and 87% of patients (N=< 34,000) prefer to die at home, the majority of which will not change their preference as their illness progresses.[109] In contrast, there are other studies which show that many of the patients who choose to die at home will actually end up dying in hospital for a number of reasons.[110] These include patients coming to believe that they are a burden to family members, an overwhelming loss of control on symptoms,[111] and lack of resource availability.[112] Wheatley and Baker discuss situations where although the patient might prefer to be cared for and die at home this may be inappropriate.[113] The authors mention cases where caring for the patient at home will result in a burden on relatives and other cases where limited resources in community care will make it difficult to deliver services at home without affecting other people who also need this service.

On the other hand, Steinhauser and colleagues found that patients and their relatives did not regard dying at home as an important determinant in the quality of dying.[114] In fact, the majority of patients ranked dying at home as the least important factor influencing end-of-life care. These data show that despite the efforts of the hospice

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106 I.J. Higginson and G.J.A. Sen-Gupta, "Place of Care in Advanced Cancer: A Qualitative Systematic Literature Review of Patient Preferences," *Journal of Palliative Medicine* 3, no. 3 (2000): 287-300.

107 United Kingdom Parliamentary Papers, (EDM #1477) "*Marie Curie Cancer Care Campaign: Supporting the choice to die at home,*" House of Commons (2004), accessed March 3, 2019, https://edm.parliament.uk/early-day-motion/24463.

108 Hal Swerissen and Stephen Duckett, "Dying well," *Grattan Institute Report* (2014), accessed March 4, 2019, https://grattan.edu.au/report/dying-well/.

109 Barbara Gomes *et al.,* "Preferences for dying at home: A systematic review," 1-13.

110 Susie Wilkinson, "Fulfilling patients' wishes: Palliative care at home," *International Journal of Palliative Nursing* 6, no. 5 (2000): 212.

111 Victoria Wheatley and Idris Baker, "Please, I want to go home: Ethical issues raised when considering choice of place of care in palliative care," *Postgraduate Medical Journal* 83, no. 984 (2007): 643-648.

112 Lee Storey *et al.,* "Place of death: Hobson's choice or patient choice?" *Cancer Nursing Practice* 2, no.1 (2003): 33–38.

113 Victoria Wheatley and Idris Baker, "Ethical issues regarding place of care," 643–648.

114 Karen Steinhauser *et al.,* "Factors considered important at the end of life," 2476-82.

movement to improve end-of-life care by facilitating death at one's own home, one cannot assume that all patients want to die at home. This also has an impact on palliative care institutions, which need to provide care for both patients who wish to die in that institution and those who prefer to die at home but for some reason this is not possible. Although evidence about the benefits of dying at home is quite conflicting, studies show that the experience of dying at home can result in achieving more holistic well-being, including spiritual well-being.[115] Also, as a result of the campaign "Supporting the Choice to Die at Home" by the Marie Curie Cancer Care, in 2004, the UK House of Commons acknowledged the need to support and respect patients' choices for dying at home.[116]

Studying the place of death can help determine where people are receiving end-of-life care, and where they prefer to die. It helps identify places where end-of-life services including SC should be implemented. As already discussed, evidence shows that the majority of cancer patients tend to die at home using hospice home care and a good proportion of elderly people, especially those over 85 years, will die in residential nursing homes. Meeting these preferences for place of death can lead to significant outcomes for palliative care and healthcare services. Respecting people's choice of place of care and death should be part of the ethical framework of healthcare systems, where the principle of autonomy together with the other principles of non-maleficence, beneficence and justice is pragmatic.[117] This also applies to SC services, which should be offered at the preferred place of care and death chosen by the patient being at home, at hospital or in a residential home.

3.5 Patients' Satisfaction and Spiritual Care

Patients satisfaction is considered an essential component in evaluating care and is related to the association between one's expectations and the actual experiences of

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115 Irene J. Higginson *et al*., "Dying at home – is it better: A narrative appraisal of the state of the science," *Palliative Medicine* 27, no. 10 (2013): 1-7.

116 United Kingdom Parliamentary Papers, "Marie Curie Cancer Care Campaign: Supporting the choice to die at home."

117 Raanan Gillon, "Ethics needs principles – four can encompass the rest – and respect for autonomy should be "first among equals"," *Journal of Medical Ethics* 29, no. 5 (2003): 307-312.

patients' needs being met.[118] In fact, Williams and colleagues found that patients who desired to discuss spiritual issues but did not have such discussions were less likely to be satisfied with the care provided during their hospitalization.[119] In addition, the same study also found that spiritual discussions also result in higher satisfaction rates even when the patient did not actively request such discussions. Another study by Clark and colleagues involving data from a large national survey- the Press Ganey Associates 2001 National Inpatient Database- studied the perceived satisfaction with care of more than 1.7 million hospitalised patients.[120] Data suggests a strong relationship between the degree to which HCPs addressed spiritual needs and overall patients' satisfaction.

Marin and colleagues studied the effects of chaplaincy visits on patients' satisfaction, and the study's data showed that chaplains' visits are associated with meeting the patients' spiritual needs which led to higher satisfaction rates with the overall care.[121] Similar findings were found in a study by VandeCreek, where patients from fourteen different hospitals in the US stated that chaplains can respond to different patients' needs in a sensitive manner and this resulted in significantly higher patient satisfaction rates.[122] Also, in another study by Pearce and colleagues 35% of advanced cancer patients reported that meeting their spiritual needs through SC would improve their satisfaction with overall hospital care.[123]

Although not focusing specifically on SC, Sandsdalen and colleagues investigated patients' perceptions on the quality of palliative care in different settings.[124] The study concluded that patients receiving inpatients hospice care were most satisfied with the

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[118] Nafisa Vaz, "Patient satisfaction," in *Healthcare administration for patient safety and engagement*, ed. Aleksandra Rosiek-Kryszewska and Krzysztof Leksowski (Pennsylvania: IGI Global, 2018), 186-200.

[119] Joshua A. Williams *et al.,* "Attention to Inpatients' Religious and Spiritual Concerns: Predictors and Association with Patient Satisfaction," *Journal of General Internal Medicine* 26, no. 11 (2011): 1265-71.

[120] Paul Alexander Clark *et al.,* "Addressing patients' spiritual needs," 659–670.

[121] Deborah B. Marin *et al.,* "Relationship between chaplain visits and patient satisfaction," *Journal of Health Care Chaplaincy* 21, no. 1 (2015): 14-24.

[122] Larry VandeCreek, "How satisfied are patients with the ministry of chaplains?" *The Journal of Pastoral Care and Counselling 58, no. 4* (2004): 335-342.

[123] Michelle Pearce *et al.,* "Unmet spiritual care needs impact spiritual well-being," 2269–76.

[124] Tuva Sandsdalen *et al*., "Patients' perceptions of palliative care quality in hospice inpatient care, hospice day care, palliative units in nursing homes, and home care: A cross-sectional study," *BMC Palliative Care* 15, no. 79 (2016): 1-18.

care given. Similarly, Grant and colleagues also noticed that patients who had received hospice care perceived a difference in the quality of care, which was attributed to the holistic approach used by the hospice staff.[125] Similarly, Gallagher and Krawczyk found that patients who received hospice or palliative care reported less unmet needs when compared to patients who received end-of-life care in acute hospitals or residential care homes.[126] Another study, this time focusing on the bereaved relatives' perceptions on quality of end-of-life care, also found that hospice services, together with avoiding hospital admissions and hospital deaths, were associated with improved quality of care.[127] The hospice environment, including a palliative team of HCPs who are sensitive to patients' spiritual needs, was found to facilitate patients' spiritual expressions, with the result that SC is more frequently provided and that patients are more satisfied with the overall care.[128]

Despite the confirmed benefits of hospice in end-of-life care, it seems that patients are referred to such service only a few days before dying, mainly due to physician related barriers.[129] Adams and colleagues studied patients' and their relatives' perceptions on hospice timing, and found that one third of them confessed that it would have been easier for them if they were referred to hospice earlier on during their illness.[130] In contrast, Schocket and colleagues found that only one in seven patients thought that they were referred to hospice later than necessary.[131] Although in minority, these patients reported more unmet needs and higher dissatisfaction with the quality of end-of-life care. Furthermore, Teno and colleagues found that more than one third of hospice referrals could not be done earlier, either because patients refused such service

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125 Elisabeth Grant *et al.,* "Spiritual issues and needs," 371–378.

126 Romayne Elizabeth Gallagher and Marian Krawczyk, "Family members' perceptions of end of life care across divers locations of care," *BMC Palliative Care* 12, no. 25 (2013): 1-9.

127 Alexi Anne Wright *et al.,* "Family Perspectives on Aggressive Cancer Care," 284-292.

128 Heather Tan, Annette J. Braunack-Mayer and Justin J. Beilby, "The Impact of the Hospice Environment on Patient Spiritual Expression," *Oncology Nursing Forum* 32, no. 5 (2005): 1049-55.

129 David D. Howell and Stephen Lutz, "Hospice Referral: An Important Responsibility of the Oncologist," *Journal of Oncology Practice* 4, no. 6 (2008): 303-304.

130 Carolyn E. Adams, Julia Bader and Kathryn V. Horn, "Timing of Hospice Referral: Assessing Satisfaction While the Patient Receives Hospice Services," *Home Health Care Management and Practice* 21, no. 2 (2009): 109-116.

131 Erica R. Schockett *et al.*, "Late referral to hospice and bereaved family member perception of quality of end-of-life care," *Journal of Pain and Symptom Management* 30, no. 5 (2005): 400-407.

or due to an acute medical complication that required hospitalisation.[132] Due to the fact that early hospice referrals are not always possible, both hospices' and hospitals' end-of-life care need to be of high quality, where all patients' needs are met, patients are given the opportunity to die with dignity, and both patients and their relatives are satisfied with the care being provided.

3.6 Quality Spiritual Care at the End of Life

As already mentioned, although there is general agreement on the importance of SC with respect to health outcomes, many patients report unmet spiritual needs.[133] This means that the spiritual needs of terminally ill patients are not being properly addressed due to various reasons. One reason could be the lack of hospital chaplains available and the fact that only a few of those chaplains are qualified in palliative care.[134] In fact, Cadge and colleagues found that between 1993 and 2003 only between 54% and 63% of hospitals in the US employed a chaplain to provide spiritual services.[135] A more recent survey however found that between 80% to 95% of US hospitals employ a chaplain, but the most important question is whether the number of employed chaplains is enough to meet the spiritual needs of every hospitalised patient who require SC, at any one time.[136] In fact, Flannelly and colleagues estimated that hospital chaplains only visit an average of 20% of hospitalised patients.[137] Likewise, Pearce and colleagues found that only 36% of hospitalised advanced cancer patients reported that they have received a visit from the chaplain during their hospital stay.[138] This lack of hospital chaplains can result in more responsibility on other members of the MDT in addressing spiritual needs

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[132] Joan M. Teno *et al.,* "It Is "Too Late" or Is It? Bereaved Family Members Perceptions of Hospice Referral When Their Family Member Was on Hospice for Seven Days or Less," *Journal for Pain and Symptom Management* 43, no. 4 (2012): 732-738.

[133] Danielle Rodin *et al*., "Practitioners' perceptions of their role in providing spiritual care," 1-8.

[134] Amy S. Kelley and R. Sean Morrison, "Palliative Care for the Seriously Ill," *New England Journal of Medicine* 373, no. 8 (2015): 747-755.

[135] Wendy Cadge, Jeremy Freese and Nicholas A. Christakis, "The provision of hospital chaplaincy in the United States: A national overview," *Southern Medical Journal* 101, no. 6 (2008): 626-630.

[136] Kevin Flannelly, George Handzo and Andrew J. Weaver, "Factors affecting Healthcare Chaplaincy and the provision of pastoral care in the United States," *Journal of Pastoral Care and Counselling* 58, no. 1-2 (2004): 127-130.

[137] Kevin Flannelly *et al.,* "To what extent are the spiritual needs being met?" 319-323.

[138] Michelle Pearce *et al.,* "Unmet spiritual care needs impact spiritual well-being," 2269–76.

at the end of life. As already mentioned (Chapter2.2.1), however, there are a number of barriers that limit HCPs' SC delivery, including lack of time, skills and even interest to assess and meet patients' spiritual needs.[139]

Also in response to the lack of training of chaplains, in 2007 the Healthcare Chaplains' Capabilities and Competences Framework was developed, whereby hospital chaplains in the UK working within the NHS are required to attain training and use evidence-based interventions, to enhance both their competency and capability in SC delivery in palliative care settings.[140] Yet studies show that there is a lack of evidence supporting the effectiveness of particular spiritual assessment tools and interventions.[141] Nevertheless, evidence shows that chaplains together with other HCPs need to be also trained in palliative care as part of their continuous clinical education.[142]

According to Clark and colleagues a 'foundational infrastructure' is necessary to properly address patients' spiritual needs and improve SC.[143] This involves the provision of basic resources, the necessary staff to meet patients' needs, SC quality improvement measures and standardised SC assessment and interventions to meet patients' spiritual needs. The authors also explain that in order for HCPs to properly respond to patients' needs they need to include patients in decision-making processes and to act sensitively to patients' problems related to their illness and hospitalization. Likewise, in a recent study on quality of end-of-life SC, Holyoke and Stephenson identified nine principles that can act as organisational guidance throughout healthcare systems so as to improve the quality of their SC services (Appendix C.10).[144] These principles view SC as something that can be incorporated in all aspects of care, is directed by the dying patient and is vocational in origin.

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139 Arndt Büssing and Harold G. Koenig, "Spiritual Needs of Patients with Chronic Diseases," 18-27.

140 National Health Statistics Edinburgh, "Spiritual and Religious Care Capabilities and Competences for Healthcare Chaplains," *Education for Scotland,* accessed March 10, 2019, http://www.ukbhc.org.uk/sites/default/files/ nes_chaplaincy_capabilities_and_competencies.pdf.

141 Amy S. Kelley and R. Sean Morrison, "Palliative Care for Seriously Ill," 747-755.

142 Christina Puchalski *et al.,* "Improving Quality of Spiritual Care," 885-904.

143 Paul Alexander Clark *et al*., "Addressing patients' spiritual needs," 659-670.

144 Paul Holyoke and Barry Stephenson, "Principles and practices to support spiritual care," 1-19.

Puchalski and colleagues also discuss issues regarding quality improvement in SC.[145] In a consensus report, the authors concluded that due to the complexity of spirituality and the variability in SC delivery, there is a need for guidelines to be developed to ensure quality SC. These guidelines would provide "an established standard of quality that can be targeted for improvement." Due to the abstract nature of SC, however, quantification of spiritual outcomes is difficult to obtain, unlike other aspects of care. The authors discuss spiritual outcome measures which use a quantitative approach to monitor quality of SC, such as the number of chaplain referrals, patients' satisfaction questionnaires, spiritual distress scales and rates of completion of spiritual assessment. Apart from these quantitative approaches, they also mention the need for more qualitative quality indicators, such as interviews with patients and their relatives, MDT meetings and reflection exercises on patients' care.

There are a number of tools that can be used to measure the quality of SC being delivered; one such tool being the Spiritual Care Competence Scale (Appendix B.10) which assesses HCPs' competences with regards to their training and education.[146] Quality indicators in healthcare services have been studied for a long time and are usually divided into three categories: the structural features of the healthcare settings, the procedures of care and the outcomes of care.[147] Claassen and colleagues, however, found that the majority of the existing palliative care quality indicators belong to the physical care area, and only a few involve social care and SC.[148] A systematic international literature review in 2009 on quality indicators in palliative care has also found that quality indicators are lacking in the psychosocial, spiritual and cultural domains; indeed only one quality indicator was found related to the spiritual domain of

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145 Christina Puchalski *et al.,* "Improving Quality of Spiritual Care," 885-904.

146 Renatus Ronaldus van Leeuwen *et al.,* "An Instrument to measure Nursing Competencies in Spiritual Care: Validity and reliability of the Spiritual Care Competence Scale (SCCS)," in *Toward Nursing Competencies in Spiritual Care,* ed. Renatus Ronaldus van Leeuwen (The Netherlands: University of Groningen, 2009), 132-151.

147 Avedis Donabedian, "The quality of care. How can it be assessed?" *The Journal of the American Medical Association* 260, no. 12 (1988): 1743-8.

148 Susanne J. J. Claessen *et al.,* "A new set of quality indicators for palliative care: Process and results of the development trajectory," *Journal of Pain and Symptom Management* 42, no. 2 (2011): 169–182.

care.[149] An update of this systematic review in 2013 found six SC quality indicators in palliative care (Appendix C.11).[150] According to the authors, the lack of quality indicators regarding SC can be due to palliative care practice paying more attention to symptom relief than to spiritual support. In order to improve the quality of end-of-life care therefore, more SC quality indicators are needed.

In fact, in 2014 the Quality of Spiritual Care Scale was developed but although preliminary testing found the tool to be a valid and reliable measure of the quality of SC, it was only tested on relatives of deceased long-term care residents.[151] In 2016, however, the HealthCare Chaplaincy Network organised an international multidisciplinary panel to provide recommendations on evidence-based indicators related to the quality of SC, with the aim of improving spiritual support and better meet the spiritual needs of patients, their relatives, and health care institutions in general.[152] The panel managed to develop eighteen quality indicators which are divided into three categories: structural, process and outcomes indicators. Apart from these quality indicators, the panel also suggested a set of metrics which measure the present quality of SC and a number of evidence-based tools to measure these metrics (Appendix C.12).

Evidence shows that the approach to SC is largely unsystematic and that SC is usually delivered randomly and not individualised to patients' needs.[153] Studies also show that there is confusion among HCPs on SC issues, and therefore there is a need for more guidelines and models regarding quality SC.[154] Quality monitoring and improvement is essential in SC, and outcome measures are needed to evaluate SC models and interventions. Qualitative data on patient's experience with SC, however, is equally

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149 Roeline Pasman *et al.,* "Quality indicators for palliative care: A systematic review," *Journal of Pain and Symptom Management* 38, no. 1 (2009): 145–156.

150 Maaike De Roo *et al.,* "Quality Indicators for Palliative Care: Update of a Systematic Review," *Journal of Pain and Symptom Management* 46, no. 4 (2013): 556–572.

151 Timothy P. Daaleman *et al*., "Development and Preliminary Testing of the Quality of Spiritual Care Scale," *Journal of Pain and Symptom Management* 47, no. 4 (2014): 793- 800.

152 HealthCare Chaplaincy Network, "What Is Quality Spiritual Care in Health Care and How Do You Measure It? (2016)," accessed March 15, 2019, http://www.healthcarechaplaincy.org/docs/research/quality_ indicators_document_2_17_16.pdf.

153 René van Leeuwen *et al.,* "Spiritual care: Implications for nurses' professional responsibility," *Journal of Clinical Nursing* 15, no. 7 (2006): 875-884.

154 Aru Narayanasamy and Jan Owens*,* "Nurses' responses to the spiritual needs of patients," 446 – 455.

important in determining quality of SC.[155] Although there is no one definition of good quality end-of-life care, there is a general agreement that this should be a dynamic process, where HCPs work with patients' relatives to help the patient achieve spiritual well-being. Furthermore, professionally trained hospital chaplains should be available to provide spiritual support especially in those cases where more complex spiritual issues are present.[156] In this way, SC at the end of life can be delivered according to the patient's values, knowledge and preferences of care.[157]

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[155] Lucy Selman *et al.,* "Spiritual care recommendations for people receiving palliative care in sub-Saharan Africa, United Kingdom (2010)," accessed March 18, 2019, https://www.kcl.ac.uk/nursing/departments/cicelysaunders/attachments/Spiritual-care-Africa-Full-report.pdf.

[156] Betty Ferrell *et al.,* "The National Agenda for Quality Palliative Care: The National Consensus Project and the National Quality Forum," *Journal of Pain and Symptom Management* 33, no. 6 (2007): 737-744.

[157] Karen Steinhauser *et al*., "Factors considered important at the end of life," 2476-82.

Conclusion

Throughout the years there has been an increased importance of spirituality in relation to healthcare. There is strong evidence that spiritual needs can influence health outcomes and may therefore also influence financial outcomes related to healthcare.[1] Acknowledging this connection between spirituality and health indicates that HCPs should address patients' spiritual needs not as an issue of faith but rather to improve patients' health outcomes, decrease spiritual suffering and ultimately help the patients die with dignity. This led to the development of the biopsychosocial-spiritual model of care (Appendix A.4.3), where the patients' spirituality became part of holistic care.[2] As the perceived importance of SC continued to increase, so did the patients' perceived right to receive this type of care, especially in end-of-life situations where spiritual issues are most prevalent. In view of the already mentioned national and international human rights conventions, all patients at the end of their life should be entitled to SC by virtue of their right to the highest attainable standard of health and their right to palliative care.

Nevertheless, there seems to be a significant gap between the recognised need for SC at the end of life and the SC which is delivered. Studies show that only a third of patients report having a spiritual discussion during their hospital stay.[3] This suggests that in practice patients are not being offered the appropriate SC to help them meet their spiritual needs. Evidence also suggests that those patients who had their spiritual needs addressed perceived a better quality of life, demanded less aggressive treatments and were more likely to receive hospice care.[4] Meeting patients' spiritual needs is also associated with increased patient satisfaction with the overall care.[5] There is a need,

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1 Paul Alexander Clark *et al.,* "Addressing patients' spiritual needs," 659-670.
2 Daniel P. Sulmasy, "A biopsychosocial-spiritual model for care at the end of life," 24-33.
3 Paul Holyoke and Barry Stephenson, "Principles and practices to support spiritual care," 1-19.
4 Michael Balboni *et al.,* "Why is spiritual care infrequent at the end of life?" 461–467.
5 Deborah B. Marin *et al.,* "Relationship between chaplain visits and patient satisfaction," 14-24.

therefore to improve SC as part of end-of-life care and to integrate cultural and educational contexts which can act as barriers in SC delivery.[6]

HCPs are concentrating more on the importance of evidence-based practice which focuses on scientific and technological advances.[7] This may sometimes result in the neglect of the spiritual dimension from the patient's plan of care. That is why HCPs need to use a holistic person-centred model of care which emphasises the respect for autonomy and self-empowerment, focusing on the patients' role in the decision making process. If patients' autonomy and self-empowerment are not respected HCPs could inadvertently cause spiritual distress instead of meeting spiritual needs.[8] Apart from this, the patients' religious beliefs may sometimes also create conflicts and restrict patients from taking autonomous decisions.

Evidence shows that for many patients and their relatives spiritual issues seem to be as important- indeed sometimes more important than physical needs.[9] Hardwing discusses the fact that for many patients, the end of life is a spiritual crisis and that issues at the end of life are completely spiritual in nature.[10] The author argues that bioethics does not consider these spiritual issues as ethical issues involved in end-of-life care; instead, it tends to focus more on the issues regarding treatment decision making, proxy consents, advanced directives and physician-assisted suicides, when in reality these are not the issues considered relevant to patients at the end of life. Hardwing believes that these bioethical issues can be resolved if the spiritual concerns of patients and their relatives are appropriately tackled. The author states that "good care for the dying is a part of bioethics" and, therefore, bioethics "cannot avoid these spiritual issues."[11]

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6 Joshua A. Williams *et al.,* "Spiritual Concerns: Association with Patient Satisfaction," 1265-71.
7 Bart Cusveller, "Spiritual and ethical pluralism in professional nursing practice," 266–273.
8 Scott Murray *et al.,* "Exploring spiritual needs of people dying of cancer," 39 –45.
9 Mary Scott, Mary Thiel and Constance M. Dahlin, "The National Agenda for Quality Spiritual Care: The Essential Elements of Spirituality in End-of-life Care," *Chaplaincy Today* 24, no. 2 (2008): 15-21.
10 John Hardwig, "Spiritual issues at the end of life," 28-30.
11 *Ibid*, 29.

In contrast, Muldoon and King discuss the connections between spirituality and bioethics.[12] They argue that both SC and bioethics address patients' concerns with the main aim to treat the patient holistically and that ethical decisions cannot be isolated from the whole person, especially in an end-of-life context. One cannot address ethical dilemmas at the end of life without considering the patient's spiritual beliefs and concerns. Spirituality is interconnected with the patient's illness. Thus, from an ethical point of view, it does not make sense to take care of the illness without taking into consideration the patient's spirituality. In fact, a study on the involvement of chaplains in bioethical issues found that most bioethical issues faced by chaplains were the ones related to end-of-life situations such as withdrawal of life-sustaining interventions, organ donation, euthanasia and requests for no resuscitation.[13] The study also concluded that the majority of chaplains helped patients cope with these bioethical issues through SC interventions.

SC can be delivered through creativity, love, play, forgiveness, empathy, trust, respect, understanding and faith.[14] As already described (chapter 2.1.2) SC can be achieved through various SC interventions which can be used by HCPs, these include: mindfulness, meditation, prayer, progressive muscle relaxation, guided imagery and yoga.[15] Apart from these interventions HCPs must also keep in mind other things which can also influence the care being delivered, these include the environment where care is being offered, the support from patients' family and the need for patients to spend some quality time with their loved ones. Also, in view of their code of ethics, HCPs are bound to ensure holistic patient-centred care, and provide spiritual support and advocacy to all patients without discrimination. Sulmasy describes the five ethical principles of SC as person-centeredness, holism, discretion, accompaniment and tolerance.[16] Likewise,

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12 Muldoon Maureen and King Norman, "Spirituality, Healthcare, and Bioethics," *Journal of Religion and Health* 34, no. 4 (1995): 329-350.

13 Lindsay Brian Carey, "Bioethical issues and health care chaplaincy in Aotearoa New Zealand," *Journal of Religion and Health* 51, no. 2 (2012): 323–335.

14 Anita J. Scandurra, "Everyday spirituality: A core unit health education and lifetime Wellness," *Journal of Health Education* 30, no. 2 (1999): 105.

15 Bei-Hung Chang *et al.,* "Relaxation response and spirituality", 93–100.

16 Daniel P. Sulmasy, "Ethical principles for spiritual care," in *The Oxford Textbook of Spirituality in Healthcare*, ed. Mark R. Cobb, Christina M. Puchalski and Bruce Rumbold (Oxford: Oxford University Press, 2012), 465–470.

Carey and Cohen claim that the four bioethical principles of autonomy, beneficence, non-maleficence and justice can be applied to SC.[17] They argue in favour of SC involvement in bioethics and explain how SC providers can be involved in bioethical issues and decisions by providing holistic patient-centred care at the personal, communal and global levels of healthcare.[18] Bioethics should provide a framework to safeguard the right of the patient to express spiritual issues and receive the necessary care. Also, in view of Hoberman's criticism of bioethics,[19] healthcare institutions together with bioethicists need to discuss issues related to cultural competence especially when it comes to SC for ethnic minorities.

As the professor and director of Centre for Death and Society at the University of Bath, Tony Walter stated "if all patients have spiritual needs, if the palliative care unit is committed to holistic care and if all members of the multi-disciplinary team can deliver this kind of spiritual care, logic then requires that they ought to deliver it."[20] The present study highlights the importance of SC as an essential component of end-of-life care as defined by both national and international health guidelines. It highlights the need for bioethics to focus more on the effects of SC when it comes to health outcomes and end-of-life bioethical dilemmas, emphasising the need for bioethicists to work together with SC providers so as to improve patients' end-of-life care.

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17 Lindsay Brian Carey and Jeffrey Cohen, "Pastoral and Spiritual Care," in *Encyclopaedia of Global Bioethics*, ed. ten Have Henk (Pittsburgh: Springer, 2016), 2136- 47.

18 *Ibid.*

19 John Hoberman, "Why Bioethics Has a Race Problem," *The Hastings Center Report* 46, no. 2 (2016): 12–18

20 Tony Walter, "Spirituality in Palliative Care," 133-39.

Limitations of the Study

The main limiting factor in this study was the lack of recent studies. The majority of reliable studies that were found to be relevant for this research were over ten years old. This highlights the need for more innovative research in this area, with special emphasis on studying patients' perceptions and satisfaction with the delivered SC whilst receiving end-of-life care. Only with this type of research can SC services be improved so as to meet patients' spiritual needs, and therefore respect the patients' right for holistic care, which also includes the spiritual dimension to care.

Another limiting factor relates to the complexity of the issue under examination and its abstract nature. Evidence is ambiguous and sometimes confusing when it comes to defining spirituality and SC. Spirituality is often considered to be inclusive of existential, emotional and religious beliefs and practices. Thus, it was difficult to find studies which focused on the general concept of SC as part of end-of-life care, and not only on a specific aspect of SC.

Although this study was intended to include all patients receiving end-of-life care, the majority of the studies used, included only advanced cancer patients and only a few focused on patients with other life-threatening illnesses such as neurodegenerative disease. One also needs to investigate the specific spiritual needs present amongst these types of patients and whether diagnosis will influence SC delivery.

Caring for spiritual needs is not only relevant to patients who are at the end of their life but it is similarly needed for patients who are suffering from long term chronic illness. Thus, although this study focused on end-of-life situations, one should remember that any patient can suffer from spiritual distress and can require SC.

Although this study focused on patients' spiritual needs, evidence also showed the presence of caregivers' spiritual needs. Patients' family and friends may serve as a source of hope and support during this difficult time. They are an integral part of the SC process, and therefore HCPs should also consider their spiritual needs. Hence, one should also ask whether caregivers too have a right to SC and, if so, who is responsible for this.

Death certificate records indicate that a good proportion of elderly patients will end up dying in long-term residential homes.[21] Although this study focused on SC services offered in palliative care facilities, there is also a need for more investigation of SC services in long-term facilities. This can also implicate the need for adequate resources and training to fill the increasingly important role these type of facilities are having in end-of-life care.

Recommendations for Protecting the Patient's Right to Spiritual Care

Practice

At the organisational level there are a number of recommendations that can assist in the implementation of quality SC to meet patients' needs. The environment where end-of-life care and death are taking place is of utmost importance. This should be considered a special place where patients can easily express their spiritual concerns and where HCPs can readily respond to these needs.[22] As already discussed (Chapter 3.3), given a choice, most patients prefer to die at home; therefore, if possible, the environment of hospital settings should feel like home, and include enough space to accommodate patients' relatives during this special time. Hospital environments should also offer privacy at the same time so that the patient can feel comfortable to discuss spiritual issues. Furthermore, policymakers should also consider the fact that for some patients seeing their pets is very important. Although currently in Malta pets are not allowed in hospital settings, arrangements should be considered to fulfil patients' last wishes without interfering with the hospital's health and safety instructions.

Apart from improving the environment, there is also a need for healthcare organizations to establish rituals and routines that can help facilitate SC practices. These will provide structure and consistency in the provision and delivery of SC, which may serve as an opportunity for HCPs to share information and foster good relationships between

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21 Kathleen England, "Annual Mortality Report (2015)."

22 Paul Holyoke and Barry Stephenson, "Principles and practices to support spiritual care," 1-19.

themselves (through regular MDT meetings, reflective exercises, retreats and commemorative events) and with the patients' relatives (through bereavement sessions and formal memorial services). For example, chaplains believe that a memorial service with staff after the patient dies can help relatives in dealing with the grief.[23] Also, standardised SC practice should be adopted and implemented in hospital policies, especially when it comes to spiritual assessments. Patients should be asked for consent before performing formal in-depth spiritual assessments. These assessments need to be an ongoing process and appropriately documented, especially due to the fact that various HCPs and different chaplains will care for the same patient during that patient's hospital stay.

Healthcare organizations need to also recognise the need for the time it takes to deal with spiritual issues, because insight into spiritual needs requires time.[24] HCPs should be comfortable with the time they have to build a relationship with the dying patient and to offer the appropriate SC. A solution for this could be an increase in the number of HCPs available, including hospital chaplains. If for any reason it is not possible to recruit more staff, than empowered volunteers may be used. Evidence shows the importance of volunteer support programmes as an essential element in the provision of quality SC at the end of life.[25] Volunteers can improve quality end-of-life care by offering person-centred care, improving family satisfaction and patient longevity.[26] Volunteers can also overcome some of the barriers faced by HCPs while delivering SC and decrease some of the burden of family caregivers by offering practical support. HCPs, together with the general public, should become aware of the benefits of this support system and how to apply for such service.[27] In Malta, the voluntary service of VolServ is present in government hospitals, and was recently extended to the oncology centre.[28] In view of

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23 Bei-Hung Chang *et al*., "End of life spiritual care at VA medical centre," 1-6.

24 Paul Holyoke and Barry Stephenson, "Principles and practices to support spiritual care," 1-19.

25 *Ibid*.

26 Barbara Pesut *et al.,* "Promoting Volunteer Capacity in Hospice Palliative Care: A Narrative Review," *The American Journal of Hospice & Palliative* Care 31, no. 1 (2012) 69-78.

27 Katrien G. LuijkxJos and M.G.A. Schols, "Volunteers in Palliative Care make a difference," *Journal of Palliative Care* 25, no. 1 (2009): 30-9.

28 "Volunteer Services (VolServ)," health.gov.mt, accessed March 20, 2019, https://deputyprimeminister.gov.mt/en/MDH/Pages/MDH-Volunteer-Services.aspx.

the effect of volunteers on patients' care, resources are needed to recruit, educate and offer ongoing training to all volunteers working in palliative settings.

Hospital settings should also consider the patient's individual needs by taking into consideration today's ethnically and religiously diverse society, where cultural competence is of utmost importance.[29] Hospitals should offer all the necessary resources to support patients in carrying out any religious rituals. In fact, at MDH a multi-faith room was set-up to practice rituals such as prayer and meditation independent of religious faith. Apart from this, multicultural staff can increase the possibility of someone from the MDT being able to attend to each patients' needs.[30] In fact, even chaplains admit that they experience limitations when providing SC to patients with different faiths.[31] Evidence however, also demonstrates how chaplains are no longer considered as representing any particular faith, but are considered SC specialists, being able to provide general SC to patients with diverse beliefs.[32]

Evidence also suggests the need for the development of a multidisciplinary quality improvement SC team in hospital settings.[33] The goal of such a team is to improve the quality of SC by coordinating various organisational and educational aspects of SC and conducting research on quality improvement. The team can also study the effectiveness of the spiritual resources and interventions used in that particular healthcare setting, and assess HCPs' competencies in SC. This can help in improving existing SC standards in end-of-life clinical care and therefore decrease the frequency of patients' unmet spiritual needs.

Education

Evidence shows that the main barrier to SC delivery seems to be related to the lack of training and education HCPs are receiving in SC. So one important recommendation is HCPs' education and training in spirituality so as to be able to recognise and respond to

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29 Mei Lang Fang *et al*., "Culturally- and spiritually- sensitive end-of-life care," 1-14.
30 Tony Walter, "Spirituality in Palliative Care," 133-39.
31 Bei-Hung Chang *et al.,* "End of life spiritual care at VA medical centre," 1-6.
32 Harriet Mowat *et al*., "*What do Chaplains do*?" 29-50.
33 Paul Alexander Clark *et al.,* "Addressing patients' spiritual needs," 659-670.

spiritual needs, to enhance self-awareness, to obtain the required skills to practice SC, and to acknowledge when to appropriately refer to specialised support.[34] Training programs should be made available to all HCPs at any level and should be an ongoing process. Apart from this, there is a need for more communication between hospital chaplains and other HCPs. This can be made possible with the use of reliable referral and communication systems.[35] One possible solution could be the use of an electronic medical record system, where all HCPs, including the hospital chaplain, can access and input information regarding patients, including spiritual assessment and any interventions used. Studies show that this will help chaplains to integrate more with the healthcare team, without requiring additional credentials.[36]

Research

In view of the lack of evidence on SC quality indicators,[37] the effectiveness of spiritual interventions,[38] and the efficacy of training programmes on HCPs' SC delivery,[39] there is a need for more research in these areas. Similarly, more research is needed on the mechanisms that link spiritual distress to health outcomes and whether these mechanisms can be modified. Also, due to the fact that the majority of past studies have focused on the nursing profession, there is a need for further research in SC delivery by other members of the MDT. Further research on patients' satisfaction with SC is also necessary and studies need to investigate why perceptions of SC vary across settings. Since patients tend to prefer hospice service at the end of life, government entities should respond to patients' preferences by improving community healthcare services, and HCPs should ensure earlier hospice enrolment. Home care services should be made available to all without discrimination so as to enable more people to fulfil their wish to die at home. This can also decrease unnecessary hospital admissions and reduce the

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34 Deborah Hayden, "Spirituality in end-of life care: Attending the person on their journey," *British Journal of Community Nursing* 16, no. 11 (2011): 546-51.

35 Bei-Hung Chang *et al.,* "End of life spiritual care at VA medical centre," 1-6.

36 Rafael Goldstein, Deborah Marin and Mari Umpierre, "Chaplains and Access to Medical Records," *Journal of Health Care Chaplaincy* 17, no. 3-4 (2011): 162-168.

37 Michael Balboni *et al.,* "Why is spiritual care infrequent at the end of life?" 461–467.

38 Peter Speck, "The evidence base for spiritual care," *Nursing Managemen*t 12, no. 6 (2005): 28-31.

39 René van Leeuwen *et al.,* "Spiritual care: Implications for nurses' professional responsibility," *Journal of Clinical Nursing* 15, no. 7 (2006): 875-884.

healthcare costs which are usually associated with high-level of medical care, and at the same time protect the patient's right to quality SC at the end of life.

Bibliography

"Barriers influencing the provision of spiritual care." *NurseKey*. Accessed January 28, 2019. https://nursekey.com/barriers-influencing-the-provision-of-spiritual-care/.

"Becoming a Healthcare Chaplain." Pastoral Counselling Organization. Accessed November 30, 2018. https://www.pastoralcounseling.org/career/healthcare-chaplain.

"Causes of Death Statistics." Eurostat Statistics Explained. Accessed January 27, 2019. https://ec.europa.eu/eurostat/statisticsexplained/index.php/Causes_of_death_statistics#Main_ findings.

"EPPIC Project." European Union's Erasmus+ Programme. Accessed January 30, 2019. http://blogs.staffs.ac.uk/epicc/.

"Linkages between health and human rights." World Health Organization. Accessed February 27, 2019. http://www.who.int/hhr/HHR%20linkages.pdf.

"Living well at the end of life: A national conversation." The Regence Foundation (2011). Accessed January 3, 2019. www.syndication.nationaljournal.com/ communications/ NationalJournalRegenceToplines.pdf.

"Nurses and Human Rights (2011)." International Council of Nurses. Accessed February 27, 2019. https://www.icn.ch/sites/default/files/inlinefiles/ E10_Nurses_Human_ Rights%281%29.pdf.

"Nurses' role in providing care to dying patients and their families." International Council of Nurses. Accessed February 15, 2019. https://www.icn.ch/sites/default/ files/inlinefiles/A12_Nurses_Role_Care_Dying_ Patients.pdf.

"The ICN Code of Ethics for Nurse (2012)." International Council of Nurses. Accessed January 24, 2019. https://www.icn.ch/sites/default/files/inlinefiles/2012_ICN_ Codeofethicsfornurses_%20eng.pdf.

"The Prague Charter- Palliative Care: A human right (2009)." European Association for Palliative Care. Accessed February 23, 2019. https://www.eapcnet.eu/ events/previouseapcevents/prague-charter.

"Volunteer Services (VolServ)." health.gov.mt. Accessed March 20, 2019. https://deputyprimeminister.gov.mt/en/MDH/Pages/MDH-Volunteer-Services.aspx.

Abu-El-Noor, Nasser. "ICU Nurses perceptions and practice of spiritual care at the end of life: Implications for policy changes*." Online Journal of Issues in Nursing* 21, no. 1 (2016): 1-6.

Adams, Carolyn, Julia Bader, and Kathryn Horn. "Timing of Hospice Referral: Assessing Satisfaction While the Patient Receives Hospice Services." *Home Health Care Management and Practice* 21, no. 2 (2009): 109-116.

Agamben Giorgio. *Homo Sacer: Sovereign Power and Bare Life*. Stanford: Stanford University Press, 1998.

Amparo, Oliver, Enric Benito, and Laura Galiana. “Evaluation tools for spiritual support in end of life care: increasing evidence for their clinical application.” *Current Opinion in Supportive and Palliative Care* 9, no. 4 (2015): 357-360.

Anandarajah, Gowri and E. Hight. “Spirituality and medical practice: Using the HOPE questions as a practical tool for spiritual assessment.” *American Family Physician* 63, no. 1 (2001): 81-89.

Andorno, Roberto. “Human Dignity and Human Rights.” In *Handbook of Global Bioethics,* edited by Henk A.M.J. ten Have and Bert Gordijn, 45- 57. Dordrecht: Springer, 2014.

Arndt, Büssing, and Koenig Harold. “Spiritual Needs of Patients with Chronic Diseases.” *Religions* 1, no. 1 (2010): 18-27.

Association of American Medical Colleges, “Report lll, Contemporary issues in Medicine: Communication in Medicine (1999).” Accessed March 23, 2019. https://smhs.gwu.edu/gwish/sites/gwish/files/1999_MSOP_III_TF_Only.pdf.

Astrow, Alan, Ann Wexler, Kenneth Texeira, M. Kai He, and Daniel P. Sulmsay. “Is failure to meet spiritual needs associated with cancer patients’ perceptions of quality of care and their satisfaction with care?” *Journal of Clinical Oncology* 25, no. 36 (2007): 5753-7.

Astrow, Alan, Christina M. Puchalski, and Daniel P. Sulmsay. “Religion, spirituality, and health care: Social, ethical, and practical considerations.” *The American Journal of Medicine* 110, no. 4 (2001): 283-287.

Attard, Mario. “The Role of the Hospital Chaplain.” In *Spirituality: The Human Dimension in Care*, edited by Donia Baldacchino and Linda Ross, 54-59. Malta: University of Malta, 2008.

Bai, Mei, and Lazenby Mark. “A Systematic Review of Associations between Spiritual Well-Being and Quality of Life at the Scale and Factor Levels in Studies among Patients with Cancer.” *Journal of Palliative Medicine* 18, no.3 (2014): 1-13.

Bai, Mei, Mark Lazenby, Sangchoon Jeon, Jane Dixon, and Ruth McCorkle. “Exploring the relationship between spiritual well-being and quality of life among patients newly diagnosed with advanced cancer.” *Palliative and Supportive Care* 13, no. 4 (2014): 1-9.

Bakitas, M., Lyons K.D., Hegel M.T., Balan S., Brokaw F.C., Seville J., Hull J.G., Li Z., Tosteson T.D., Byock I.R., and Ahles T.A. “Effects of palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial.” *Journal of American Medical Association* 302, no. 1 (2009): 741–749.

Balboni, Michael, Adam Sullivan, Adaugo Amobi, Andrea Phelps, Daniel Gorman, and Angelika Zolfrank. “Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and physicians and the role of training.” *Journal of Clinical Oncology* 31, no. 4 (2013): 461–467.

Balboni, Michael, Adam Sullivan, Andrea Enzinger, Zachary Epstein-Peterson, Yolanda Tseng, and Christine Mitchell. “Nurse and Physician Barriers to Spiritual Care

Provision at the End of Life." *Journal of Pain and Symptom Management* 48, no. 3 (2014): 400–410.

Balboni, Michael, Christina M. Puchalski, and John R. Peteet. "The Relationship between Medicine, Spirituality and Religion: Three Models for Integration." *Journal of Religion and Health* 53, no. 5 (2014): 1586–98.

Balboni, Micheal, Amenah Babar, Jennifer Dillinger, Andrea Phelps, Emily George, Susan Block, Lisa Kachnic, Jessica Hunt, John Peteet, Holly G. Prigerson, Tyler J. VanderWeele, and Tracy A. Balboni. ""It Depends": Viewpoints of Patients, Physicians, and Nurses on Patient-Practitioner Prayer in the Setting of Advanced Cancer." *Journal of Pain and Symptom Management* 41, no. 5 (2011): 836-847.

Balboni, Tracy, Lauren Vanderwerker, Susan Block, Elisabeth Paulk, Christopher Lathan, John Peteet, and Holly Prigerson. "Religiousness and spiritual support among advanced cancer patients and associations with end of life treatment preferences." *Journal of Clinical Oncology* 25, no. 5 (2007): 555-560.

Balboni, Tracy, Mary Elizabeth Paulk, Michael J. Balboni, Andrea C. Phelps, Elizabeth Trice Loggers, Alexi A. Wright, Susan D. Block, Eldrin F. Lewis, John R. Peteet, and Holly Gwen Prigerson. "Provision of spiritual care to patients with advanced cancer: Associations with medical care and quality of life near death." *Journal of Clinical Oncology* 28, no. 3 (2010): 445–452.

Balboni, Tracy, Michael Balboni, Elizabeth Paulk, Andrea Phelps, Alexi Wright, John Peteet, Susan Block, Chris Lathan, Tyler Vanderweele, Holly Prigerson. "Support of cancer patients' spiritual needs and associations with medical care costs at the end of life." *Cancer* 117, no. 23 (2011): 5383–91.

Baldacchino, Donia R. "Spiritual Care Education of Health Care Professionals." *Religions* 6 (2015): 594-613.

Baldacchino, Donia R. "Teaching on spiritual care: The perceived impact on qualified nurses." *Nurse Education in Practice* 11, no. 1 (2011): 47-53.

Baldacchino, Donia R. "Teaching on the spiritual dimension in care to undergraduate nursing students: The content and teaching methods." *Nurse Education Today* 28, no. 5 (2008): 550–562.

Baldacchino, Donia R., and Peter Draper. "Spiritual coping strategies: A review of the nursing research literature." *Journal of Advanced Nursing* 34, no. 6 (2001): 833 – 841.

Benatar, David. "Bioethics and health and human rights: A critical view." *Journal of Medical Ethics* 32, no. 1 (2006): 17–20.

Billingham, Matthew James, and Sarah Jane Billingham. "Congruence between preferred and actual place of death according to the presence of malignant or non-malignant disease: A systematic review and meta-analysis." *Supportive and Palliative Care* 3, no. 2 (2013): 144-154.

Binagwaho, Agnes, Sardis H. Harward, Theophile Dushime, Jean de Dieu Ngirabega, Parfait Uwaliraye, Cathy Mugeni, Kirstin W. Scott, Marie Aimee Muhimpundu, and Jean Pierre Nyemazi. "Extending the Right to Health to the Moment of Death: End of Life Care and the Right to Palliation in Rwanda." *Health and Human Rights* 17, no. 2

(2015). Accessed January 30, 2019. https://www.hhrjournal.org/2015/12/extending-the-right-to-health-to-the-moment-of-death-end-of-life-care-and-the-right-to-palliation-in-rwanda/.

Blaber, Michael, June Jones, and Derek Willis. "Spiritual care: Which is the best assessment tool for palliative settings?" *International Journal of Palliative Nursing* 21, no. 9 (2015): 430-438.

Boston, Patricia, Anne Bruce, and Rita Schreiber. "Existential suffering in the palliative care setting: an integrated review of the literature." *Journal of Pain Symptom Management* 41, no. 3 (2011): 604-618.

Bradshaw, P.L. "Fitness for Practice." *Journal of Nursing Management* 8, no. 1 (2001): 1–2.

Bradshow, Ann. "Teaching spiritual care to nurses: An alternative approach." *International Journal of Palliative Nursing* 3, no. 1 (1997): 51-57.

Breitbart William, B. Rosenfeld, H. Pessin, M. Kaim, J. Feistiest, M. Galietta, C.J. Nelson, and R. Brescia. "Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients with Cancer." *The Journal of the American Medical Association* 284, no. 22 (2000): 2907-11.

Brennan, Frank. "Palliative Care as an International Human Right." *Journal of Pain and Symptom Management* 33, no. 5 (2007): 494-499.

Broad, Joanna, Gott M., Kim H., Boyd M., Chen H., Connolly M.J. "Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics." *International Journal of Public Health* 58, no. 2 (2013): 257–267.

Broadhurst, Kathleen, and Ann Harrington. "A Thematic Literature Review: The Importance of Providing Spiritual Care for End-of-Life Patients Who Have Experienced Transcendence Phenomena." *The American Journal of Hospice and Palliative Care* 33, no. 9 (2015): 1-13.

Buck, Harleah, and McMillan Susan C. "The Unmet Spiritual Needs of Caregivers of Patients with Advanced Cancer." *Journal of Hospice and Palliative Nursing* 10, no. 2 (2008): 91-99.

Bugeja, Anton. "Spirituality in General Practice." *Maltese Family Doctor* 19, no. 1 (2010): 26-31.

Bush, Tony, and Nina Bruni. "Spiritual care as a dimension of holistic care: A relational interpretation." *International Journal of Palliative Nursing* 14, no. 11 (2008): 539-545.

Büssing, Arndt, Andreas Michalsen, Hans-Joachim Balzat, Ralf-Achim Grünther, Thomas Ostermann, Edmund A. M. Neugebauer, and Peter F. Matthiessen. "Are Spirituality and Religiosity Resources for Patients with Chronic Pain Conditions?" *Pain Medicine* 10, no. 2 (2009): 327-339.

Buta Gelu Mircea, Chirilă Pavel, and Adina Rebeleanu. "Bioethics and the identity of the human person." *Romanian Journal of Bioethics* 8, no. 3 (2010): 129-135.

Byock, Ira R. “The Meaning and Value of Death.” *Journal of Palliative Medicine* 5, no.2 (2002): 279-288.

Byock, Ira R. “Where do we go from here? A palliative care perspective.” *Critical Care Medicine* 34, no. 11 (2006): 416-420.

Cadge, Wendy, Jeremy Freese, and Nicholas Christakis. “The provision of hospital chaplaincy in the United States: A national overview.” *Southern Medical Journal* 101, no. 6 (2008): 626-630.

Caldeira, Silvia, and Fiona Timmins. “Implementing spiritual care interventions.” *Nursing standard: Official Newspaper of the Royal College of Nursing* 31, no. 34 (2017): 54-60.

Caldeira, Sílvia, Fiona Timmins, Emília Campos de Carvalho, and Margarida Vieira. “Clinical Validation of the Nursing Diagnosis Spiritual Distress in Cancer Patients Undergoing Chemotherapy.” *International Journal of Nursing Knowledge* 28, no. 1 (2017): 44–52.

Caldeira, Sílvia, Sara Pinto, and Manuel Luís Capelas. “Implementing spiritual care at the end of life: Portugal.” *European Journal of Palliative Care* 24, no. 4 (2017): 175-176.

Camilleri, Neil. “23,000 foreign nationals from 151 countries living in Malta.” *Malta Independent.* Accessed February 23, 2019. https://www.mccv.org.au/23000-foreign-nationals-from-151-countries-living-in-malta/.

Canadian National Statistics Department. “Deaths, by place of death (hospital or non-hospital)” *Statistics Canada* (2017). Accessed March 3, 2019. https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1310071501.

Carey Lindsay, Brian. “Bioethical issues and health care chaplaincy in Aotearoa New Zealand.” *Journal of Religion and Health* 51, no. 2 (2012): 323–335.

Carey, Lindsay Brian, and Cohen Jeffrey. “Pastoral and Spiritual Care.” In *Encyclopaedia of Global Bioethics*, edited by ten Have Henk, 2136- 47. Pittsburgh: Springer, 2016.

Carmodya, James, George Reedb, Jean Kristellerc, and Phillip Merriamd. “Mindfulness, spirituality, and health-related symptoms.” *Journal of Psychosomatic Research* 64, no.4 (2008): 393-403.

Carroll, Barbara. “A phenomenological exploration of the nature of spirituality and spiritual care.” *Mortality* 6, no. 1 (2001): 81-98.

Carson Verna, Benner, and Ruth Gerardi. “Spirituality for credit: Finding a place in the secular curriculum. 1985.” *Journal of Christian Nursing* 30, no. 1 (2013): 34-37.

Carson, Verna Benner. “Application of nursing theory to spiritual needs.” In *Spiritual Dimensions of Nursing Practice*, edited by V.B. Carson and H.G. Koeing, 148–179. Philadelphia: Templeton Press, 2008.

Caruana, Claire. “Mass attendance set to collapse in the years to come.” *Times of Malta.* Accessed January 27, 2019. https://www.timesofmalta.com/articles/view/20190127/local/mass-attendance-set-to-collapse-in-the-years-to-come.700305.

Casey, Aggie, Bei-Hung Chang, James Huddleston, Narmin Virani, Herbert Benson, and Jeffery A. Dusek. “A Model for Integrating a Mind/Body Approach to Cardiac

Rehabilitation: Outcomes and correlators." *Journal of Cardiopulmonary Rehabilitation and Prevention* 29, no. 4 (2009): 230–238.

Cassell, Eric J. "The Nature of Suffering and the Goals of Medicine." *New England Journal of Medicine* 306, no. 11 (1982): 639-645.

Chan Cecilia, Petula Sik Ying Ho, and Esther Chow. "A Body-Mind-Spirit Model in Health." *Social Work in Health Care* 34, no. 3-4 (2002): 261-282.

Chang, Bei-Hung, Aggie Casey, Jeffery A. Dusek, and Benson Herbert. "Relaxation response and spirituality: Pathways to improve psychological outcomes in cardiac rehabilitation." *Journal of Psychosomatic Research* 69, no. 2 (2010): 93–100.

Chang, Bei-Hung, Nathan R. Stein, Kelly Trevino, Max Stewart, Ann Hendricks and Lara M. Skarf. "End-of-life spiritual care at a VA medical centre: Chaplains' perspectives." *Palliative and Support Care* 10, no.4 (2012): 1-6.

Chang, Sung, Soo Yeon, Cho Myung-Ok, Choi Kyung Sook, Kong Eun Suk, Kim Chun-Gill, Kim Hee Kyung, Lee Young Whee, Song Misoon, and Kim Nam. "Identifying perceptions of health professional regarding deathbed visions and spiritual care in end-of –life care: A Delphi consensus study." *Journal of Hospice Palliative Nursing* 19, no. 2 (2017): 177-184.

Chinball, John, S. D. Videen, P. N. Duckro, and D. K. Miller. "Psychosocial- spiritual correlates of death distress in patients with life threatening medical conditions." *Palliative Medicine* 16, no.4 (2002): 331-39.

Chirico, Francesco. "Spiritual well-being in the 21st century: It's time to review the current WHO's health definition?" *Journal of Health and Social Sciences* 1, no. 1 (2016): 11-16.

Chochinov, Harvey Max, T. Hassard, Susanne McClement, T. Hack, L.J. Kristjanson, M. Harlos, Shane Sinclair, and A. Murray. "The landscape of distress in the terminally ill." *Journal of Pain and Symptom Management* 38, no. 5 (2009): 641-649.

Chochinov, Harvey Max, Thomas Hack, Susan McClement, Linda Kristjanson, and Mike Harlose. "Dignity in the terminally ill: A developing empirical model." *Social Science and Medicine* 54, no. 3 (2002): 433–443.

Chochinov, Harvey Max. "Dignity and the Essence of Medicine: The A, B, C, and D of Dignity Conserving Care." *British Medical Journal* 335, no. 7612 (2007): 184-187.

Chochinov, Harvey Max. "Dignity conserving care: A new model for palliative care." *Journal of American Medical Association* 287, no. 17 (2002): 2253–60.

Claessen, Susanne, Anneke L. Francke, Hella E. Belarbi, Roeline W. Pasman, Marianne van der Putten, and Luc Deliens. "A new set of quality indicators for palliative care: Process and results of the development trajectory." *Journal of Pain and Symptom Management* 42, no. 2 (2011): 169–182.

Clark, Paul Alexander, Maxwell Drain, and Mary P. Malone. "Addressing Patients' Emotional and Spiritual Needs." *Joint Commission Journal on Quality and Safety* 29, no. 12 (2004): 659-670.

Cohen, Robin S., Balfour M. Mount, Michael G. Strobel, and France Bui. “The McGill Quality of Life Questionnaire: A measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability.” *Palliative Medicine* 9, no. 3 (1995): 207-219.

Cohen, Robin. “McGill Quality of Life Questionnaire” (1997). Accessed October 28, 2019. https://www.promotingexcellence.org/downloads/measures/mcgill_qol.pdf.

Committee on the Rights of the Child, *General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24)* (2013).

Costa, Vania, Craig C. Earle, Mary Jane Esplen, Robert Fowler, Russell Goldman, Daphna Grossman, Leslie Levin, Douglas G. Manuel, Shirlee Sharkey, Peter Tanuseputro, and John J. You. “The determinants of home and nursing home death: A systematic review and meta-analysis.” *BMC Palliative Care* 15, no. 1 (2016): 1-15.

Crighton, Margaret H., Bridget Coyne, Judith Tate, Valerie Swigart, and Mary Beth Happ. “Transitioning to End-of-Life Care in the Intensive Care Unit.” *Cancer Nursing* 31, no. 6 (2008): 478-484.

Cusveller, Bart. “Cut from the right wood: Spiritual and ethical pluralism in professional nursing practice.” *Journal of Advanced Nursing* 28, no. 2 (1998): 266–273.

Daaleman, Timothy P., and Larry VanCreek. “Placing religion and spirituality in end of life care.” *Journal of the American Medical Association* 284, no. 19 (2000): 2514-17.

Daaleman, Timothy P., Barbara M. Usher, Sharon W. Williams, Jim Rawlings, and Laura C. Hanson. “An Exploratory Study of Spiritual Care at the End of Life.” *The Annals of Family Medicine* 6, no. 5 (2008): 406-411.

Daaleman, Timothy P., David Reed, Lauren W. Cohen, and Sheryl Zimmerman. “Development and Preliminary Testing of the Quality of Spiritual Care Scale.” *Journal of Pain and Symptom Management* 47, no. 4 (2014): 793- 800.

Damen, Annelieke, D. Labuschagne, L. Fosler, S. O'Mahony, S. Levine, G. Fitchett. “What Do Chaplains Do: The Views of Palliative Care Physicians, Nurses, and Social Workers*.” American Journal of Hospice & Palliative Medicine* 2, no. 1 (2018): 1-6.

Dawson, Norma Jean. “Need satisfaction in terminal care settings.” *Social Science and Medicine 32, no. 1 (1991): 83-87.*

De Roo, Maaike, Kathleen Leemans, Susanne Claessen, Joachim Cohen, Roeline Pasman, Luc Deliens, and Anneke Francke. “Quality Indicators for Palliative Care: Update of a Systematic Review.*” Journal of Pain and Symptom Management* 46, no. 4 (2013): 556–572.

Dein, S., and J. Stygall. “Does being religious help or hinder coping with chronic illness? A critical literature review.” *Palliative Medicine* 11, no. 4 (1997): 291-298.

Delgado-Guay, Marvin, David Hui, Henrique Parson, Kathy Govanb, Maxine De la Cruz, Steven Thorney, and Eduardo Bruera. “Spirituality, religiosity, and spiritual pain in advanced cancer patients.” *Journal of Pain & Symptom Management* 41, no. 6 (2011) 986-994.

Donabedian, Avedis. “The quality of care. How can it be assessed?” *The Journal of the American Medical Association* 260, no. 12 (1988): 1743-8.

Draper, Peter, and Wilfred McSherry. “A critical view of spirituality and spiritual assessment.” *Journal of Advanced Nursing* 39, no. 1 (2002): 1-2.

Dreyer, Lukas, and Sonja Dreyer. “Spiritual well-being and Health.” *Journal for Physical Health Education, Recreation and Dance* 7, no. 1 (2001): 142-152.

Edwards, Adrian Gwyn. “The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: A meta-study of qualitative research.” *Palliative Medicine* 24, no. 8 (2010): 753-770.

Edwin, Dana, and King B. Bushwick. “Beliefs and Attitudes of Hospital Inpatients about Faith Healing and Prayer.” *The Journal of Family Practice* 39, no. 4 (1994): 349-352.

Ehman, John. “References to Spirituality, Religion, Beliefs, and Cultural Diversity.” *The Joint Commission's Comprehensive Accreditation Manual for Hospitals*. Accessed February 20, 2019. http://www.acperesearch.net/JCAHO_Spirit_refs_2015_HOSPITAL.pdf.

El Nawawi, Norma M., Balboni Michael, and Balboni Tracy A. “Palliative care and spiritual care: The crucial role of spiritual care in the care of patients with advanced illness.” *Current Opinion in Supportive and Palliative Care* 6, no. 2 (2012): 269-74.

Ellershaw, John, and Chris Ward. “Care of the dying patient: The last hours or days of life.” *BMJ (online)* 326, no. 7379 (2003): 30-34.

Elwell Walter A. *Baker’s Evangelic Dictionary of Biblical Theology.* Michigan: Baker Books, 1996.

Emblen, J.D., and Halstead L. “Spiritual needs and interventions: Comparing the views of patients, nurses, and chaplains.” *Clinical Nurse Specialist* 7, no. 4 (1993): 175-182.

England, Kathleen. “Annual Mortality Report (2015).” *Maltese Department of Health Information and Research*. Accessed March 2, 2019. https://deputyprimeminister.gov.mt/en/dhir/Documents/Deaths/Annual%20Mortality%20Report%202015.pdf.

European Commission. “Eurobarometer Social values, Science and Technology (2005).” Accessed February 25, 2019. https://web.archive.org/web/20070406155642/http://ec.europa.eu/public_opinion/archives/ebs/ebs_225_report_en.pdf.

Evans, Natalie, Arantza Meñaca, V.W. Andrew, Jonathan Koffman, Richard Harding, Irene J. Higginson, Robert Pool, and Marjolein Gysel. “Systematic Review of the Primary Research on Minority Ethnic Groups and End-of-Life Care from the United Kingdom.” *Journal of Pain and Symptom Management* 43, no. 2 (2012): 261-286.

Faber, Neil, Susan Y. Urban, Virginia U. Collier, Michael Metzger, Joan Weiner, and Gil Boyer. “Frequency and perceived competence in providing palliative care to terminally ill patients: A survey of primary care physicians.” *Journal of Pain and Symptom Management* 28, no. 4 (2004): 364-372.

Fagerström, Lisbeth, Katie Eriksson, and Ingegerd Bergbom. “The patient’s perceived caring needs: Measuring the unmeasurable.” *International Journal of Nursing Practice* 5, no. 4 (2000): 199-208.

Fang, Mei Lan, Judith Sixsmith, Shane Sinclair, and Glen Horst. “A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: Findings from a scoping review.” *BMC Geriatrics* 16, no. 107 (2016): 1-14.

Fawcett, Tonks N., and Amy Noble. “The challenge of spiritual care in a multi-faith society experienced as a Christian nurse.” *Journal of Clinical Nursing* 13, no. 2 (2004): 136-142.

Ferrell, Betty, Stephen R. Connor, Anne Cordes, Constance M. Dahlin, Perry G. Fine, Nancy Hutton, Mark Leenay, Judy Lentz, Judi Lund Person, Diane E. Meier, and Ken Zuroski. “The National Agenda for Quality Palliative Care: The National Consensus Project and the National Quality Forum.” *Journal of Pain and Symptom Management* 33, no. 6 (2007): 737-744.

Field, David. “Palliative medicine and the medicalization of death.” *European Journal of Cancer Care* 3, no. 2 (1994): 58-62.

Finocchiaro, Darlene N. “Supporting the patient's spiritual needs at the end of life.” *Nursing Critical Care* 12, no. 2 (2017): 32-36.

Fitchett, George, Peter M. Meye, and Laurel Arthur Burton. “Spiritual Care in the Hospital: Who Requests It? Who Needs It?” *The Journal of Pastoral Care* 54, no. 2 (2000): 173-186.

Flannelly, Kevin, George Handzo and Andrew J. Weaver. “Factors affecting Healthcare Chaplaincy and the provision of pastoral care in the United States.” *Journal of Pastoral Care and Counselling* 58, no. 1-2 (2004): 127-130.

Flannelly, Kevin, Kathleen Galek, and George F. Handzo. “To what extent are the spiritual needs of hospital patients being met?” *The International Journal of Psychiatry in Medicine* 35, no. 3 (2005): 319-323.

Flannelly, Kevin. “The Relative Prevalence of Various Spiritual Needs.” *Health and Social Care Chaplaincy* 9, no. 2 (2006): 25-30.

Flory, James, Young-Xu Yinong, Gurol Ipek, Levinsky Norman, Ash Arlene, and Emanuel Ezekiel. “Place of death: U.S. trends since 1980.” *Health Affairs* 23, no. 3 (2004): 194-200.

Folkman, S., and R.S. Lazarus. *Stress, Appraisal and Coping.* 1984. Quoted in Donia Baldacchino and Peter Draper. “Spiritual coping strategies: A review of the nursing research literature.” *Journal of Advanced Nursing* 34, no. 6 (2001): 833 – 841.

Fox, Ellen, Kristen Landrum-McNiff, Zhenshao Zhong, Neal V. Dawson, Albert W. Wu, and Joanne Lynn. “Evaluation of Prognostic Criteria for Determining Hospice Eligibility in Patients with Advanced Lung, Heart, or Liver Disease.” *The Journal of the American Medical Association* 282, no. 17 (1999): 1638-45.

Fryback, Patricia B., and Bonita R. Reinert. “Alternative therapies and control for health in cancer and AIDS.” *Clinical Nurse Specialist* 11, no.2 (1997): 64-69.

Fryback, Patricia B., and Bonita R. Reinert. “Spirituality and people with potentially fatal diagnoses.” *Nursing Forum* 34, no. 1 (1999): 13-22.

Galek, Kathleen, Kevin Flannelly, Adam Vane, and Rose Galek. “Assessing a Patient’s Spiritual Needs: A Comprehensive Instrument.” *Holistic Nursing Practice* 19, no. 2 (2005): 62-69.

Gall, Terry Lynn, and Mark W. Cornblat. “Breast cancer survivors give voice: A qualitative analysis of spiritual factors in long-term adjustment.” *Psycho-Oncology* 11, no. 6 (2002): 524–535.

Gallagher, Romayne Elizabeth, and Marian Krawczyk. “Family members’ perceptions of end of life care across divers locations of care.” *BMC Palliative Care* 12, no. 25 (2013): 1-9.

Gerrish, Kate. “Preparation of nurses to meet the needs of an ethnically diverse society: Educational implications.” *Nurse Education Today* 17, no. 5 (1997): 359-365.

Gholam, Esa Jafaria, Reza Dehshirib, Hosein Eskandarib, Mahmoud Najafic, Rasoul Heshmatid, and Jafar Hoseinifar. “Spiritual well-being and mental health in university students.” *Procedia Social and Behavioural Sciences* 5, no.1 (2010) 1477–81.

Gijsberts, Marie-Jose, Anke Liefbroer, René Otten, and Erik Olsman. “Spiritual Care in Palliative Care: A systematic Review of the recent European Literature.” *Medical Science* 25, no. 7 (2019): 1-21.

Gillon, Raanan. “Ethics needs principles – four can encompass the rest – and respect for autonomy should be “first among equals”.” *Journal of Medical Ethics* 29, no. 5 (2003): 307-312.

Goldstein, Rafael, Deborah Marin, and Mari Umpierre. “Chaplains and Access to Medical Records.” *Journal of Health Care Chaplaincy* 17, no. 3-4 (2011): 162-168.

Gomes, Barbara, Natalia Calanzani, Marjolein Gysels, Sue Hall, and Irene J. Higginson. “Heterogeneity and changes in preferences for dying at home: A systematic review.” *BMC Palliative Care* 12, no. 7 (2013): 1-13.

González-Celis, Ana Luisa, and Juana Gómez-Benito. “Spirituality and Quality of Life and Its Effect on Depression in Older Adults in Mexico.” *Psychology* 4, no. 3 (2013): 178-182.

Gordon, Tom, and David Mitchell. “A competency model for the assessment and delivery of spiritual care.” *Palliative Medicine* 18, no. 7 (2004): 646-651.

Government of United Kingdom. “Public Health England Statistical Commentary: End of Life Care Profiles (2018).” *Gov.uk* Accessed March 1, 2019. https://www.gov.uk/government/publications/end-of-life-care-profiles-february-2018-update/statistical-commentary-end-of-life-care-profiles-february-2018-update.

Govier, Ian. “Spiritual care in nursing: A systematic approach.” *Nursing Standard* 14, no. 17 (2000): 32-36.

Grant, Elisabeth, S.A. Murray, M. Kendall, K. Boyd, S. Tilley, and D. Ryan. “Spiritual issues and needs: Perspectives from patients with advanced cancer and non-malignant disease. A qualitative study.” *Palliative and Supportive Care* 2, no. 4 (2005): 371-378.

Greer, David, Vincent Mor, John N. Morris, Sylvia Sherwood, David Kidder, and Howard Birnbaum. “An alternative in terminal care: Results of the National Hospice Study.” *Journal of Chronic Diseases* 39, no. 1 (1986): 9-26.

Gula, Richard M. “Spirituality and Ethics in Healthcare.” *Health Progress* 81, no. 4 (2000): 17-19.

Gulherme, Caroline. “Spiritual distress in cancer patients: Nursing interventions.” *Revista de Enfermagem UFPE on-line* 5, no. 2 (2011): 290-294.

Gunaratnam, Yasmin. “Intercultural palliative care: Do we need cultural competence?” *International Journal of Palliative Nursing* 13, no. 10 (2007): 470-477.

Gwyther, Liz, Frank Brennan, and Richard Harding. “Advancing Palliative care as a Human Right.” *Journal of Pain and Symptom Management* 38, no. 5 (2009): 767-774.

Hanson, Laura, Debra Dobbs, Barbara M. Usher, Sharon Williams, Jim Rawlings, and Timothy P. Daaleman. “Providers and Types of Spiritual Care during Serious Illness.” *Journal of Palliative Medicine* 11, no. 6 (2008): 907-914.

Hardwing, John. “Spiritual Issues at the End of Life: A Call for Discussion.” *The Hastings Centre Report* 30, no. 2 (2000): 28-30.

Hart, Alton, Jeff Kohlwes, Rick Deyo, Lorna A. Rhodes, and Deborah J. Bowen. “Hospice patients' attitudes regarding spiritual discussions with their doctors.” *American Journal of Hospice and Palliative Medicine* 20, no. 2 (2003): 135-139.

Hatamipour, Khadijeh, Maryam Rassouli, Farideh Yaghmaie, Kazem Zendedel, and Hamid Alavi Majd. “Spiritual Needs of Cancer Patients: A Qualitative Study.” *Indian Journal of Palliative Care* 21, no. 1 (2015): 61-67.

Hayden, Deborah. “Spirituality in end-of life care: Attending the person on their journey.*” British Journal of Community Nursing* 16, no. 11 (2011): 546-51.

Health Service Executive. “A Question of Faith: The Relevance of Faith and Spirituality in Health Care Dublin: Health Service Executive (2011).” Accessed February 28, 2019. http://www.hse.ie/eng/services/publications/corporate/Your_Service,_Your_Say_Consumer_Affairs/Reports/questionoffaith.pdf.

HealthCare Chaplaincy Network. “What Is Quality Spiritual Care in Health Care and How Do You Measure It? (2016).” Accessed March 15, 2019. http://www.healthcarechaplaincy.org/docs/research/quality_indicators_document_2_17_16.pdf.

Herman, Carla. “Spiritual needs of dying patients: A qualitative study.” *Oncology Nursing Forum* 28, no. 1 (2001): 67-72.

Higginson, I.J., and G.J.A. Sen-Gupta. “Place of Care in Advanced Cancer: A Qualitative Systematic Literature Review of Patient Preferences.” *Journal of Palliative Medicine* 3, no. 3 (2000): 287-300.

Higginson, Irene, Vera P. Sarmento, Natalia Calanzani, Hamid Benalia, and Barbara Gomes. “Dying at home – is it better: A narrative appraisal of the state of the science.” *Palliative Medicine* 27, no. 10 (2013): 1-7.

Hills, Judith, Judith A. Paice, Jacqueline R. Cameron, and Susan Shott. “Spirituality and Distress in Palliative Care Consultations.” *Journal of Palliative Medicine* 8, no. 4 (2005): 782-788.

Hinshaw, Daniel B. “The spiritual needs of the dying patient.” *Journal of American College of Surgeons* 195, no. 4 (2002): 565-568.

Hirai, Kei, Tadashi Kudo, Miki Akiyama, Motohiro Matoba, Mariko Shiozaki, Teruko Yamaki, Akemi Yamagishi, Mitsunori Miyashita, Tatsuya Morita, and Kenji Eguchi. “Public Awareness, Knowledge of Availability, and Readiness for Cancer Palliative Care Services: A Population-Based Survey across Four Regions in Japan.” *Journal of Palliative Medicine* 14, no. 8 (2011): 918-922.

Hoberman, John. "Why Bioethics Has a Race Problem." *The Hastings Centre Report* 46, no. 2 (2016): 12–18

Hodge, David R. “A Template for Spiritual Assessment: A Review of the JCAHO Requirements and Guidelines for Implementation.” *Social Work* 51, no. 4 (2006): 317-326.

Hodge, David R. “Why Conduct a Spiritual Assessment? A Theoretical Foundation for Assessment.” *Advances in Social Work* 5, no. 2 (2004): 183-196.

Hodge, David, and Crystal Holtrop. “Spiritual assessment: A review of complementary assessment models.” In *Spiritual Assessment: Handbook for Helping Professionals*, edited by David Hodge, 167-192. Botsford: North American Association of Christians in Social Work, 2003.

Holland, Karen. “Cultural Care: Knowledge and skills for implementation in practice.” In *Cultural Awareness in Nursing and Health Care,* edited by Karen Holland and Christine Hogg, 58- 77. United States of America: Routledge, 2010.

Holloway, Margaret, Sue Adamson, Wilfred McSherry, and John Swinton. “Spiritual care at the end of life: A systematic review of the literature.” *Universities of Hull, Staffordshire and Aberdeen* (2010). Accessed October 1, 2018. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215798/dh_123804.pdf.

Holmes, Seth M., Micheal W. Rabow, and Dibble Suzanne L. “Screening soul: Communication regarding spiritual concerns among primary care physicians and seriously ill patients approaching the end of life.” *American Journal of Hospice and Palliative Medicine* 23, no. 1 (2006) 25-33.

Holyoke, Paul, and Barry Stephenson. “Organization-level principles and practices to support spiritual care at the end of life: A qualitative study.” *BMC Palliative Care* 16, no. 24 (2017): 1-19.

Howell, David D. and Stephen Lutz. “Hospice Referral: An Important Responsibility of the Oncologist.” *Journal of Oncology Practice* 4, no. 6 (2008): 303-304.

Hui, David, M. de la Cruz M, S. Thorney, H.A. Parsons, M. Delgado-Guay, and E. Bruera. "The Frequency and Correlates of Spiritual Distress Among Patients with Advanced Cancer Admitted to an Acute Palliative Care Unit." *American Journal of Hospice & Palliative Medicine* 28, no. 4 (2011): 264-270.

Hummel, Leonard, Kathleen Galek, Kathryn M. Murphy, Helen P. Tannenbaum, and Laura T. Flannelly. "Defining Spiritual Care: An Exploratory Study." *Journal of Health Care Chaplaincy* 15, no. 1 (2008): 40–51.

Hungelmann, Joann, E. Kenkel-Rossi, L. Klassen, R.M Stonenwerk. "Spiritual well- being in older adults: Harmonious interconnectedness." *Journal of Religion Health* 24, no. 2 (1985): 147- 153.

Hungelmann, Joann, Eileen Kenkel-Rossi, Loretta Klassen, and Ruth Stollenwerk. "Focus on spiritual well-being: harmonious interconnectedness of mind-body-spirit – use of the JAREL spiritual well-being scale." *Geriatric Nursing* 17, no. 6 (1996): 262–266.

Hunt, John, Mark Cobb, Vaughan Keeley, and Sam Hjelmeland Ahmedzai. "The quality of spiritual care – developing a standard." *International Journal of Palliative Nursing* 9, no. 5 (2003): 208-215.

Inbadas, Hamilton, Shahaduz Zaman, Alexander Whitelaw, and David Clark. "Palliative Care Declarations: Mapping a New Form of Intervention." *Journal of Pain and Symptom Management* 52, no. 3 (2016): 7-15.

International Health Conference. "Constitution of the World Health Organisation" (2005). Accessed October 5, 2018. http://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf.

Jeffrey, David. "Appropriate palliative care: when does it begin?" *European Journal of Cancer Care* 4, no. 3 (2007): 122-126.

Jenkins, Richard A., and Kenneth Pargament. "Religion and Spirituality as Resources for Coping with Cancer." *Journal of Psychosocial Oncology* 13, no. 1-2 (1995): 51-7.

Joint Commission Standard. "Joint Commission Review Crosswalk for Chaplain Services." *The Joint Commission on Accreditation of Healthcare Organizations* (2011). Accessed November 11, 2018. http://www.healthcarechaplaincy.org/userimages/Joint%20Commission%20Review%20Crosswalk%20for%20Chaplain%20Services%20by%20APC.pdf.

Jones, June, and Derek Willis. "In search of a good death: What is a good death?" *BMJ (online)* 327, no. 7408 (2003): 224.

Kaldjian, Lauris C., James F. Jekel, and Gerald Friedland. "End-of-life decisions in HIV-positive patients: The role of spiritual beliefs." *AIDS* 12, no. 1 (1998): 103-107.

Kaur, Darpan, Gingh Mohinder, and Ajnya Shaunak. "Spirituality and Religion in Modern Medicine." *Indian Journal of Psychological Medicine* 34, no. 4 (2012): 399-402.

Kelley, Amy S., and R. Sean Morrison. "Palliative Care for the Seriously Ill." *New England Journal of Medicine* 373, no. 8 (2015): 747-755.

Kennedy, Christine, and Sharon E. Cheston. “Spiritual distress at life’s end: Finding meaning in the maelstrom.” *Journal of Pastoral Care and Counselling* 57, no. 2 (2003): 131–141.

Kernohan, George W., Mary Waldron, Caroline McAfee, Barbara Cochrane, and Felicity Hasson. “An evidence base for a palliative care chaplaincy service in Northern Ireland.” *Palliative Medicine* 21, no. 6 (2007): 519-525.

Kim, Jo, Allen Heinemann, Rita Bode, James A. Sliwa, and Rosemarie Bridget King. “Spirituality, Quality of Life, and Functional Recovery after Medical Rehabilitation.” *Rehabilitation Psychology* 45, no. 4 (2000): 365-368.

Koenig, Harold G. “Religion, Spirituality, and Medicine: Research Findings and Implications for Clinical Practice.” *Holistic Nursing Practice* 19, no. 2 (2005): 62-69.

Kourie, Celia. "The 'turn' to spirituality." *Acta Theologica Supplement 8* 27, no. 2 (2007): 19 - 40.

Kuuppelomaki, Merja. “Spiritual support for terminally ill patients: Nursing staff assessments.” *Journal of Clinical Nursing* 10, no. 5 (2001): 660–670.

La Pierre, Lawrence L. “JCAHO safeguards spiritual care.” *Holistic Nursing Practice* 17, no. 4 (2003): 219.

Larson, James S. “The World Health Organization's definition of health: Social versus spiritual health.” *Social Indicators Research* 38, no. 2 (1996): 181-192

Lawrence, Raymond J. “The Witches’ Brew of Spirituality and Medicine.” *The Society of Behavioural Medicine* 24, no. 1 (2002): 74-76.

Laws of Malta. *Constitution* (1964).

Leach, Mark M., and Lark Russell. “Does spirituality add to personality in the study of trait forgiveness?” *Personality and Individual Differences* 37, no. 1 (2004): 147-156.

LeBech, Mette. “What is Human Dignity?” *Maynooth Philosophical Papers*. Accessed February 19, 2019. http://mural.maynoothuniversity.ie/392/1/Human_Dignity.pdf.

Ledbetter, Timothy J. “Screening for Pastoral Visitations Using the Clinical and Coping Score.” *Journal of Pastoral Care and Counselling* 62, no. 4 (2008): 367-374.

Lichter, David A. “Studies show spiritual care linked to better health outcomes.” *Health Progress* 94, no. 2 (2013): 62-66.

Lin, Hung-Ru, and Susan Bauer-Wu. “Psycho-spiritual well-being in patients with advanced cancer: An integrative review of the literature.” *Journal of Advanced Nursing* 44, no. 1 (2003): 69-80.

Lloyd-Williams, Mari, and David Field. “Are undergraduate nurses taught palliative care during their training?” *Nurse Education Today* 22, no. 7 (2002): 589-592.

Long, Ann. “Nursing: A spiritual perspective.” *Nursing Ethics* 4, no. 6 (1997): 496–510

Lucas, Arthur M. “Introduction to the discipline for pastoral care giving.” In *The Discipline for Pastoral Care Giving: Foundations for Outcome Oriented Chaplaincy*, edited by Larry Vande Creek and Arthur M. Lucas, 1-35. New York: Routledge, 2001.

LuijkxJos, Katrien G. and M.G.A. Schols. “Volunteers in Palliative Care make a difference.” *Journal of Palliative Care* 25, no. 1 (2009): 30-9.

Lukoff, David, Lu Francis, and Turner Robert. “Cultural considerations in the assessment and treatment of religious and spiritual problems.” *Psychiatric Clinics of North America* 18, no. 3 (1995): 467-485.

MacLaren, Jessica. “A kaleidoscope of understandings: Spiritual nursing in a multi-faith society.” *Journal of Advanced Nursing* 45, no. 5 (2004): 457-464.

MacLean, Charles D., Beth Susi, Nancy Phifer, Linda Schultz, Deborah Bynum, Mark Franco, Andria Klioze, Michael Monroe, Joanne Garrett, and Sam Cykert. “Patient Preference for Physician Discussion and Practice of Spirituality.” *Journal of General Internal Medicine* 18, no. 1 (2003): 38-43.

Mako, Caterina, Kathleen Galek, and Shannon Poppito. “Spiritual Pain among Patients with Advanced Cancer in Palliative Care.” *Journal of Palliative Medicine* 9, no. 5 (2006): 1106-13.

Males, J., and C. Boswell. “Spiritual needs of people with mental handicap.” *Nursing Standard* 48, no. 4 (1990): 35-37.

Malta Parliamentary Secretariat for Health. *Patient Charter* (2016). Accessed January 29, 2019. https://meae.gov.mt/en/public_consultations/meh-health/documents/patient%20charter% 20%28in%20english%29.pdf.

Mann, Jonathan, Lawrence Gostin, Sofia Gruskin, Zita Lazzarini, Troyen Brennan, and Harvey Fineberg. “Health and human rights.” *Health and Human Rights* 1, no. 1 (1994): 6–23.

Mann, Jonathan. “Health and Human Rights: If Not Now, When?” *Health and Human Rights* 2, no. 3 (1997): 113-120.

Marin, Deborah B., Vanshdeep Sharma, Eugene Sosunov, Natalia Egorova, Rafael Goldstein, and George F. Handzo. “Relationship between chaplain visits and patient satisfaction.” *Journal of Health Care Chaplaincy* 21, no. 1 (2015): 14-24.

Martins, Helga, and Silvia Caldeira. “Spiritual Distress in Cancer Patients: A Synthesis of Qualitative Studies.” *Religions* 9, no. 10 (2018): 285.

Martsolf, Donna S. “Cultural aspects of spirituality in cancer care.” *Seminars in Oncology Nursing* 13, no. 4 (1997): 231–236.

Masso, Malcom, Samuel Frederic Allingham, Maree Banfield, Claire Elizabeth Johnson, Tanya Pidgeon, Patsy Yates, and Kathy Eagar. “Palliative care phase: inter-rater reliability and acceptability in a national study.” *Palliative Medicine* 29, no. 1 (2015): 22-30.

Maugans, T.A. “The SPIRITual History.” *Archives of Family Medicine* 5, no. 1 (1996): 11–16.

Maureen, Muldoon, and Norman King. “Spirituality, Healthcare, and Bioethics.” *Journal of Religion and Health* 34, no. 4 (1995): 329-350.

McBride, J. Lebron, G. Arthur, R. Brooks, L. Pilkington. “The relationship between a patient's spirituality and health experiences.” *Family Medicine* 30, no. 2 (1998): 122-126.

McBride, LeBron J., Pilkington Lloyd, and Arthur Gary L. “Development of brief pictorial instruments for assessing spirituality in primary care.” *Journal of Ambulatory Care Management* 21, no. 4 (1998): 53–61.

McClain, Colleen S., Rosenfeld Barry, and Breitbart William. “Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patient.” *The Lancet* 361, Issue. 9369 (2003): 1603-7.

McClung, Emily, Grossoehme Daniel H., and Jacobson Ann. “Collaborating with Chaplains to Meet Spiritual Needs.” *Medsurg nursing: Official Journal of the Academy of Medical-Surgical Nurses* 15, no. 3 (2006): 147-156.

McCord, Gary, Valerie J. Gilchrist, Steven D. Grossman, Bridget D. King, Kenelm F. McCormick, Allison M. Oprandi, Susan Labuda Schrop, Brian A. Selius, William D. Smucker, David L. Weldy, Melissa Amorn, Melissa A. Carter, Andrew J. Deak, Hebah Hefzy, and Mohit Srivastava. “Discussing spirituality with patients: A rational and ethical approach.” *The Annals of Family Medicine* 2, no. 4 (2004): 356-361.

Mcilfatrick, Sonya, H. Noble, N.K. McCorry, A. Roulston, F. Hasson, D. McLaughlin, G. Johnston, L. Rutherford, C. Payne, G. Kernohan, S. Kelly, and A. Craig. “Exploring public awareness and perceptions of palliative care: A qualitative study.” *Palliative Medicine* 28, no. 3 (2013): 273-280.

McSherry, Wilfred, and Draper Peter. “The spiritual dimension: Why the absence within nursing curricula?” *Nurse Education Today* 17, no. 5 (1997): 413-417.

McSherry, Wilfred, and Keith Cash. “The language of spirituality: an emerging taxonomy.” *International Journal of Nursing Studies* 41, no.1 (2004): 151-161.

McSherry, Wilfred, Cash Keith, and Ross Linda. “Meaning of Spirituality: Implications for Nursing Practice.” *Journal of Clinical Nursing* 13, no. 8 (2004): 934-941.

McSherry, Wilfred. “Nurses’ perceptions of spirituality and spiritual care.” *Nursing Standards* 13, no. 4 (1998): 36–41.

Mehta, Anita, and Chan Lisa S. “Understanding of the Concept of ‘‘Total Pain”.” *Journal of Hospice and Palliative Nursing* 10, no. 1 (2008): 26-32.

Meredith, Pamela J., Judith Murray, Trish Wilson, Geoff Mitchell, and Richard Hutch. “Can spirituality be taught to health care professionals?” *Journal of Religion and Health* 51, no. 3 (2012): 879-889.

Mitchell David. *Standards for Hospice and Palliative Care Chaplaincy*. London: Association of Hospice and Palliative Care Chaplains, 2006.

Mitchell, Geoffrey. “Rapidly increasing end-of-life care needs: A timely warning.” *BMC Medicine* 15, no. 126 (2017): 1-2.

Moadel, Alyson, Carole Morgan, Anne Fatone, Jennifer Grennan, Jeanne Carter, Gia Laruffa, Anne Skummy, and Janice Dutcher. “Seeking meaning and hope: Self-

reported spiritual and existential needs among an ethnically-diverse cancer patient population." *Psycho-Oncology* 8, no. 5 (1999): 378–385.

Mowat Harriet, John Swinton, Clare Guest, and Liz Grant. *What do Chaplains do? The role of the Chaplain in meeting the spiritual needs of patients.* Aberdeen: University of Aberdeen and Mowat Research, 2007.

Murray, Scott, Marilyn Kendall, Geoffrey Keith Mitchell, Sébastien Moine, Jordi Amblàs Novellas, and Kirsty Boyd. "Palliative care from diagnosis to death." *BMJ Clinical Research* 356, no. 878 (2017): 1-5.

Murray, Scott, Marilyn Kendall, Kirsty Boyd, Allison Worth, and T. Fred Benton. "Exploring the spiritual needs of people dying of lung cancer or heart failure: A prospective qualitative interview study of patients and their carers." *Palliative Medicine* 18, no. 1 (2004): 39-45.

Murtagh, Fliss, Claudia Bausewein, Julia Verne, E. Iris Groeneveld, Yvonne E. Kaloki, and Irene J. Higginson. "How many people need palliative care? A study developing and comparing methods for population-based estimates." *Palliative Medicine* 28, no. 1 (2014): 49 –58.

Nagase, Masako. "Does a Multi-Dimensional Concept of Health Include Spirituality? Analysis of Japan Health Science Council's Discussions on WHO's 'Definition of Health' (1998)." *International Journal of Applied Sociology* 2, no. 6 (2012): 71-77.

Nakamura, Shunsuke, Masafumi Kuzuya,Yoshimasa Funaki, Wataru Matsui, and Naoki Ishiguro. "Factors influencing death at home in terminally ill cancer patients." *Geriatrics and Gerontology International* 10, no. 2 (2010): 154-160.

Narayanasamy, Aru, and Jan Owens. "A critical incident study of nurses' responses to the spiritual needs of their patients." *Journal of Advanced Nursing* 33, no. 4 (2001): 446–455.

Narayanasamy, Aru. "Nurses' awareness and educational preparation in meeting their patients' spiritual needs." *Nurse Education Today* 13, no. 3 (1993): 196-201.

Narayanasamy, Aru. "Spiritual coping mechanisms in chronically ill patients." *British Journal of Nursing* 11, no. 22 (2002): 159-175.

National Coalition for Hospice and Palliative Care. "Clinical Practice Guidelines for Quality Palliative Care in Clinical Practice Guidelines for Quality Palliative Care (2018)." Accessed January 20, 2019. https://www.nationalcoalitionhpc.org/wpcontent/uploads/2018/10/NCHPCNCPGuidelines_4thED_web_FINAL.pdf.

National Health Statistics Edinburgh. "Spiritual and Religious Care Capabilities and Competences for Healthcare Chaplains." *Education for Scotland.* Accessed March 10, 2019. http://www.ukbhc.org.uk/sites/default/files/nes_chaplaincy_capabilities_and_competencies.pdf.

Neely, David and Eunice J. Minford. "FAITH: Spiritual history-taking made easy." *The Clinical Teacher* 6, no. 3 (2009) 181–185.

Neely, David, and Eunice J. Minford. "Current status of teaching on spirituality in UK medical schools." *Medical Education* 42, no. 2 (2008): 176–182.

Nelson, Christian J., Barry Rosenfeld, William Breitbart, and Michele Galietta. "Spirituality, Religion, and Depression in the Terminally Ill." *Psychosomatics* 43, no. 3 (2002): 213-220.

Nolan, Steve, P. Saltmarsh, and Carlo Leget. "Spiritual care in palliative care: Working towards an EAPC task force." *European Public Law* 18, no. 2 (2011): 86–89.

Noys, Benjamin. "Bioethics and Death." In *The Culture of Death,* edited by Benjamnin Noys, 77-79. New York: Bloomsbury Academic, 2005.

Nursing and Midwifery Board. "Maltese Code of Ethics for Nurses and Midwives." Accessed January 28, 2019. https://deputyprimeminister.gov.mt/en/phc/pdu/documents/maltese_code_of_ethics_nurses.pdf.

Nursing and Midwifery Board. "Maltese Code of Ethics for Nurses and Midwives (1997)." Accessed January 28, 2019. https://deputyprimeminister.gov.mt/en/phc/pdu/documents/maltese_code_of_ethics_nurses.pdf.

O'Connor, Moira, Andrew Guilfoyle, Lauren Breen, F. Mukhardt, and Colleen Fisher. "Relationships between quality of life, spiritual well-being, and psychological adjustment styles for people living with leukaemia: An exploratory study." *Mental Health Religion and Culture* 10, no. 6 (2007): 631–664.

Office of the High Commissioner of Human Rights. "CESR General Comment No.14: The Right to the Highest Attainable Standard of Health (Art. 12)" (2000). Accessed February 17, 2019. https://www.ohchr.org/Documents/Issues/Women/WRGS/Health/GC14.pdf.

Office of the United Nations High Commissioner for Human Rights and World Health Organization. "The Right to Health" (2008). Accessed February 18, 2019. https://www.ohchr.org/Documents/Publications/Factsheet31.pdf.

Organization of American States. "Inter-American Convention on Protecting the Human Rights of Older Persons" (2015). Accessed February 14, 2019. http://www.oas.org/en/sla/dil/docs/inter_american_treaties_A-70_human_rights_older_persons.pdf.

Otto, R. *The idea of the Holy: An Inquiry into the non-rational factor in the idea of the divine and its relation to the rational*. 1950. Quoted in Donia Baldacchino and Peter Draper. "Spiritual coping strategies: A review of the nursing research literature." *Journal of Advanced Nursing* 34, no. 6 (2001): 833 – 841.

Paley, John. "Spirituality and nursing: A reductionist approach." *Nursing Philosophy* 9, no. 1 (2008): 3–18.

Paley, John. "Spirituality and secularization: Nursing and the sociology of religion." *Journal of Clinical Nursing* 17, no. 2 (2008): 175–186.

Parameshwaran, Ramakrishnan. "Theory and practice of chaplain's spiritual care process: A psychiatrist's experiences of chaplaincy and conceptualizing trans-personal model of mindfulness." *Indian Journal of Psychiatry* 57, no. 1 (2015): 21-29.

Pargament, Kenneth I., Harold Koenig and Lisa M. Perez. "The many methods of religious coping: Development and initial validation of the RCOPE." *Journal of Clinical Psychology* 56, no. 4 (2000): 519-543.

Pargament, Kenneth I., Harold Koenig, Nalini Tarakeshwar, and June Hahn. “Religious struggle as a predictor of mortality among medically ill elderly patients: A 2-year longitudinal study.” *Archives of International Medicine* 161, no. 15 (2001): 1881–5.

Park, Crystal L., Wortmann Harlow, and Jennifer Donald Edmondson. “Religious Struggle as a Predictor of Subsequent Mental and Physical Well-Being in Advanced Heart Failure Patients.” *The Journal of Behavioural Medicine* 34, no. 6 (2009): 426-436.

Parliamentary Assembly Council of Europe. *Protection of the Human Rights and Dignity of the Terminally Ill and Dying* (1999).

Pasman, Roeline, Hella E. Brandt, Luc Deliens, and Anneke L. Francke. “Quality indicators for palliative care: A systematic review.” *Journal of Pain and Symptom Management* 38, no. 1 (2009): 145–156.

Pearce, Michelle J., April D. Coan, James E. HerndonII, Harold G. Koenig, and Amy P. Abernethy. “Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients.” *Supportive Care in Cancer* 20, no. 10 (2011): 2269-76.

Pesut, Barbara, Brenda Hooper, Suzanne Lehbauer, and Miranda Dalhuisen. “Promoting Volunteer Capacity in Hospice Palliative Care: A Narrative Review.” *The American Journal of Hospice & Palliative Care* 31, no. 1 (2012) 69-78.

Peterman, Amy H., George Fitchett, Marianne J. Brady, Lesbia Hernandez, and David Cella “Measuring spiritual well-being in people with cancer: The Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being scale (FACIT-Sp).” *Annals of Behavioural Medicine* 24, no. 1 (2002): 49-58.

Phelps, Andrea C., Katharine E. Lauderdale, Sara Alcorn, Jennifer Dillinger, Michael T. Balboni, Michael Van Wert, Tyler J. VanderWeele, and Tracy A. Balboni. “Addressing spirituality within the care of patients at the end of life: Perspectives of patients with advanced cancer, oncologists, and oncology nurses.” *Journal of Clinical Oncology* 30, no. 20 (2012): 2538–44.

Phibal, Anong, and Hatthakit Urai. “The Spiritual Care Needs and Spiritual Care Received.” *Supportive and Palliative Care* 3, no. 2 (2013): 248-249.

Poole, Rob, and Christopher C. Cook. “Praying with a patient constitutes a breach of professional boundaries in psychiatric practice.” *British Journal of Psychiatry* 199, no. 2 (2011): 94-8.

Price, Connie C., and Stephen Sodeke. “Letter to the Editor: End-of-Life Care and Racial Disparities: All Social and Health Care Sectors Must Respond!” *The American Journal of Bioethics* 6, no. 5 (2006): 33-34.

Puchalski, Christina M. “Spirituality and Medicine: Curricula in Medical Education.” *Journal of Cancer Education* 21, no. 1 (2006): 14-18.

Puchalski, Christina M. “Spirituality and the Care of Patients at the End-of-Life: An Essential Component of Care.” *Journal of Death and Dying* 56, no.1 (2007): 33-46

Puchalski, Christina M. “The FICA Spiritual History Tool.” *Journal of Palliative Medicine* 17, no. 1 (2014): 105-106.

Puchalski, Christina M., B. Ferrell, R. Virani, S. Otis-Green, P. Baird, J. Bull, H. Chochinov, G. Handzo, H. Nelson-Becker, M. Prince-Paul, K. Pugliese, and D. Sulmasy. “Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference.” *Journal of Palliative Medicine* 12, no. 10 (2009): 885-904.

Puchalski, Christina M., Beverly Lunsford, Mary H. Harris, and Tamara Miller. “Interdisciplinary Spiritual Care for Seriously Ill and Dying Patients: A Collaborative Model.” *The Cancer Journal* 12, no. 5 (2006): 398-413.

Puchalski, Christina M., Shelley Dean Kilpatrick, Michael McCullough, and David B. Larson. “A systematic review of spiritual and religious variables in Palliative Medicine, American Journal of Hospice and Palliative Care, Hospice Journal, Journal of Palliative Care and Journal of Pain and Symptom Management.” *Palliative and Supportive Care* 1, no. 1 (2003): 7–13.

Puchalski, Christina, and D.B. Larson. “Developing curricula in spirituality and medicine.” *Academic Medicine* 73, no. 9 (1998): 970-974.

Puchalski, Christina. “The role of spirituality in health care.” *Proceedings (Baylor University Medical Centre)* 14, no. 4 (2001): 352-357.

Puchaski, Christina M., Robert Vitillo, Sharon K. Hull, and Nancy Reller. “Improving the spiritual dimension of the whole person care: Reaching national and international consensus.” *Journal of Palliative Medicine* 17, no. 6 (2014): 642-656.

Rasinski, Kenneth A., Youssef G. Kalad, John D. Yoon, and Farr A. Curlin. “An assessment of US physicians’ training in religion, spirituality, and medicine.” *Medical Teacher* 33, no. 11 (2011): 944-945.

Reed, Pamela G. “Preferences for spirituality-related nursing interventions among terminally ill and non-terminally ill hospitalized adults and well adults.” *Applied Nursing Research* 4, no. 3 (1991): 122-128.

Ripamonti, Carla, Federico Giuntoli, Silvia Gonella, and Guido Miccinesi. “Spiritual Care in Cancer Patient: A need or an option?” *Current Opinion in Oncology* 30, no. 4 (2018): 1-7.

Robinson, Mary, Mary Thiel, Kezia Shirkey, David Zurakowski, and Elaine C. Meyer. “Efficacy of Training Interprofessional Spiritual Care Generalists.” *Journal of Palliative Medicine* 19, no. 8 (2016): 814-821.

Rodin, Danielle, Michael Balboni, Christine Mitchell, Patrick T. Smith, Tyler J. VanderWeele, and Tracy A. Balboni. “Whose role? Oncology practitioners’ perceptions of their role in providing spiritual care to advanced cancer patients.” *Journal of Pain and Symptom Management* 49, no. 2 (2015)1-8.

Rushton, Lucy. “What are the barriers to spiritual care in a hospital setting?” *British Journal of Nursing* 23, no. 7 (2014): 370-374.

Saguil, Aaron, and Karen Phelps. “The Spiritual Assessment.” *American Family Physician* 86, no. 6 (2012): 546-550.

Sandsdalen, Tuva, Vigdis Abrahamsen Grondahl, Reidun Hov, Sevald Hoye, Ingrid Rystedt, and Bodil Wilde-Larsson. “Patients’ perceptions of palliative care quality in

hospice inpatient care, hospice day care, palliative units in nursing homes, and home care: A cross-sectional study." *BMC Palliative Care* 15, no. 79 (2016): 1-18.

Scandurra, Anita J. "Everyday spirituality: A core unit health education and lifetime Wellness." *Journal of Health Education* 30, no. 2 (1999): 105.

Schnoll, Robert A., Lisa Harlow, and Lisa Brower. "Spirituality, demographic and disease factors, and adjustment to cancer." *Cancer Practice* 8, no. 6 (2000): 298-304.

Schockett, Erica R., Joan M. Teno, Susan C. Miller, Brad Stuart. "Late referral to hospice and bereaved family member perception of quality of end-of-life care." *Journal of Pain and Symptom Management* 30, no. 5 (2005): 400-407.

Schultz, Michael, Netta Bentur, Ziv Rei Koren, and Gil Bar-Sela. "From pastoral care to spiritual care- Transforming the conception of the role of the spiritual care provider." *Harefuah* 156, no. 11 (2017): 735-739.

Scott, Mary, Mary Thiel, and Constance M. Dahlin. "The National Agenda for Quality Spiritual Care: The Essential Elements of Spirituality in End-of-life Care." *Chaplaincy Today* 24, no. 2 (2008): 15-21.

Selman, Lucy, Lisa Jane Brighton, Shane Sinclair, Ikali Karvinen, Richard Egan, Peter Speck, Richard A. Powell, Ewa Deskur-Smielecka, Myra Glajchen, Shelly Adler, Christina Puchalski, Joy Hunter, Nancy Gikaara, and Jonathon Hope. "Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries." *Palliative Medicine* 32, no. 1 (2017): 1-15.

Selman, Lucy, Richard Harding, Peter Speck, Vicky Robinson, Anna Aguma, Ann Rhys, Nana Kyei-Baffour, and Irene J. Higginson. "Spiritual care recommendations for people from Black and minority ethnic groups receiving palliative care in the UK." *The Cicely Saunders Foundation.* Accessed March 18, 2019. https://www.kcl.ac.uk/cicelysaunders/attachments/Spiritualcarerecommendations-Fullreport.pdf.

Selman, Lucy, Vicky Robinson, Lara Klass, Shaheen Khan, Rob George, Kate Shepherd, Rachel Burman, and Jonathan Koffman. "Improving confidence and competence of healthcare professionals in end-of-life care: An evaluation of the 'Transforming End of Life Care' course at an acute hospital trust." *BMJ Supportive and Palliative Care* 6, no. 2 (2016): 231–236.

Sessanna, Loralee, Finnell Deborah, and Jezewski Mary Ann. "Spirituality in Nursing and Health-Related Literature a Concept Analysis." *Journal of Holistic Nursing* 25, no. 4 (2008): 252-262.

Sharma, Rashmi K., Alan B. Astrow, Kenneth Texeira, and Daniel P. Sulmasy. "The Spiritual Needs Assessment for Patients (SNAP): Development and validation of a comprehensive instrument to assess unmet spiritual needs." *Journal of Pain and Symptom Management* 44, no. 1 (2012): 44-51.

Sherman, Allen, Stephanie Simonton, Umaira Latif, Rebecca Spohn, and Guido Tricot. "Religious Struggle and Religious Comfort in Response to Illness: Health Outcomes among Stem Cell Transplant Patients." *Journal of Behavioural Medicine* 28, no. 4 (2005): 359-367.

Sinclair, Shane, and Chochinov Harvey Max. “Communicating with patients about existential and spiritual issues: SACR-D work.” *Progress in Palliative Care* 20, no. 2 (2012): 72-76.

Sinclair, Shane, Pereira Jose, and Raffin Shelley. “A thematic review of the spirituality literature within palliative care.” *Journal of Palliative Medicine* 9, no. 2 (2006): 464-479.

Sinclair, Shane, Shelley Raffin Bouchal, Harvey Chochinov, Neil Hagen, and Susan McClement. “Spiritual care: How to do it.” *Supportive and Palliative Care* 2, no. 4 (2012): 319-327.

Singer, Peter A., Martin Douglas, and Kelner Merrijoy. “Quality End-of-Life Care: Patients' Perspectives.” *The Journal of the American Medical Association* 281, no. 2 (1999): 163-168.

Singer, Peter. “A dubious distinction.” *The Guardian.* Accessed January 23, 2019. https://www.theguardian.com/commentisfree/2007/jan/17/comment.health.

Sloan, Richard P., Bagiella Emilia, and Powell Tia. “Religion, Spirituality, and Medicine.” *The Lancet* 353, no. 9153 (1999): 664-667.

Speck, Peter. “The evidence base for spiritual care.” *Nursing Management* 12, no. 6 (2005): 28-31.

Steinhauser, Karen E., Nicholas A. Christakis, Elizabeth C. Clipp, Maya McNeilly, Lauren McIntyre, and James A. Tulsky. “Factors considered important at the end of life by patients, family, physicians, and other care providers.” *The Journal of the American Medical Association* 284, no. 19 (2000): 2476-82.

Stephenson, Pam, Claire Draucker, and Donna S. Martsolf. “The Experience of Spirituality in the Lives of Hospice Patients.” *Journal of Hospice and Palliative Nursing* 5, no. 1 (2003): 51-58.

Storey, Lee, Chris Pemberton, Anne Howard, and Lee O’Donnell. “Place of death: Hobson’s choice or patient choice?” *Cancer Nursing Practice* 2, no.1 (2003): 33–38.

Stranahan, Susan. “Spiritual Perception, Attitudes about Spiritual Care, and Spiritual Care Practices among Nurse Practitioners.” *Western Journal of Nursing Research* 23, no. 1 (2001): 90-104.

Strang, Susann, Peter Strang, and Britt-Marie Ternestedt. “Spiritual needs as defined by Swedish nursing staff.” *Journal of Clinical Nursing* 11, no. 1 (2002): 48-57.

Sulmasy, Daniel P. “A biopsychosocial-spiritual model for care of patients at the end of life.” *The Gerontologist* 42, no. 3 (2002): 24-33.

Sulmasy, Daniel P. “Ethical principles for spiritual care.” In *The Oxford Textbook of Spirituality in Healthcare*, edited by Mark R. Cobb, Christina M. Puchalski and Bruce Rumbold, 465–470. Oxford: Oxford University Press, 2012.

Sulmasy, Daniel P. “Spiritual Issues in the Care of Dying Patients “. . . It’s Okay Between Me and God”.” *Journal of American Medical Association* 296, no. 11 (2006): 1385-92.

Swerissen, Hal and Duckett Stephen. “Dying well.” *Grattan Institute Report* (2014). Accessed March 4, 2019. https://grattan. edu.au/report/dying-well/.

Swift, Chris James, Calcutawalla Sara, and Elliot Rosie. “Nursing attitudes towards recording of religious and spiritual data.” *British Journal of Nursing* 16, no. 20 (2007): 1279–82.

Swinton, John, and Stephen Pattison. “Spirituality. Come all ye faithful.” *Health Service Journal* 111, Issue 5786 (2001): 24–25.

Swinton, John. “Rediscovering Mystery and Wonder: Toward a Narrative-Based Perspective on Chaplaincy.” *Journal of Health Care Chaplaincy* 13, no. 1 (2002): 223-236.

Tan, Heather, Braunack-Mayer Annette J., and Beilby Justin J. “The Impact of the Hospice Environment on Patient Spiritual Expression.” *Oncology Nursing Forum* 32, no. 5 (2005): 1049-55.

Tanyi, Ruth A. “Towards Clarification of the meaning of spirituality.” *Journal of Advanced Nursing* 39, no. 5 (2002): 500-509.

Taylor, Elizabeth Johnston. “Spiritual Care: Evangelism by the bedside?” *Journal of Christian Nursing* 28, no. 4 (2011): 194-202.

Taylor, Johnston Elizabeth. “Spiritual needs of patients with cancer and family caregivers.” *Cancer Nursing* 26, no. 4 (2003): 260-266.

Temel, Jennifer S., Joseph A. Greer, Alona Muzikansky, Emily R. Gallagher, Sonal Admane, Vicki A. Jackson, Constance M. Dahlin, Craig D. Blinderman, Juliet Jacobsen, William F. Pirl, Andrew Billings, and Thomas J. Lynch. “Early palliative care for patients with metastatic non-small-cell-lung cancer.” *New England Journal of Medicine* 363, no. 8 (2010): 733–742.

Teno, Joan M., David Casarett, Carol Spence, and Stephen Connor. “It Is “Too Late” or Is It? Bereaved Family Members Perceptions of Hospice Referral When Their Family Member Was on Hospice for Seven Days or Less.” *Journal for Pain and Symptom Management* 43, no. 4 (2012): 732-738.

The Hastings Centre. “Hastings Centre Calls on Health Care Professionals and Organizations to Meet Standards for Good Care Near the End of Life.” (2013). Accessed March 18, 2019. https://medicalxpress.com/pdf287148911.pdf.

The Joint Commission on Accreditation of Healthcare Organizations. “Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centred Care: A Roadmap for Hospitals.” (2010). Accessed November 13, 2018. https://www.jointcommission.org/roadmap_for_hospitals/.

Thomas, Joan, and Andrew Retsa. “Transacting self-preservation: a grounded theory of the spiritual dimensions of people with terminal cancer.” *International Journal of Nursing Studies* 36, no. 3 (1999) 191-201.

Thoresen, Carl E. “Spirituality and health: Is there a relationship?” *Journal of Health Psychology* 4, no. 3 (1999): 291-300.

Tiew, Lay Hwa, Jian Hui Kwee, Debra K. Creedy, and Moon Fai Chan. “Hospice Nurses’ Perspectives of Spirituality.” *Journal of Clinical Nursing* 22, no. 19-20 (2013): 2923–33.

Timmins, Fiona, and Sílvia Caldeira. “Assessing the Spiritual Needs of Patients.” *Nursing Standard* 31, no. 29 (2017): 47–53.

Timmins, Fiona. “Nurses’ Views of Spirituality and Spiritual Care in the Republic of Ireland.” *Journal for the Study of Spirituality* 3, no. 2 (2013): 123-139.

Tloczynski, Joseph, Knoll Christa, and Fitch Andrew. “The relationship among Spirituality, Religious Ideology, and Personality.” *Journal of Psychology and Theology* 25, no. 2 (1997): 208-213.

Touhy, Theris A., Brown Cynthia, and Smith Carol J. “Spiritual Caring: End of Life in a Nursing Home.” *Journal of Gerontological Nursing* 31, no. 9 (2005): 27-35.

Treloar, Linda L. “Integration of spirituality into healthcare practice by nurse practitioners.” *Journal of the American Academy of Nurse Practitioners* 12, no. 7 (2000): 280-285.

Turner, Helen, and Christopher C. H. Cook. “Perceptions of Physiotherapists in Relation to Spiritual Care.” *Journal for the Study of Spirituality* 6, no. 1 (2016): 58–77.

UNESCO, *Universal Declaration on Bioethics and Human Rights* (2006).

United Kingdom Parliamentary Papers. (EDM #1477) “Marie Curie Cancer Care Campaign: Supporting the choice to die at home.” *House of Commons* (2004). Accessed March 3, 2019. https://edm.parliament.uk/early-day-motion/24463.

United Nations Committee on Economic, Social and Cultural Rights. “The right to the highest attainable standard of health, General Comment No. 14 (2000).” Accessed February 3, 2019. http://www.escr-net.org/docs/i/425238.

United Nations, *Convention on the Rights of the Child* (1989).

United Nations, *International Convention on the Elimination of All Forms of Racial Discrimination* (1965).

United Nations, *International Covenant on Economic, Social and Cultural Rights* (1966).

United Nations, *The Universal Declaration of Human Rights* (1948).

Vachon, Melanie, Marie Achille, and Lise Fillion. “A conceptual analysis of spirituality at the end of life.” *Journal of Palliative Medicine* 12, no. 1 (2009): 53-59.

van Leeuwen, Renatus Ronaldus. “An Instrument to measure Nursing Competencies in Spiritual Care: Validity and reliability of the Spiritual Care Competence Scale (SCCS).” In *Toward Nursing Competencies in Spiritual Care*, edited by Renatus Ronaldus van Leeuwen, 132-151. The Netherlands: University of Groningen, 2009.

van Leeuwen, René, Lucas J. Tiesinga, Doeke Post, and H. Jochemsen. “Spiritual care: Implications for nurses’ professional responsibility.” *Journal of Clinical Nursing* 15, no. 7 (2006): 875-884.

VandeCreek, Larry, and Laurel Burton. “Professional Chaplaincy: Its Role and Importance in Healthcare.” *The Journal of Pastoral Care* 55, no. 1 (2001): 81-97.

Vandecreek, Larry, J. Thomas, A. Jessen, J. Gibbons, A. Jessen, S. Strasser. “Patient and family perceptions of hospital chaplains.” *Hospital & Health Services Administration* 36, no. 3 (1991): 455-467.

VandeCreek, Larry. “How satisfied are patients with the ministry of chaplains?” *The Journal of Pastoral Care and Counselling* 58, no. 4 (2004): 335-342.

Vaz, Nafisa. “Patient Satisfaction.” In *Healthcare Administration for Patient Safety and Engagement,* edited by Aleksandra Rosiek-Kryszewska and Krzysztof Leksowski, 186-200. Pennsylvania: IGI Global, 2018.

Wai Fong, Ellen, Peter French Yeung, and Anna Leung Oi Sang. “The impact of hospice inpatient care on the quality of life of patients terminally ill with cancer.” *Cancer Nursing* 22, no. 5 (1999): 350-357.

Wallace, Cara. “Hospice Eligibility and Election: Does Policy Prepare Us to Meet the Need?” *Journal of Aging and Social Policy* 27, no. 4 (2015): 364- 380.

Walter, Tony. “Spirituality in Palliative Care: Opportunity or Burden?” *Palliative Medicine* 16, no. 2 (2002): 133-139.

Walter, Tony. “The ideology and organization of spiritual care.” *Palliative Medicine* 11, no. 1 (1997) 21-30.

Weis, Andrew. “Matters of Life and Death Through Agamben: From Bare Life to Forms-of-Life.” *University of Toronto, Canada* (2009). Accessed January 26, 2019. https://www.academia.edu/1161898/Matters_of_Life_and_Death_Through_Agamben_From_Bare_Life_to_Forms-of-Life.

Westlake, Cheryl, and Kathleen Dracup. “Role of spirituality in adjustment of patients with advanced heart failure.” *Progress in Cardiovascular Nursing* 16, no. 3 (2001): 119-125.

Wheatley, Victoria, and Idris Baker. ‘‘Please, I want to go home: Ethical issues raised when considering choice of place of care in palliative care.” *Postgraduate Medical Journal* 83, no. 984 (2007): 643-648.

Wilkinson, Susie. “Fulfilling patients’ wishes: Palliative care at home.” *International Journal of Palliative Nursing* 6, no. 5 (2000): 212.

Williams, Joshua A., David Meltzer, Vineet Arora, Grace Chung, and Farr A. Curlin. “Attention to Inpatients’ Religious and Spiritual Concerns: Predictors and Association with Patient Satisfaction.” *Journal of General Internal Medicine* 26, no. 11 (2011): 1265-71.

Williams, Sharon W., Hanson Laura, and Rawlings Jim, “An Exploratory Study of Spiritual Care at the End of life.” *The Annals of Family Medicine* 6, no. 5 (2008): 406-411.

Winkelman, William D., Katharine Lauderdale, Michael J. Balboni, Andrea C. Phelps, John R. Peteet, Susan D. Block, Lisa A. Kachnic, Tyler J. VanderWeele, and Tracy A. Balboni. “The relationship of spiritual concerns to the quality of life of advanced cancer patients: Preliminary findings.” *Journal of Palliative Medicine* 14, no. 9 (2011): 1022-8.

Winter-Pfändler, Urs, and Christoph Morgenthaler. “Who Needs Chaplain's Visitation in General Hospitals? Assessing Patients with Psychosocial and Religious Needs.” *The Journal of Pastoral Care and Counselling* 65, no. 2 (2001): 1-9.

World Health Assembly. “Strengthening of palliative care as a component of comprehensive care throughout the life course (2014).” Accessed January 28, 2019. http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf.

World Health Organisation, *A Declaration on the Promotion of Patients in Europe* (1994).

World Health Organisation. “Executive Board 101st Session, Resolutions and Decisions.” *World Health Assembly* (1998). Accessed March 22, 2019. http://www.who.int/iris/handle/10665/79503.

World Health Organisation. “Strengthening of palliative care as a component of integrated treatment within the continuum of care.” *World Health Assembly* (2014). Accessed January 5, 2019. http://apps.who.int/gb/ebwha/pdf_files/EB134/B134_R7-en.pdf.

World Health Organization. “National cancer control programmes: Policies and Managerial Guidelines.” *World Health Assembly* (2002). Accessed February 18, 2019. http://www.who.int/cancer/media/en/408.pdf.

World Health Organization. “Palliative care: Symptom management and end-of-life care. Integrated management of adolescent and adult illness (2004).” Accessed January 23, 2019. https://www.who.int/hiv/pub/imai/genericpalliativecare082004.pdf?ua=1.

World Health Organization. “The spiritual dimension in the global strategy for health for all by the year 2000.” *World Health Assembly* (1984). Accessed January 25, 2019. http://www.who.int/iris/handle/10665/160950.

World Health Organization. “WHO Definition of Palliative.” Accessed January 17, 2019. www.who.int/cancer/palliative/definition/en/.

Wright, Alexi Anne, Nancy L. Keating, John Z. Ayanian, Elizabeth A. Chrischilles, Katherine L. Kahn, Christine S. Ritchie, Jane C. Weeks, Craig C. Earle, and Mary Beth Landrum. “Family Perspectives on Aggressive Cancer Care Near the End of Life.” *The Journal of the American Medical Association* 315, no. 3 (2016): 284-292.

Wright, Kathy B. “Professional, ethical, and legal implications for spiritual care in nursing.” *Image: Journal of Nursing Scholarship* 30, no. 1 (1998): 81-83.

Wright, Michael C. “Chaplaincy in hospice and hospital: Findings from a survey in England and Wales.” *Palliative Medicine* 15, no. 3 (2001): 229-242.

Yang, Grace M., Yung Ying Tan, Yin Bun Cheung, Patricia Soek Hui Neo, Weng Kit Lye, Sock Hui Amy Lim, Wan Ru Ng, and Christina Puchalski. “Effect of a spiritual care training program for staff on patient outcomes.” *Palliative and Supportive Care* 15, no. 4 (2016): 1-10.

Yardley, Sarah, Catherine E. Walshe, and A. Parr. “Improving training in spiritual care: A qualitative study exploring patient perceptions of professional educational requirements.” *Palliative Medicine* 23, no. 7 (2009): 601-617.

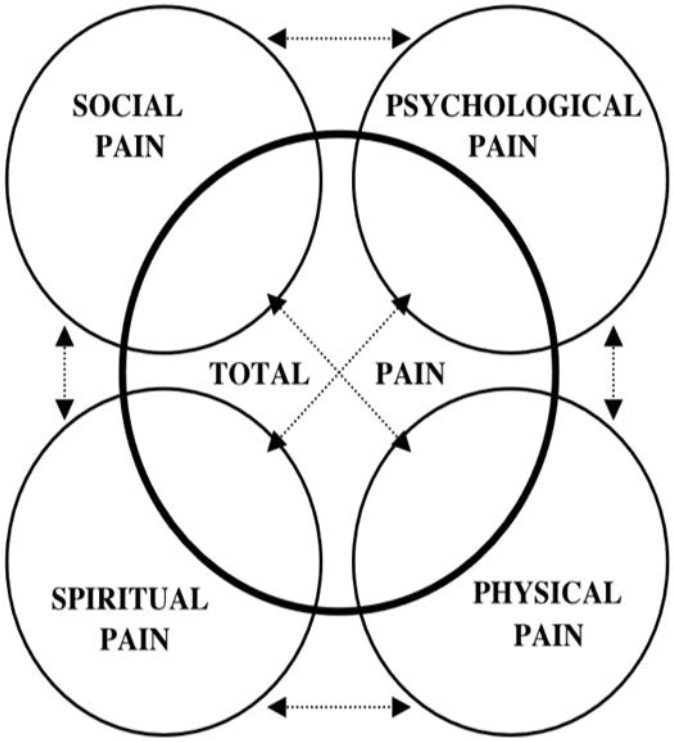
Zimmermann, Camilla, Nadia Swami, Monika Krzyzanowska, Natasha Leighl, Anne Rydall, Gary Rodin, Ian Tannock, and Breffni Hannon. “Perceptions of palliative care among patients with advanced cancer and their caregivers.” *Canadian Medical Association Journal* 188, no. 10 (2016): 1-11.

Zinnbauer, Brian J., Kenneth I. Pargament, Brenda Cole, Mark S. Rye, Eric M. Butfer, Timothy G. Belavich, Kathleen Hipp, Allie B. Scott, and Jill L. Kadar. “Religion and Spirituality: Unfuzzying the Fuzzy.” *Journal for the Scientific Study of Religion* 36, no. 4 (1997): 549-564.

Appendix A: Models and Frameworks

1. 'Total pain' Interactive Model

Mehta and Chan describe the interactive model of pain developed by Dame Cicely Saunders in 1964, through the following diagram:[1]

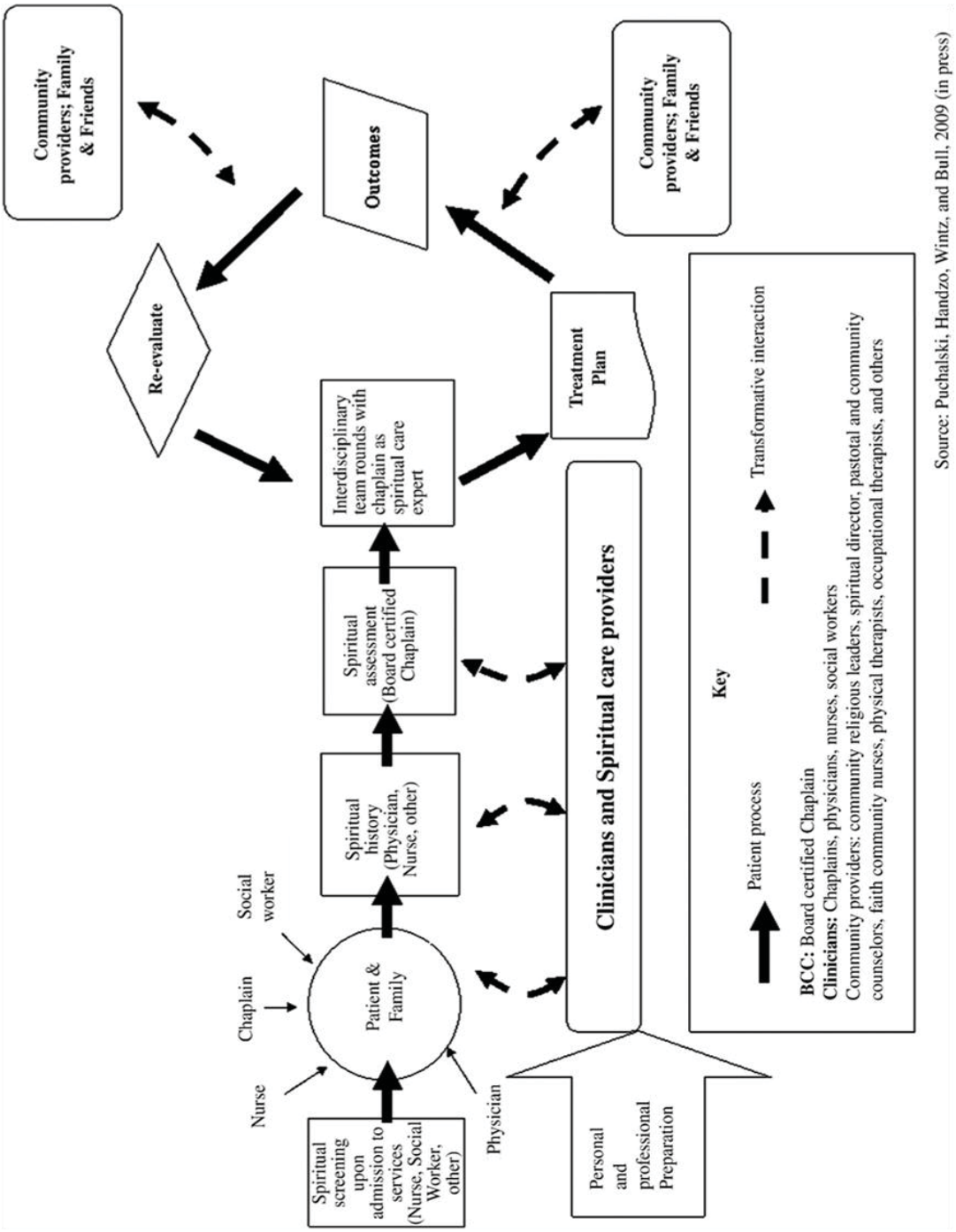


The total pain experience: an interactive model.

[1] Anita Mehta and Lisa S. Chan, "Understanding of the Concept of 'Total Pain'," *Journal of Hospice and Palliative Nursing* 10, no. 1 (2008): 26-32.

2. Inter-professional Model of Spiritual Care

Puchalski and colleagues proposed the inter-professional model of SC emphasising the need for a multidisciplinary and interdisciplinary approach to SC.[2]



[2] Christina Puchalski, Betty Ferrell, Rose Virani and Daniel Sulmasy, "Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference," *Journal of Palliative Medicine* 12, no.10 (2009): 885-904.

3. The ABCD Framework of Dignity Conserving Care

Chochinov developed an A, B, C and D framework of dignity conserving care, helping clinicians to treat patients under their care with dignity.[3] An outline and description of this framework can be found below:

A. Attitudes

Questions to be asked:

- How would I be feeling in this patient's situation?
- What is leading me to draw those conclusions?
- Have I checked whether my assumptions are accurate?
- Am I aware how my attitude towards the patient may be affecting him or her?
- Could my attitude towards the patient be based on something to do with my own experiences, anxieties, or fears?
- Does my attitude towards being a healthcare provider enable or disenable me to establish open and empathic professional relationships with my patients?

Actions to be taken:

- Make a conscious effort to make these questions a part of your reflection on the care of each and every patient.
- Discuss the issue of healthcare providers' attitudes and assumptions, and how they influence caring for patients, as a regular part of case reviews and clinical teaching.
- Include ongoing professional development activities that have you challenge and question your attitudes and assumptions as they might affect patient care.
- Create a culture among your colleagues and within your healthcare setting in which acknowledgement and discussion of these issues becomes a standard part of providing care.

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[3] Harvey Max Chochinov, "Dignity and the Essence of Medicine: The A, B, C, and D of Dignity Conserving Care," *British Medical Journal* 335, no. 7612 (2007): 184-187.

B. Behaviours

Disposition:

- Treat contact with patients as you would in any potent and important clinical intervention.
- Professional behaviours towards patients must always include respect and kindness.
- Lack of curative options should never rationalise or justify a lack of ongoing patient contact.

Clinical examination:

- Always ask the patient's permission to perform a physical examination.
- Always ask the patient's permission to include students or trainees in the clinical examination.
- Although an examination may be part of routine care, it is rarely routine for the patient, so always, as far as possible, take time to set the patient at ease and show that you have some appreciation for what they are about to go through (for example, "I know this might feel a bit uncomfortable"; "I'm sorry that we have to do this to you"; "I know this is an inconvenience"; "This should only hurt for a moment"; "Let me know if you feel we need to stop for any reason"; "This part of the examination is necessary because ...").
- Limit conversations with patients during an examination (aside from providing them with instruction or encouragement) until they have dressed or been covered appropriately.

Facilitating communication:

- Act in a manner that shows the patient that he or she has your full and complete attention.
- Always invite the patient to have someone from his or her support network present, particularly when you plan to discuss or disclose complex or "difficult" information.
- Personal issues should be raised in a setting that attempts to respect the patient's need for privacy.
- When speaking with the patient, try to be seated at a comfortable distance for conversation, at the patient's eye level when possible.
- Given that illness and changing health status can be overwhelming, offer patients and families repeated explanations as requested.
- Present information to the patient using language that he or she will understand; never speak about the patient's condition within their hearing distance in terms that they will not be able to understand.
- Always ask if the patient has any further questions and assure them that there will be other opportunities to pose questions as they arise.

C. Compassion

Getting in touch with one's own feelings requires the consideration of human life and experience:

- Reading stories and novels and observing films, theatre, art that portray the pathos of the human condition.
- Discussions of narratives, paintings, and influential, effective role models.
- Considering the personal stories that accompany illness.
- Experiencing some degree of identification with those who are ill or suffering.

Ways to show compassion:

- An understanding look.
- A gentle touch on the shoulder, arm, or hand.
- Some form of communication, spoken or unspoken, that acknowledges the person beyond their illness.

D. Dialogue

<u>Acknowledging personhood:</u>

- "This must be frightening for you."
- "I can only imagine what you must be going through."
- "It's natural to feel pretty overwhelmed at times like these."

<u>Knowing the patient:</u>

- "What should I know about you as a person to help me take the best care of you that I can?"
- "What are the things at this time in your life that are most important to you or that concern you most?"
- "Who else (or what else) will be affected by what's happening with your health?"
- "Who should be here to help support you?" (friends, family, spiritual or religious support network, etc).
- "Who else should we get involved at this point, to help support you through this difficult time?" (psychosocial services; group support; chaplaincy; complementary care specialists, etc).

<u>Psychotherapeutic approaches:</u>

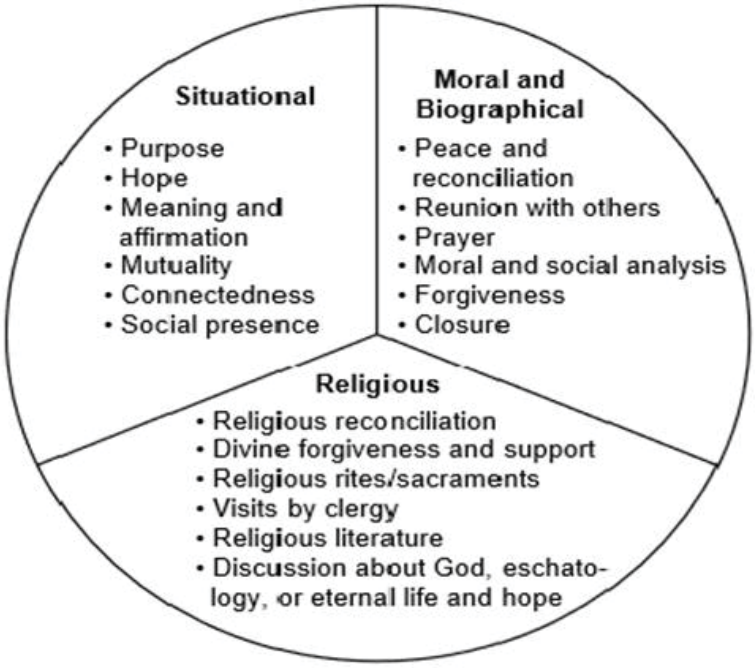
- Dignity therapy.
- Meaning centred therapy.
- Life review/reminiscence.

4. Spiritual Care Models (ordered by date)

A systematic review by Holloway and colleagues found nine SC models, which are portrayed below:[4]

4.1. Kellehear's Model of Needs.

A theoretical model of spiritual needs in palliative care where three sources of transcendence are identified: the situational, the moral and biographical, and the religious.[5] The author suggests that there is considerable interaction and overlap between these three sources of transcendence.



Dimensions of spiritual need

[4] Margaret Holloway *et al.,* "Spiritual care at the end of life: A systematic review of the literature," *Universities of Hull, Staffordshire and Aberdeen* (2010), accessed October 1, 2018, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215798/dh_123804.pdf.

[5] Allan Kellehear, "Spirituality and palliative care: A model of needs," *Palliative Medicine* 14, no. 2 (2000): 149-155.

4.2 Walter's Four-fold Typology.

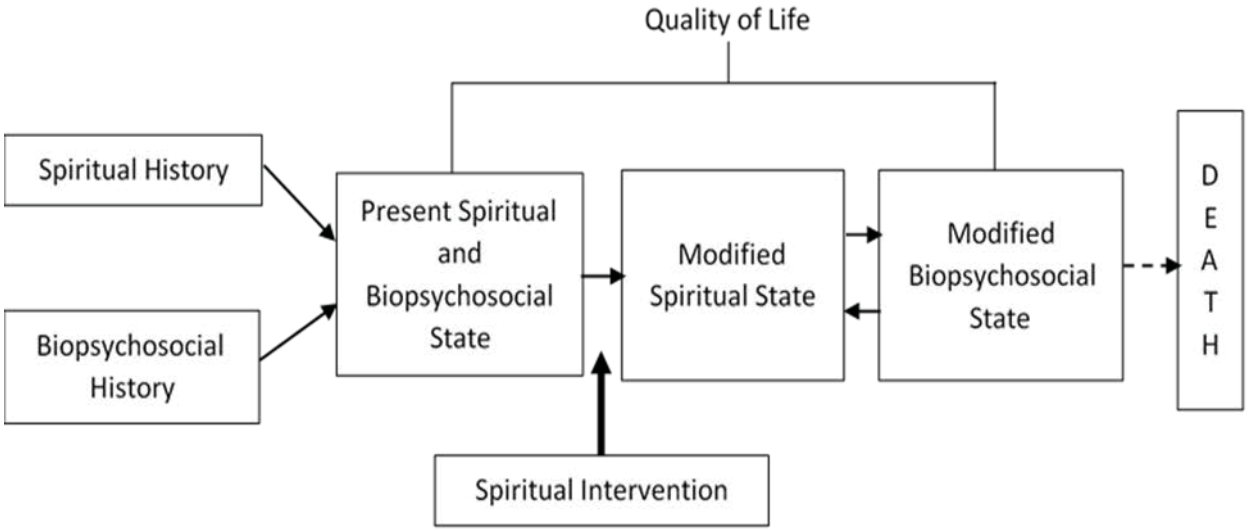
The author developed a four-fold typology of patients' approaches to religion and spirituality, indicating the potential for HCPs to identify those patients who actually need SC, rather than presuming a universal need for SC.[6] This will reduce the obligation for HCPs to offer SC to all patients routinely.

BELONG TO A CHURCH (or other formal belief system)	BELIEVE IN GOD / AFTERLIFE: YES	BELIEVE IN GOD / AFTERLIFE: NO
YES	*Formal religion* Christianity / Islam / Hinduism / Buddhism	*Explicit secularism* Humanism Atheism
NO	*Folk religion* (reunion in heaven, contact through medium, etc) *Spirituality* (New Age, feminist, etc)	*Implicit secularism* 'When you're dead, you're dead'

[6] Tony Walter, "Spirituality in Palliative Care: Opportunity or burden?" *Palliative Medicine* 16, no. 2 (2002): 133-139.

4.3 Sulmasy's Biopsychosocial-spiritual Model of Care.

Sulmasy developed the biopsychosocial-spiritual model of care, highlighting the need for a holistic approach to patients' care, which needs to include the spiritual dimension of patients' care.[7]



4.4 Vogt's Christian Model of Dying Well.

The author shows how Christian theological reflection upon the nature of patience, compassion, and hope influence a 'good death' and help dying patients through their last journey.[8] Vogt also questions whether Jesus' death can be a model of dying well for contemporary Christians.

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[7] Daniel P. Sulmasy, "A biopsychosocial-spiritual model for the care of patients at the end of life," *The Gerontologist* 42, no. 3 (2002): 24–33.

[8] Christopher P. Vogt, "Practicing patients, compassion, and hope at the end of life: Mining the passion of Jesus in Luke for a Christian model of dying well," *Journal of the Society of Christian Ethics* 23, no. 1 (2003): 135-158.

4.5 Gordon and Mitchell's Competency Model of Assessment and Delivery of Spiritual Care.

Gordon and Mitchell developed a competency model of SC, describing the necessary competencies of HCPs to assess and deliver SC.[9] The competencies have four levels, each level identifying the HCPs and volunteers to whom it applies, followed by a summary statement of the competence expected:

Level 1	All staff and volunteers who have casual contact with patients and their families. This level seeks to ensure that all staff and volunteers understand that all people have spiritual needs, and distinguishes spiritual and religious needs. It seeks to encourage basic skills of awareness, relationships and communication, and an ability to refer concerns to members of the multidisciplinary team (MDT).
Level 2	Staff and volunteers whose duties require contact with patients and families/carers. This level seeks to enhance the competencies developed at level 1 with an increased awareness of spiritual and religious needs and how they may be identified and responded to. In addition to increased communication skills, identification and referral of difficult needs should be achievable along with an ability to identify personal training needs.
Level 3	Staff and volunteers who are members of the multidisciplinary team. This level seeks to further enhance the skills of levels 1 and 2. It moves into the area of assessment of spiritual and religious need, developing a plan for care and recognizing complex spiritual, religious and ethical issues. This level also introduces confidentiality and the recording of sensitive and personal patient information.
Level 4	Staff or volunteers whose primary responsibility is for the spiritual and religious care of patients, visitors and staff. Staff working at level 4 are expected to be able to manage and facilitate complex spiritual and religious needs in patients, families/carers, staff and volunteers, in particular the existential and practical needs arising from the impact on individuals and families from issues in illness, life, dying and death. In addition, they should have a clear understanding of their own personal beliefs and be able to journey with others focused on those persons' needs and agendas. They should liaise with external resources as required. They should also act as a resource for support, training and education of health care professionals and volunteers, and seek to be involved in professional and national initiatives.

[9] Tom Gordon and David Mitchell, "A competency model of the Assessment and Delivery of Spiritual Care," *Palliative Medicine* 18, no. 7 (2004): 646-651.

4.6 McConville's Dynamic Model of Spiritual Care.

In her study, the author investigates all the understandings of religion and spirituality in an Irish palliative care setting.[10] Aspects of religion and spirituality have been explored within a multi-layered cultural setting to reveal a complex idea of spirituality, an idea that is continuously changing.

4.7 American Association of Critical-Care Nurses (AACN) Synergy Model.

The AACN Synergy Model for Patient Care identifies 8 characteristics of nurses and 8 characteristics of patients within the hospital setting.[11] The focus of care is considered to be the patient-HCP relationship. The model highlights the need for nurses' competencies to coincide with patients' needs. It is termed the Synergy Model because it suggests that by matching nurses' competencies to complement patients' characteristics, something more than the sum of the parts occurs. Four areas of the model can be related to SC: 2 characteristics of patients: resiliency and resource availability; and 2 characteristics of nurses: caring practices and response to diversity.

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[10] Una MacConville, "Mapping Religion and Spirituality in an Irish Palliative Care Setting," *Journal of Death and Dying* 53, no. 1 (2006): 137-152.

[11] Amy Rex Smith, "Using the Synergy Model to provide spiritual nursing care in critical care settings," *Critical Care Nurse* 26, no. 4 (2006): 41-47.

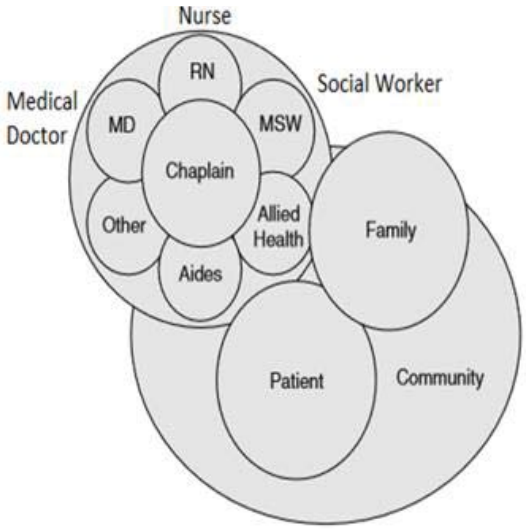
4.8 Puchalski and colleagues' Interdisciplinary Spiritual Care Model.

The authors describe the importance of an interdisciplinary approach to SC, and discuss some of the HCPs' characteristics and competencies, which can help them deliver appropriate SC, as illustrated in the table below:[12]

Compassionate Presence	Intention to openness Intention to connection to others Intention to be comfortable with uncertainly
Relationship- Centred Care	Partnership Not agenda driven Listening to patients' fears, hopes, dreams, meaning
Spirituality of Healthcare Professional	Awareness of one's own spirituality Awareness of one's own mortality Having a spiritual practice
Extrinsic Spiritual Care	Taking a spiritual history Recognising patients' spiritual issues Recognising patients' spiritual problems or spiritual pain Recognising patients' resources of inner strength or lack of resources Incorporating patients' spirituality into treatment or care plans (presence, referral, rituals, meditation, journaling, arts and humanities, retreat etc.) Work with interdisciplinary team to develop and implement treatment plan

[12] Christina M. Puchalski *et al.,* "Interdisciplinary Spiritual Care for Seriously Ill and Dying Patients: A Collaborative Model," *The Cancer Journal* 12, no. 5 (2006): 398-413.

The figure below also shows the interaction between various HCPs and patients, taking into consideration their relatives and community in general:



Interdisciplinary Spiritual care model.

4.9 Stirling's Multidisciplinary Model of Spiritual Care.

The author makes an attempt to map the territory of the provision of SC within a MDT of professionals working in hospice.[13] It introduces two SC frameworks, offering a brief overview of some of the key issues within medicine, nursing, occupational therapy and social work. It also discusses the interface between chaplains and the rest of the MDT, highlighting the importance of providing care through compassion, to both the spirit and the body.

5. The ABCDE Acronym for the Components of Spiritual Care

Caldeira and Timmins developed a SC framework focusing on the dynamic process of SC.[14] The ABCDE framework for SC is based on a therapeutic relationship between the HCP and the patient. The table below illustrates the necessary components of this SC framework:

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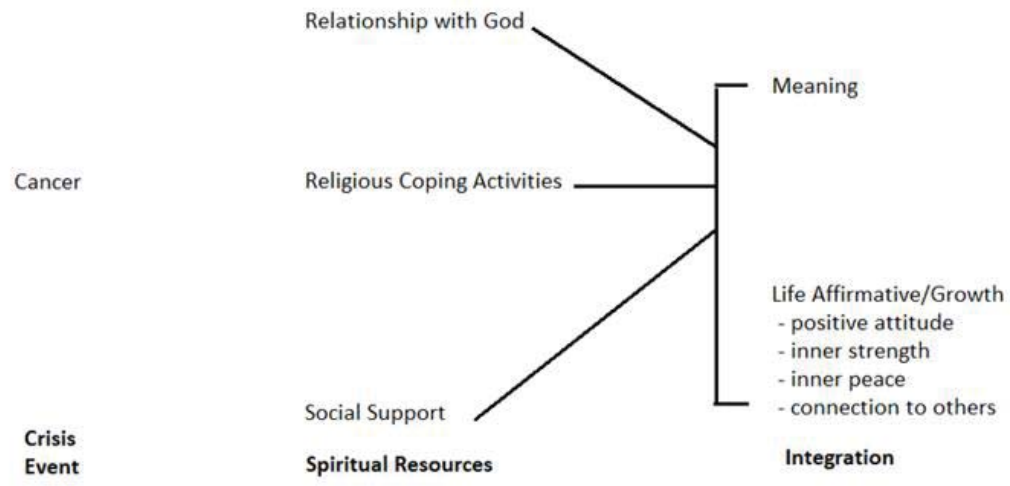
[13] Ian Stirling, "The provision of spiritual care in a hospice: Moving towards a multi-disciplinary perspective," *Health and Social Care Chaplaincy* 10, no. 2 (2013): 21-27.

[14] Sílvia Caldeira and Fiona Timmins, "Implementing spiritual care interventions," *Nursing Standard: Official Newspaper of the Royal College of Nursing* 31, no. 34 (2017): 54-60.

Assessment	Being	Collaboration	Diagnosis	Ethics
-Observation -Questioning -Use of spiritual assessment tools	-Presence -Listening -Touching -Feeling	-Healthcare team -Family -Other resources	-Identify the indicators of spiritual distress -Recognise the risk factors associated with spiritual distress -Evaluate the outcomes	-Be respectful -Be truthful -Maintain Confidentiality -Provide dignity preserving care

6. A Cognitive Model of Adjustment

Gall and Cornblat developed a cognitive model of adjustment to explain how spiritual resources can help patients with a life threatening illness, to make meaning of their illness and help them establish a sense of life affirmation and personal growth.[15] The diagram below shows the relationship between these spiritual resources and patients' sense of meaning and wellbeing:

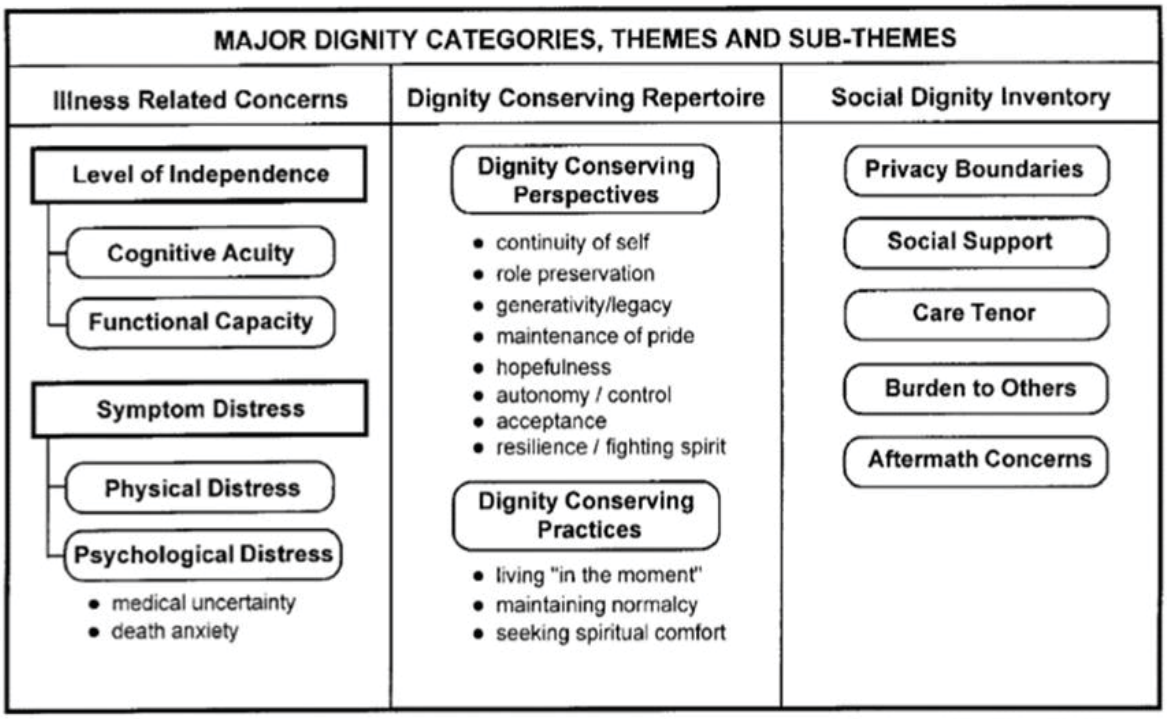


Cognitive model of the role of religious /spiritual factors in long-term adjustment to breast cancer.

[15] Terry Lynn Gall and Mark W. Cornblat, "Breast cancer survivors give voice: A qualitative analysis of spiritual factors in long-term adjustment," *Psycho-Oncology* 11, no.1 (2002): 524–535.

7. Dignity-Conserving Model

Chochinov and colleagues developed the dignity-conserving model of care, to explain the result of illness related concerns on the patient's sense of dignity.[16] The diagram below shows the main components of this model:



[16] Harvey Max Chochinov *et al.,* "Dignity in the terminally ill: A developing empirical model," *Social Science & Medicine* 54, no. 3 (2002): 433–443.

Appendix B: Tools

1. HOPE

The table below shows the spiritual assessment tool developed by Anandarajah and Hight.[17]

Category	Sample Questions
H: Sources of hope, meaning, comfort, strength, peace, love and connection	• We have been discussing your support systems. I was wondering, what is there in your life that gives you internal support? • What are your sources of hope, strength, comfort and peace? • What do you hold on to during difficult times? • What sustains you and keeps you going? • For some people, their religious or spiritual beliefs act as a source of comfort and strength in dealing with life's ups and downs; is this true for you? • If the answer is 'Yes', go on to O and P questions. • If the answer is 'No', consider asking: Was it ever? If the answer is 'Yes', ask: What changed?
O: Organised religion	• Do you consider yourself part of an organised religion? • How important is this to you? • What aspects of your religion are helpful and not so helpful to you? • Are you part of a religious or spiritual community? Does it help you? How?
P: Personal spirituality/practices	• Do you have personal spiritual beliefs that are independent of organised religion? What are they? • Do you believe in God? What kind of relationship do you have with God?

[17] Gowri Anandarajah and E. Hight, "Spirituality and medical practice: Using the HOPE questions as a practical tool for spiritual assessment," *American Family Physician* 63, no. 1 (2001): 81-89.

	• What aspects of your spirituality or spiritual practices do you find most helpful to you personally? (e.g. prayer, meditation, reading scripture, attending religious services, listening to music, hiking, communing with nature)
E: Effects on medical care and end-of-life issues	• Has being sick (or your current situation) affected your ability to do the things that usually help you spiritually? (Or affected your relationship with God?) • As a doctor, is there anything that I can do to help you access the resources that usually help you? • Are you worried about any conflicts between your beliefs and your medical situation/care/decisions? • Would it be helpful for you to speak to a clinical chaplain/community spiritual leader? • Are there any specific practices or restrictions I should know about in providing your medical care? (e.g., dietary restrictions, use of blood products) • If the patient is dying: How do your beliefs affect the kind of medical care you would like me to provide over the next few days/weeks/months?

2. SPIRITual

The table below shows the spiritual assessment tool developed by Maugans.[18]

Category	Sample Questions
S: Spiritual belief system	• Do you have a formal religious affiliation? • Can you describe this?
P: Personal spirituality	• Describe the beliefs and practices of your religion that you personally accept. • Describe those beliefs and practices that you do not accept or follow. • In what ways is your spirituality/religion meaningful for you? • What is the importance of your spirituality/religion to daily life?
I: Integration with a spiritual community	• Do you belong to any religious or spiritual groups or communities? • How do you participate in this group/community? • What importance does this group have for you? • What types of support and help does or could this group provide for you in dealing with health issues?
R: Ritualised practices and restrictions	• What specific practices do you carry out as part of your religious and spiritual life? • What lifestyle activities or practices does your religion encourage, discourage or forbid? • To what extent have you followed these guidelines? • What significance do these practices and restrictions have to you?
I: Implications for medical practice	• Are there specific elements of medical care that your religion discourages or forbids? • To what extent have you followed these guidelines? • What aspects of your religion/spirituality would you like to keep in mind as I care for you? • Would you like to discuss religious or spiritual implications of healthcare? • What knowledge or understanding would strengthen our relationship as physician and patient? • Are there any barriers to our relationship based on religious / spiritual issues?
T: Terminal events planning	• Are there particular aspects of medical care that you wish to forgo or have withheld because of your religion/spirituality? • As we plan for your medical care near the end of life, in what ways will your religion and spirituality influence your decisions.

[18] T.A. Maugans, "The SPIRITual History," *Archives of Family Medicine* 5, no. 1 (1996): 11–16.

3. FAITH

The table below shows the spiritual assessment tool developed Neely and Minford.[19]

Category	Sample Questions
F: Faith / Spiritual beliefs	• Do you have any particular faith, religious or spiritual beliefs? • What gives your life meaning? • What helps you cope in times of stress or illness?
A: Application	• In what ways do you apply your faith in your daily life? • Do you belong to a particular church or community? • Is prayer or meditation important to you?
I: Influence / importance of faith in life, in this illness and on healthcare decisions	• How do your faith and spiritual beliefs influence your life? • Are they important to you? • How do your faith and spiritual beliefs influence you in this illness? • Have they altered your attitude or behaviour? • Has this illness influenced your faith? • Do your beliefs influence or affect your healthcare decisions that would be helpful for me to know about?
T: Talk / terminal events planning	• Do you have anyone you can trust to talk to about spiritual or religious issues? • Do you have any specific requests if you were to become terminally ill? (e.g. terminal care options, living will or end-of-life requests)
H: Help	• Is there any way I or another member of the healthcare team can help you? • Do you require assistance or help with prayer? (e.g. facilities or accompaniment) • Would you like to speak to a chaplain? • Would you like to discuss spiritual issues or your beliefs with your doctor?

[19] D. Neely and E. Minford, "FAITH: Spiritual history-taking made easy," *The Clinical Teacher* 6, no. 3 (2009) 181–185.

4. FICA

The table below shows the spiritual assessment tool developed by Puchalski.[20]

Category	Sample Questions
F: Faith or Beliefs	• What is your faith or belief? • Do you consider yourself spiritual or religious? • What things do you believe in that give meaning to your life?
I: Importance and Influence	• Is it [faith or belief] important in your life? • What influence does it have on how you take care of yourself? • How have your beliefs influenced your behaviour in this illness? • What role do your beliefs play in regaining your health?
C: Community	• Are you part of a spiritual or religious community? • Is this of support to you and how? • Is there a person or group of people you really love or who are really important to you?
A: Address	• How would you like me, your healthcare provider, to address these issues in your healthcare?

[20] Christina M. Puchalski, "The FICA Spiritual History Tool," *Journal of Palliative Medicine* 17, no. 1 (2014): 105-106.

5. Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being Scale

A spiritual well-being scale developed by Paloutzian and Ellison in 1982. Currently there are two versions: the 12-scale and the 23-scale questionnaires.[21]

FACIT-Sp-12 (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

		Not at all	A little bit	Some-what	Quite a bit	Very much
Sp1	I feel peaceful	0	1	2	3	4
Sp2	I have a reason for living	0	1	2	3	4
Sp3	My life has been productive	0	1	2	3	4
Sp4	I have trouble feeling peace of mind	0	1	2	3	4
Sp5	I feel a sense of purpose in my life	0	1	2	3	4
Sp6	I am able to reach down deep into myself for comfort	0	1	2	3	4
Sp7	I feel a sense of harmony within myself	0	1	2	3	4
Sp8	My life lacks meaning and purpose	0	1	2	3	4
Sp9	I find comfort in my faith or spiritual beliefs	0	1	2	3	4
Sp10	I find strength in my faith or spiritual beliefs	0	1	2	3	4
Sp11	My illness has strengthened my faith or spiritual beliefs	0	1	2	3	4
Sp12	I know that whatever happens with my illness, things will be okay	0	1	2	3	4

[21] FACIT.org. "Questionnaires" (2010), Accessed October 25, 2019, http://www.facit.org/FACITOrg/Questionnaires.

FACIT-Sp-Ex (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

		Not at all	A little bit	Some-what	Quite a bit	Very much
Sp1	I feel peaceful	0	1	2	3	4
Sp2	I have a reason for living	0	1	2	3	4
Sp3	My life has been productive	0	1	2	3	4
Sp4	I have trouble feeling peace of mind	0	1	2	3	4
Sp5	I feel a sense of purpose in my life	0	1	2	3	4
Sp6	I am able to reach down deep into myself for comfort	0	1	2	3	4
Sp7	I feel a sense of harmony within myself	0	1	2	3	4
Sp8	My life lacks meaning and purpose	0	1	2	3	4
Sp9	I find comfort in my faith or spiritual beliefs	0	1	2	3	4
Sp10	I find strength in my faith or spiritual beliefs	0	1	2	3	4
Sp11	My illness has strengthened my faith or spiritual beliefs	0	1	2	3	4
Sp12	I know that whatever happens with my illness, things will be okay	0	1	2	3	4
Sp13	I feel connected to a higher power (or God)	0	1	2	3	4
Sp14	I feel connected to other people	0	1	2	3	4
Sp15	I feel loved	0	1	2	3	4
Sp16	I feel love for others	0	1	2	3	4
Sp17	I am able to forgive others for any harm they have ever caused me	0	1	2	3	4
Sp18	I feel forgiven for any harm I may have ever caused	0	1	2	3	4
Sp19	Throughout the course of my day, I feel a sense of thankfulness for my life	0	1	2	3	4
Sp20	Throughout the course of my day, I feel a sense of thankfulness for what others bring to my life	0	1	2	3	4
Sp21	I feel hopeful	0	1	2	3	4
Sp22	I feel a sense of appreciation for the beauty of nature	0	1	2	3	4
Sp23	I feel compassion for others in the difficulties they are facing	0	1	2	3	4

6. McGill Quality of Life Questionnaire

A quality of life questionnaire developed by Cohen, as illustrated below:[22]

McGILL QUALITY OF LIFE QUESTIONNAIRE

STUDY IDENTIFICATION #:_____ DATE: _____

Instructions

The questions in this questionnaire begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite.
Please circle the number between 0 and 10 which is most true for you.
There are no right or wrong answers.
Completely honest answers will be most helpful.

EXAMPLE:

I am hungry:

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

- If you are not even a little bit hungry, you would circle 0.
- If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.
- If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.
- If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.
- If you are extremely hungry, you would circle 10.

BEGIN HERE:

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW YOU HAVE BEEN FEELING *JUST IN THE PAST TWO (2) DAYS*.

PART A

Considering all parts of my life - physical, emotional, social, spiritual, and financial - *over the past two (2) days* the quality of my life has been:

very bad 0 1 2 3 4 5 6 7 8 9 10 **excellent**

Please continue on the next page...

[22] Robin Cohen, "McGill Quality of Life Questionnaire," (1997) accessed October 28, 2019, https://www.promotingexcellence.org/downloads/measures/mcgill_qol.pdf.

PART B: Physical Symptoms or Physical Problems

(1) *For the questions in Part "B", please list the* **PHYSICAL SYMPTOMS OR PROBLEMS** *which have been the biggest problem for you over the past* **two (2)** *days. (Some examples are: pain, tiredness, weakness, nausea, vomiting, constipation, diarrhea, trouble sleeping, shortness of breath, lack of appetite, sweating, immobility. Feel free to refer to others if necessary).*

(2) *Circle the number which best shows how big a problem each one has been for you* ***OVER THE PAST TWO (2) DAYS.***

(3) *If, over the past two (2) days, you had* **NO** *physical symptoms or problems, or only one or two, answer for each of the ones you have had and write "none" for the extra questions in Part B, then continue with Part C.*

1. Over the past two (2) days,
one troublesome symptom has been:_____.
(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 **tremendous problem**

2. Over the past two (2) days,
another troublesome symptom has been:_____.
(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 **tremendous problem**

3. Over the past two (2) days,
a third troublesome symptom has been:_____.
(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 **tremendous problem**

Please continue on the next page...

4. Over the past two (2) days I have felt:

physically terrible	0	1	2	3	4	5	6	7	8	9	10	**physically well**

PART C *Please choose the number which best describes your feelings and thoughts* ***OVER THE PAST TWO (2) DAYS.***

5. Over the past two (2) days, I have been depressed:

not at all	0	1	2	3	4	5	6	7	8	9	10	**extremely**

6. Over the past two (2) days, I have been nervous or worried:

not at all	0	1	2	3	4	5	6	7	8	9	10	**extremely**

7. Over the past two (2) days, how much of the time did you feel sad?

never	0	1	2	3	4	5	6	7	8	9	10	**always**

8. Over the past two (2) days, when I thought of the future, I was:

not afraid	0	1	2	3	4	5	6	7	8	9	10	**terrified**

9. Over the past two (2) days, my life has been:

utterly meaningless and without purpose	0	1	2	3	4	5	6	7	8	9	10	**very purposeful and meaningful**

10. Over the past two (2) days, when I thought about my whole life, I felt that in achieving life goals I have:

made no progress whatsoever	0	1	2	3	4	5	6	7	8	9	10	**progressed to complete fulfillment**

Please continue on the next page...

11. Over the past two (2) days, when I thought about my life, I felt that my life to this point has been:

completely worthless	0	1	2	3	4	5	6	7	8	9	10	**very worthwhile**

12. Over the past two (2) days, I have felt that I have:

no control over my life	0	1	2	3	4	5	6	7	8	9	10	**complete control over my life**

13. Over the past two (2) days, I felt good about myself as a person.

completely disagree	0	1	2	3	4	5	6	7	8	9	10	**completely agree**

14. To me, the past two (2) days were:

a burden	0	1	2	3	4	5	6	7	8	9	10	**a gift**

15. Over the past two (2) days, the world has been:

an impersonal unfeeling place	0	1	2	3	4	5	6	7	8	9	10	**caring and responsive to my needs**

16. Over the past two (2) days, I have felt supported:

not at all	0	1	2	3	4	5	6	7	8	9	10	**completely**

Please continue on the next page...

PART D

Please list or describe the things which had the greatest effect on your quality of life in the past two (2) days. Please tell us whether each thing you list made your quality of life better or worse during this time. If you need more space, please continue on the back of this page.

Thank you very much for your help.

7. Clinical and Coping Score

Ledbetter developed a screening tool that can be used by chaplains to assess how urgent patients need SC, based on patients' medical condition and coping resources, as illustrated by the following diagram:[23]

Screen for "Insufficient Coping" using Clinical and Coping Score

Pastoral Response to 'Insufficient Coping"	**Coping-0** *Full* (missing 0 of 3 coping resources)	**Coping-1** *Adequate* (missing 1 of 3 coping resources)	**Coping -2** *Marginal* (missing 2 of 3 coping resources)	**Coping- 3** *Deficient* (missing 3 of 3 coping resources)
Stable condition-1 (manageable)	1= No Contact	2= No Contact	3= Important	4= Important
Serious condition-2 (life-impacting)	2= No Contact	3= Important	4= Important	5= Urgent
Critical condition-3 (life-threatening)	3= Important	4= Important	5= Urgent	6= Urgent

Coping Resources= Vitality, Support, Faith.

[23] T.J. Ledbetter, "Screening for Pastoral Visitations Using the Clinical and Coping Score," *Journal of Pastoral Care and Counselling* 62, no. 4 (2008): 367-374.

8. Spiritual Needs Assessment for Patients (SNAP)

Rashmi and colleagues developed a 23-item spiritual need assessment tool, which is divided into three domains: psychosocial, spiritual and religious.[24] An outline and description of this tool can be found below:

Psychosocial needs

1. Getting in touch with other patients with similar illnesses?
2. Relaxation or stress management?
3. Learning to cope with feelings of sadness?
4. Sharing your thoughts and feelings with people close to you?
5. Worries you have about your family?

Spiritual needs

6. Finding meaning in your experience of illness?
7. Finding hope?
8. Overcoming fears?
9. Personal meditation or prayer practices?
10. Your relationship with God or something beyond yourself?
11. Becoming closer to a community that shares your spiritual beliefs?
12. Coping with any suffering you may be experiencing?
13. The meaning and purpose of human life?
14. Death and dying?
15. Finding peace of mind?
16. Resolving old disputes, hurts, or resentments among family of friends
17. Finding forgiveness?
18. Making decisions about your medical treatment that are in keeping with your spiritual or religious beliefs?

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[24] Sharma Rashmi *et al.,* "The Spiritual Needs Assessment for Patients (SNAP): Development and validation of a comprehensive instrument to assess unmet spiritual needs," *Journal of Pain and Symptom Management* 44, no. 1 (2012): 44-51.

Religious needs

19. Visits from clergy of your faith community?
20. Visits from a hospital chaplain?
21. Visits from fellow members of your faith community?
22. Religious rituals such as chant, prayer, lighting candles or incense, anointing, or communion?
23. Someone to bring you spiritual texts such as Torah, Qur'an (Koran), Bible, Analects of Confucius, or Tibetan Book of the Dead?

9. Spiritual need survey

Galek and colleagues developed a 29-item, multidimensional instrument designed to assess patients' spiritual needs.[25]

Spiritual needs survey

At any time while you were in the hospital did you have a need:	Yes	No	How important was it to you? Slightly	Moderately	Very	Extremely
1. To review your life?	☐	☐	☐	☐	☐	☐
2. To be accepted as a person?	☐	☐	☐	☐	☐	☐
3. To participate in religious or spiritual services?	☐	☐	☐	☐	☐	☐
4. To feel hopeful?	☐	☐	☐	☐	☐	☐
5. To find meaning in the suffering?	☐	☐	☐	☐	☐	☐
6. To feel a sense of connection with the world?	☐	☐	☐	☐	☐	☐
7. To be thankful or grateful?	☐	☐	☐	☐	☐	☐
8. To address unmet issues before death?	☐	☐	☐	☐	☐	☐
9. For companionship?	☐	☐	☐	☐	☐	☐
10. To have someone pray with or for you?	☐	☐	☐	☐	☐	☐
11. For peace and contentment?	☐	☐	☐	☐	☐	☐
12. To experience or appreciate beauty?	☐	☐	☐	☐	☐	☐
13. To find meaning and purpose in life?	☐	☐	☐	☐	☐	☐
14. For guidance from a power outside yourself?	☐	☐	☐	☐	☐	☐
15. To live a moral and ethical life?	☐	☐	☐	☐	☐	☐
16. To experience or appreciate music?	☐	☐	☐	☐	☐	☐
17. To address concerns about life after death?	☐	☐	☐	☐	☐	☐
18. To give or receive love?	☐	☐	☐	☐	☐	☐
19. To perform religious or spiritual rituals?	☐	☐	☐	☐	☐	☐
20. To keep a positive outlook?	☐	☐	☐	☐	☐	☐
21. To read spiritual or religious material?	☐	☐	☐	☐	☐	☐
22. To talk with someone about death and dying?	☐	☐	☐	☐	☐	☐
23. For compassion and kindness?	☐	☐	☐	☐	☐	☐
24. To have a quiet space to meditate or reflect?	☐	☐	☐	☐	☐	☐
25. For respectful care to your bodily needs?	☐	☐	☐	☐	☐	☐
26. To experience or appreciate nature?	☐	☐	☐	☐	☐	☐
27. To forgive yourself and others?	☐	☐	☐	☐	☐	☐
28. To understand why this medical problem occurred?	☐	☐	☐	☐	☐	☐
29. To experience a sense of laughter and humor?	☐	☐	☐	☐	☐	☐

[25] Kathleen Galek *et al.,* "Assessing a Patient's Spiritual Needs: A Comprehensive Instrument," *Holistic Nursing Practice* 19, no. 2 (2005): 62-69.

10. Spiritual Care Competence Scale

van Leeuwen developed the SC competence scale as an instrument to assess SC competence in HCPs.[26] An outline and description of this scale can be found below:

Nursing Competencies for SC:

Assessment and implementation of spiritual care:

1. Oral nursing report on the spiritual functioning of the patient.
2. Written nursing reports on spiritual functioning of the patient.
3. Documenting the nurse's contribution to spiritual care in the patient's care plan.
4. Coordinating spiritual care in multidisciplinary consultation.
5. Coordinating spiritual care in dialogue with the patient.
6. Oral and written reporting of the spiritual needs of the patient.

Professionalization and improving the quality of spiritual care:

7. Policy recommendations to management regarding spiritual care.
8. Contributing to professionalism and expertise in spiritual care.
9. Coaching healthcare workers in providing spiritual care.
10. Implementing quality improvement projects in spiritual care.
11. Contributing to quality of care regarding spiritual care.
12. Addressing work related problems in relation to spiritual care.

Personal Support and patient counselling:

13. Helping the patient to continue his daily spiritual customs and rituals.
14. Providing spiritual care to the patient.
15. Providing information to the patient regarding facilities for spirituality and spiritual care in the healthcare institution.

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[26] Renatus Ronaldus van Leeuwen, "An Instrument to measure Nursing Competencies in Spiritual Care: Validity and reliability of the Spiritual Care Competence Scale (SCCS)," in *Toward Nursing Competencies in Spiritual Care,* edited by Renatus Ronaldus van Leeuwen (The Netherlands: University of Groningen, 2009), 132-151.

16. Addressing questions regarding spirituality to the patient's relatives.
17. Attending to the patient's spirituality during daily care.
18. Evaluating spiritual care with the patient and the team.

Referral to professionals:

19. Referring the patient with spiritual needs adequately to another healthcare worker.
20. Assigning spiritual care adequately.
21. Knowing when to consult chaplaincy.

Attitude toward patient spirituality:

22. Being open (other) spiritual beliefs in patients.
23. Not forcing personal spirituality upon patients.
24. Showing respect for the patient's spiritual beliefs.
25. Recognizing personal limitations in spiritual care.

Communication:

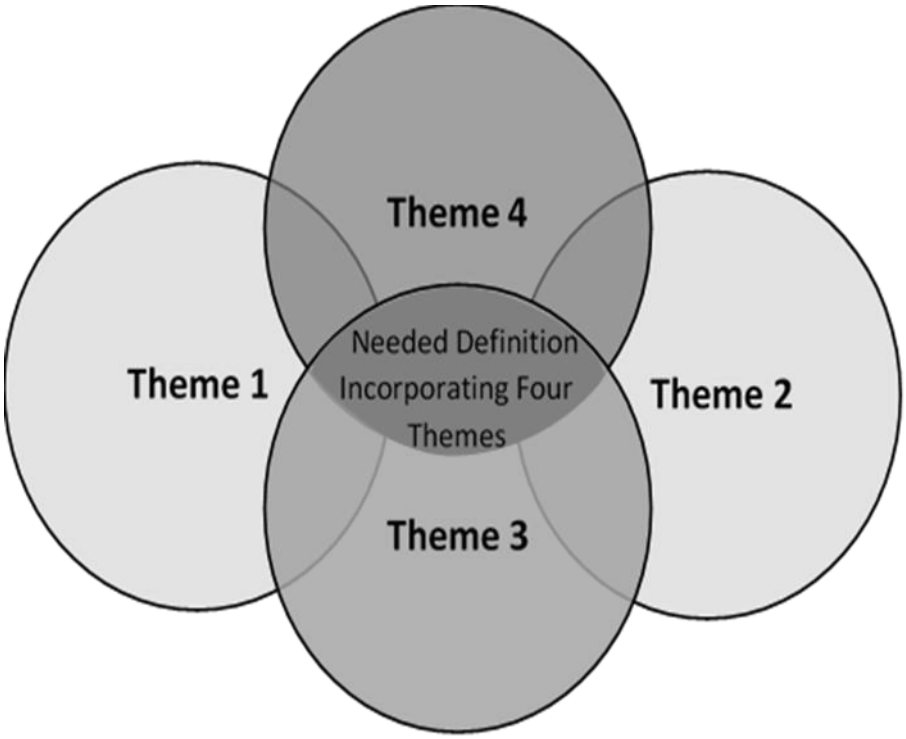
26. Listening actively to the patient's 'life story'.
27. Showing an accepting attitude toward the patient's spirituality.

Appendix C: Other Information

1. Definitions of Spirituality

A systematic review on definitions of spirituality by Loralee Sessanna and colleagues discovered four themes that should be incorporated in definitions of spirituality:[27]

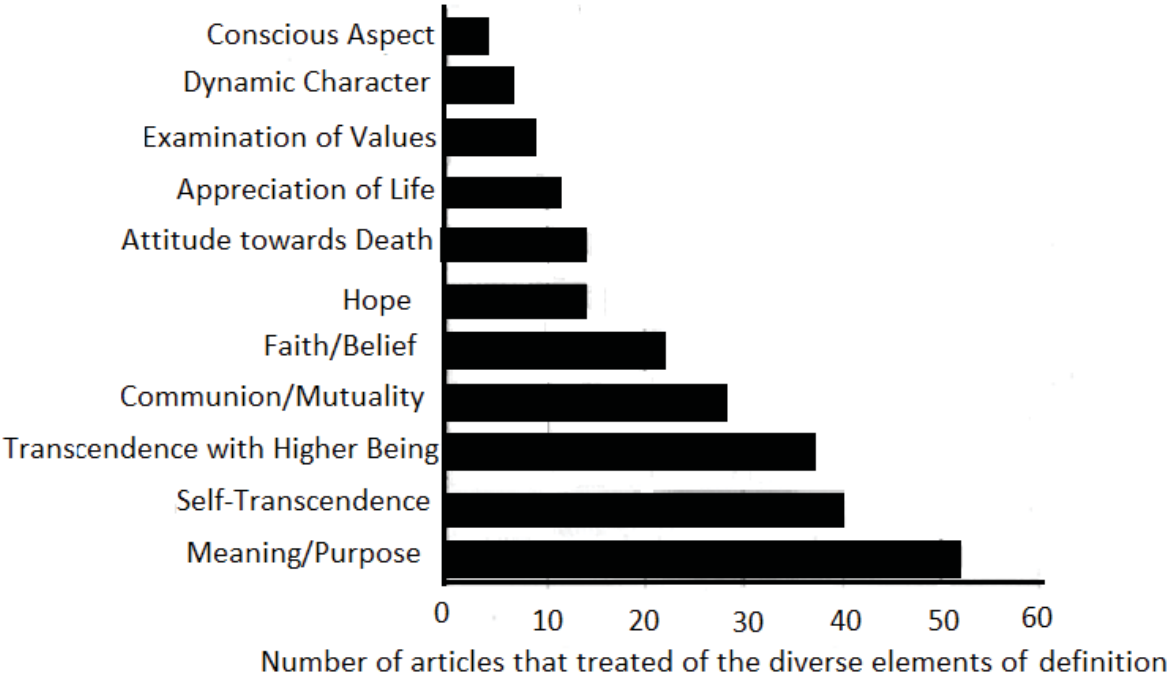
- Theme 1= spirituality as religious systems of beliefs and values (spirituality = religion);
- Theme 2= spirituality as life meaning, purpose, and connection with others;
- Theme 3= spirituality as non-religious systems and values;
- Theme 4= spirituality as metaphysical or transcendental phenomena.



[27] Loralee Sessanna, Deborah Finnell and Mary Ann Jezewski, "Spirituality in Nursing and Health-Related Literature: A Concept Analysis," *Journal of Holistic Nursing* 25, no. 4 (2008): 252-262.

2. Dimensions of Spirituality

Vachon and colleagues performed a concept analysis of the empirical literature on definitions of spirituality which resulted in the discovery of eleven dimensions of spirituality.[28] The diagram below shows these eleven dimensions with the number of studies that used this dimension to define spirituality.



[28] M. Vachon, M. Achille and L. Fillion, "A conceptual analysis of spirituality at the end of life," *Journal of Palliative Medicine* 12, no. 1 (2009): 53-59.

3. JCAHO Guideline Questions for Initial Spiritual Assessment

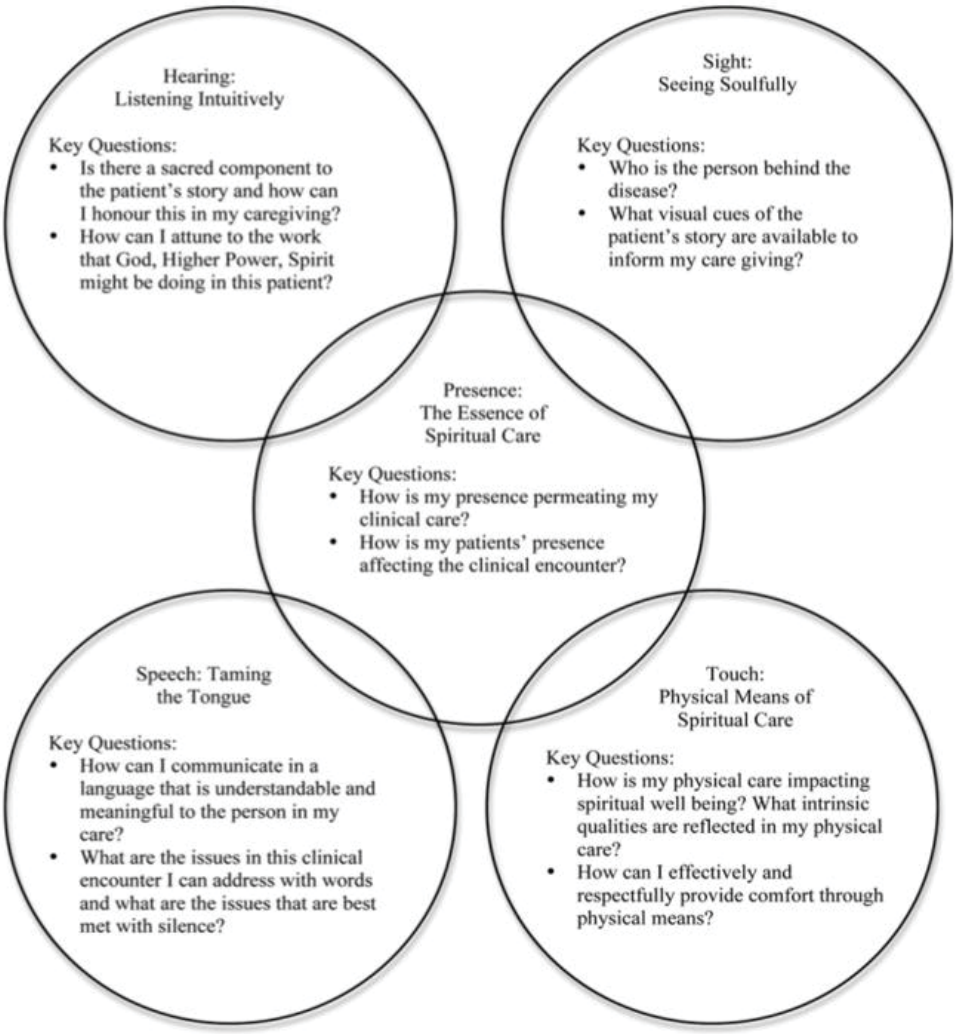
The JCAHO developed a number of guideline questions that can be used in the initial brief assessment done by HCPs on patient's admission.[29] A list of these questions can be found below:

- Who or what provides the patient with strength and hope?
- Does the patient use prayer in their life?
- How does the patient express their spirituality?
- How would the patient describe their philosophy of life?
- What type of spiritual/religious support does the patient desire?
- What is the name of the patient's clergy, ministers, chaplains, pastor, rabbi?
- What does suffering mean to the patient?
- What does dying mean to the patient?
- What are the patient's spiritual goals?
- Is there a role of church/synagogue in the patient's life?
- How does your faith help the patient cope with illness?
- How does the patient keep going day after day?
- What helps the patient get through this health care experience?
- How has illness affected the patient and his/her family?

[29] The Joint Commission on Accreditation of Healthcare Organizations, "Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centred Care: A Roadmap for Hospitals" (2010), accessed November 13, 2018, https://www.jointcommission.org/roadmap_for_hospitals/.

4. The five senses of Spiritual Care

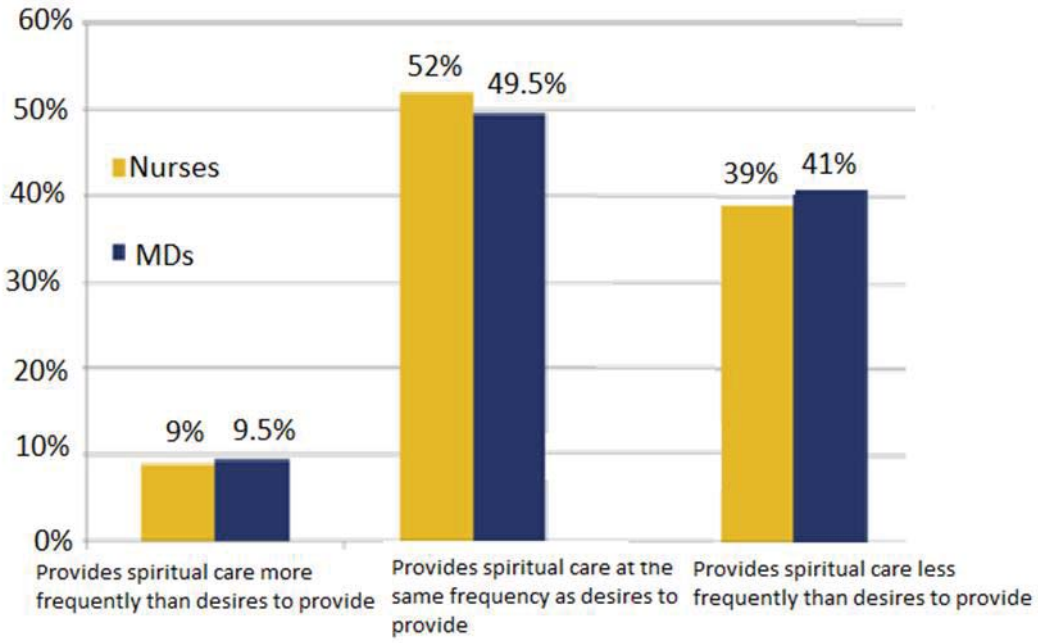
Results from a qualitative analysis by Sinclair and colleagues, resulted in the identification of five senses of SC: Hearing, Sight, Speech, Touch and Presence.[30] The diagram below shows these five senses divided into five categories with their respective themes and subthemes and relevant questions involved:



[30] Shane Sinclair *et al.,* "Spiritual care: How to do it," *Supportive and Palliative Care* 2, no. 4 (2012): 319-327.

5. SC Provision by Nurses and Physicians

In their study Balboni and colleagues use the following table of figures, to illustrate the percentages of nurses' and physicians' desire to provide SC and the actual provision of SC in their practice.[31]



Comparison of nurses' (n= 113) and physicians' (n= 200) desire to provide spiritual care and self- reported frequency of spiritual care provision. On seven-point Likert scales, medical professionals were asked, "How often do you desire to offer any type of spiritual care during the course of your relationship with an advanced, incurable cancer patient?" Nurse/physician responses included: "never" (8%/11%), "rarely" (6%/11%), "seldom" (13%/16%), "occasionally" (34%/20%), "frequently" (18%/23%), "almost always" (11%/8%), and "always" (9%/3%). Nurses and physicians were also asked, "How often

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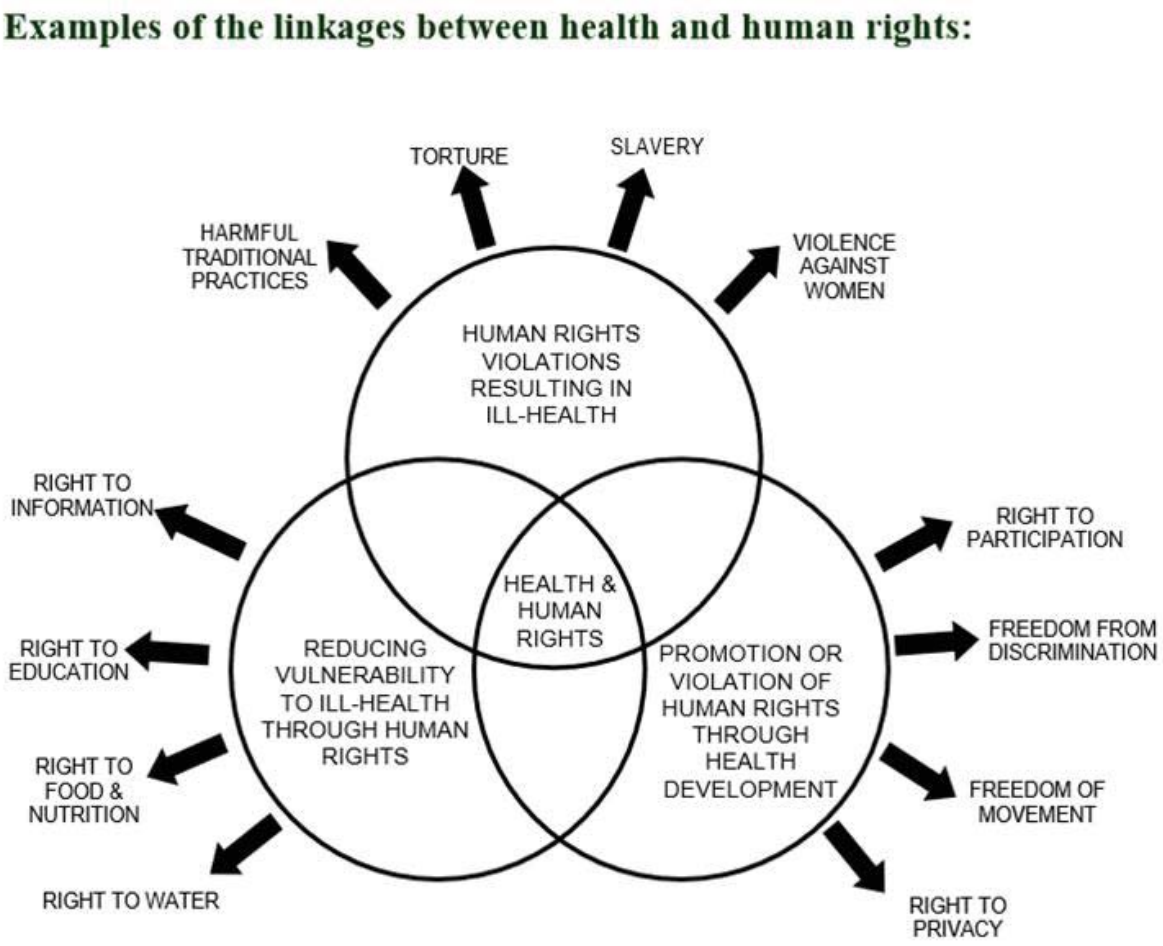
[31] Michael Balboni *et al., "*Nurse and Physician Barriers to Spiritual Care Provision at the End of Life," *Journal of Pain and Symptom Management* 48, no. 3 (2014): 400–410.

do you offer any type of spiritual care during the course of your relationship with an advanced, incurable cancer patient?"

6. Linkages between health and human rights

The WHO discuss some of the important connections between health and human rights.[32] The diagram below shows some examples of such connections:



[32] World Health Organization, "Linkages between health and human rights," accessed December 12, 2019, https://www.who.int/hhr/HHR%20linkages.pdf.

7. Palliative Care Declarations

A systematic review by Indabas and colleagues between 1983 and 2016 found 34 national and international palliative care declarations, as showed in following table:[33]

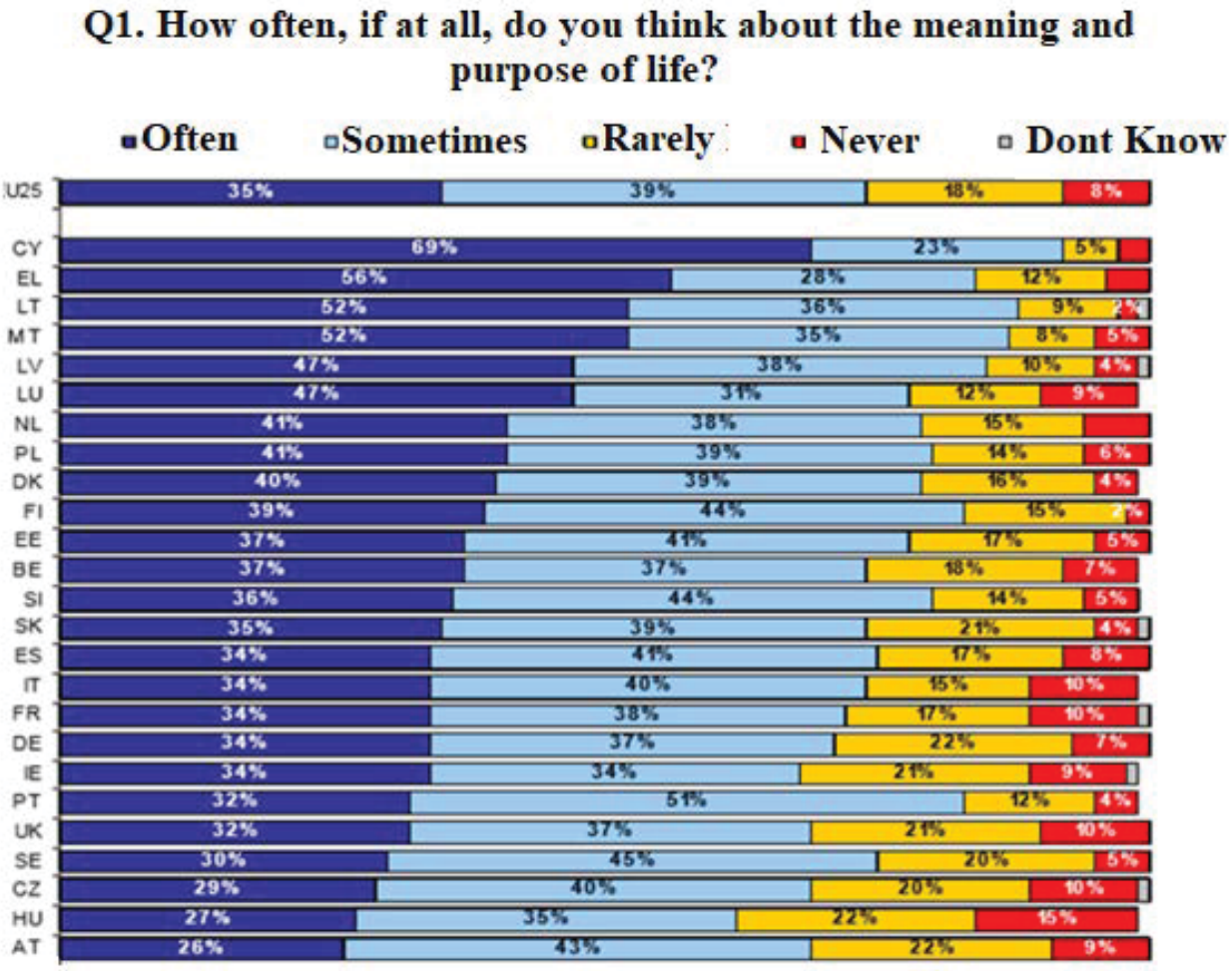
Year	Name of Declaration and Geographical Scope
1983	Declaration of Venice on terminal illness (Global)
1994	The Declaration of Florianopolis (Latin America)
1995	Barcelona Declaration on Palliative Care (Developing Countries)
1998	The Poznan Declaration (Eastern Europe)
2002	Cape Town Declaration (Eastern Europe)
2004	Charter for the Normalization of Death, Dying and Loss (Global)
2004	Palliative Care Manifesto (UK)
2005	Korea Declaration on Hospice and Palliative care (Global)
2006	WMA Resolution of Venice on Terminal Illness (Global)
2006	The Declaration of Venice: Palliative care research (Developing Countries)
2007	Budapest Commitments (Global)
2008	International Children's Palliative Care Network Charter (Global)
2008	Panama Proclamation (Latin America)
2009	Wuhan Declaration (China
2009	IAHPC-WPCA joint Declaration (Global)
2009	End-of-life Care Manifesto 2010 (UK)
2010	Declaration on Palliative Care and MDR/XDR-TB (Global)
2011	WMA Declaration on End-of-Life Medical Care (Global)
2011	The Lisbon Challenge (Global)
2011	Declaration of Partnership and Commitment to Action (Ontario province, Canada)

[33] Hamilton Indabas *et al.,* "Palliative Care Declarations: Mapping a New Form of Intervention," *Journal of Pain and Symptom Management* 52, no. 3 (2016): 7-15.

2011	OPCARE9 Liverpool Declaration (UK, Germany, Netherlands, Sweden, Slovenia, Switzerland, Argentina, New Zealand)
2011	Lucknow Declaration/Palliative Care Declaration (India)
2012	Manifesto- Better Palliative Care for Older People (Europe)
2013	The Prague Charter (Global)
2013	The Charter for the Rights of the Dying Child (Global)
2014	Mumbai Declaration (Global)
2014	WHO: World Health Assembly Resolution (Global)
2014	Manifesto- The crisis facing terminally ill people and their families (UK)
2014	Montreal Declaration On Hospice and Palliative Care (Global)
2014	European Declaration on Palliative Care (Europe)
2015	Declaration by the People of Kerala (Kerala, India)
2015	Compassionate Cities Charter (Global)
2015	Religions of the World Charter for Children's Palliative Care (Global)
2016	Pune Declaration (India)

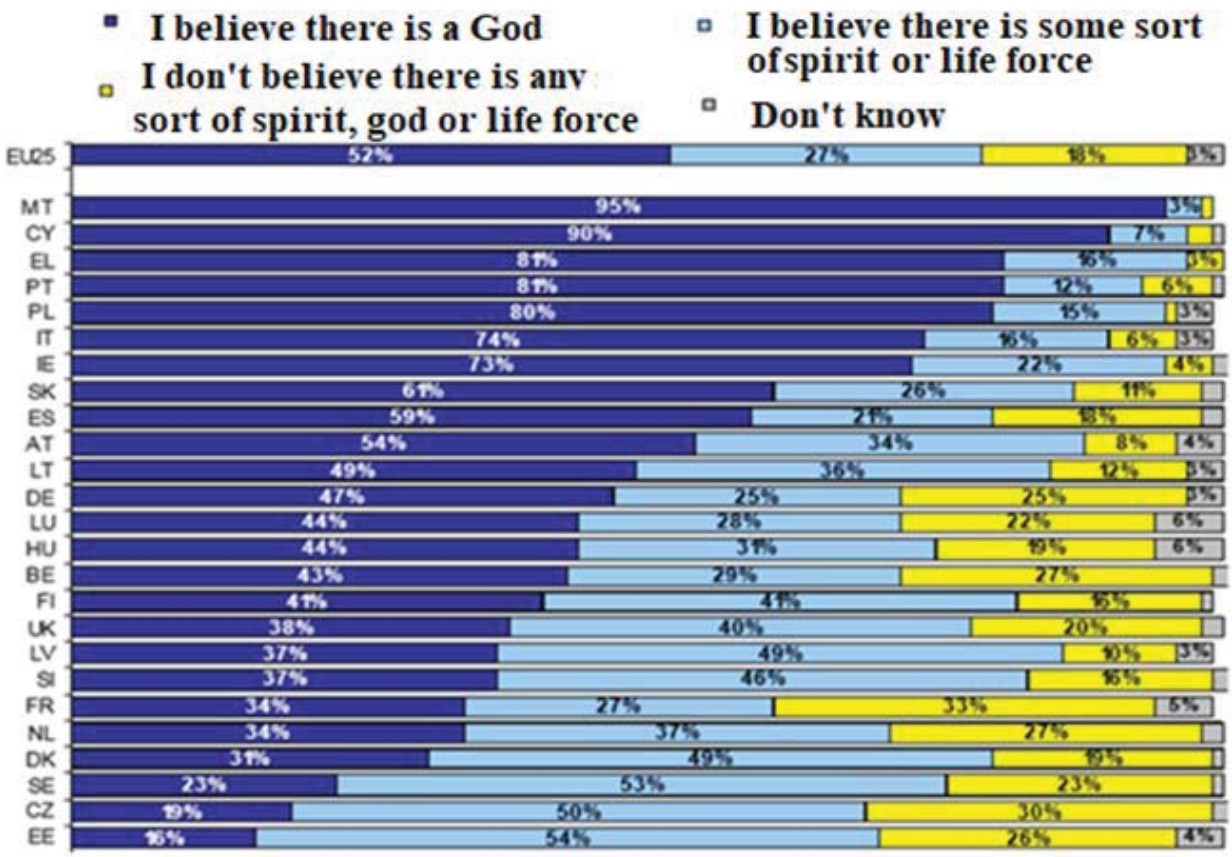
8. Eurobarometer Poll Survey

The figures below show the results of a survey by the European Commission about spiritual beliefs among European citizens.[34] MT refers to Malta.



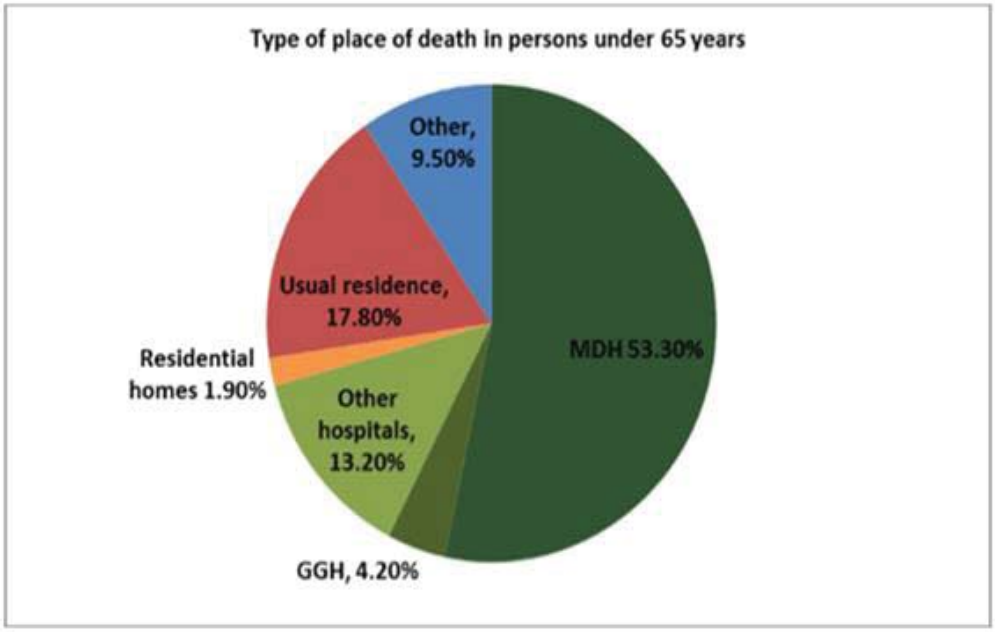
[34] "Special Eurobarometer Social values, Science and Technology," (2005) 7-9, accessed January 18, 2019, https://web.archive.org/web/20070406155642/http://ec.europa.eu/public_opinion/archives/ebs/ebs_225_report_en.pdf.

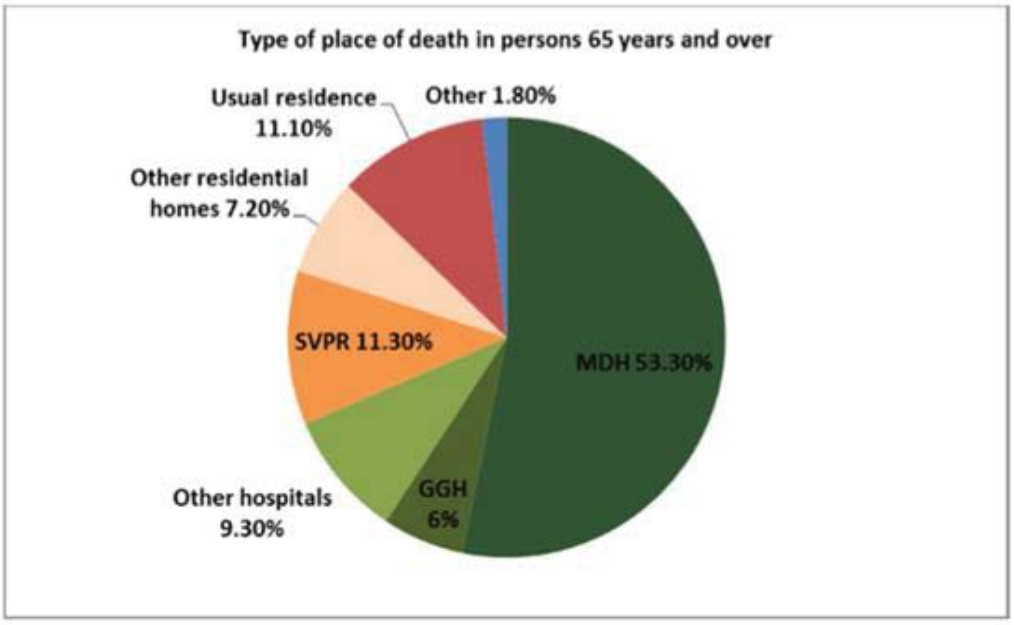
Q2. Which of these statements comes closest to your beliefs?



9. Annual Mortality Report

The diagrams below represent data on the percentage of deaths by place of death in Malta.[35] MDH refers to Mater Dei Hospital, GGH refers to Gozo General Hospital and SVPR refers to St Vincent De Paule Residence.





[35] Kathleen England, "Annual Mortality Report (2015)," Maltese Department of Health Information and Research, accessed March 2, 2019, https://deputyprimeminister.gov.mt/en/dhir/Documents/Deaths/Annual%20Mortality%20Report%202015.pdf.

10. The Nine Principles for Quality Spiritual Care

Holyoke and Stephenson describe the nine principles for quality SC, which can act as organisational guidance throughout healthcare systems so as to improve the quality of SC services.[36] A description of these nine principles can be found below:

The Nine Principles

Foundational principles that influence the organisation of spiritual care:

1. Quality spiritual care incorporates the spiritual into every other aspect of hospice palliative care such that the spiritual is not merely a part or element of care, but rather a descriptor of the kind, nature and quality of all care.
2. More profoundly than in any other area of care, quality spiritual care is guided and directed by the dying person and the family.
3. Hospice palliative care is fundamentally a vocation, and the work is inherently spiritual.

Principles that enable a high-quality approach to spiritual care by care providers:

4. Quality spiritual care requires care providers to allow spiritual questions and issues to emerge.
5. Quality spiritual care entails the act of 'witnessing'.
6. Quality spiritual care considers place as sacred.

Principles that enable the spiritual care practices of care providers:

7. Quality spiritual care includes rituals and times dedicated to marking transitions and processing experiences.
8. Quality spiritual care involves creating and sustaining relationships beyond those typical between co-workers.

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[36] Paul Holyoke and Barry Stephenson, "Organization-level principles and practices to support spiritual care at the end of life: A qualitative study," *BMC Palliative Care* 16, no. 24 (2017): 1-19.

9. Quality spiritual care emphasizes the role of volunteers, whose presence and work reinforces and ensures that hospice palliative care is grounded as vocational and spiritual.

11. Spiritual Care Quality Indicators (ordered by date)

A systematic review by De Roo and colleagues, on SC quality indicators in palliative care found six studies mentioning these indicators.[37] Below is a list of these six studies, cited according to their respective authors:

11.1. Mularski and colleagues.

The quality indicator used in this study was regarded as the spiritual support for patients and family, measured through documentation by HCPs that spiritual support was offered.[38]

11.2. Nelson and colleagues.

Similarly, this study used the SC quality indicator as a measure of the spiritual support for patients/families by using the percentage of patients with documentation that spiritual support was offered.[39]

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[37] Maaike De Roo *et al.,* "Quality Indicators for Palliative Care: Update of a Systematic Review," *Journal of Pain and Symptom Management* 46, no. 4 (2013): 556–572.

[38] Richard Mularski *et al.,* "Proposed quality measures for palliative care in the critically ill: A consensus from the Robert Wood Johnson Foundation Critical Care Workgroup," *Critical Care Medicine* 34, no. 11 (2006): 404-411.

[39] J.E. Nelson *et al.,* "Improving comfort and communication in the ICU: A practical new tool for palliative care performance measurement and feedback," *Quality and Safety in Health Care* 15, no. 4 (2006): 264-271.

11.3. Mitsunori and colleagues.

Quality indicators in this study were described as follows: [40]

Psychosocial and spiritual concern

1. Degree and content of patient's anxiety
2. Emotional reaction to explanation of medical condition
3. Patient's preference of daily living
4. Patient's religion
5. Patient's preference for bowel and bladder excretion
6. Coordination of social resources when patient had no family or friends

11.4. Kazuki and colleagues.

Similar to the previous study, SC quality indicators in this study were described as follows: [41]

Psychosocial and spiritual concern

1. Degree and content of patient's anxiety
2. Patient's religion
3. Patient's preference's and expectations
4. Patient's preference for bowel and bladder excretion

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[40] Mitsunori Miyashita *et al.,* "Identification of Quality Indicators of End-of-Life Cancer Care from Medical Chart Review Using a Modified Delphi Method in Japan," *American Journal of Hospice and Palliative Medicine* 25, no. 1 (2008): 33-38.

[41] Kazuki Sato *et al.,* "Reliability Assessment and Findings of a Newly Developed Quality Measurement Instrument: Quality Indicators of End-of-Life Cancer Care from Medical Chart Review at a Japanese Regional Cancer Centre," *Journal of Palliative Medicine* 11, no. 5 (2008): 729-737

11.5. Schenck and colleagues.

In this study, the authors use the percentage of patients who have documented a spiritual discussion, as a quality indicator.[42]

11.6. Claessen and colleagues.

Quality indicators in this study were describes as: [43]

Care for Spiritual well-being

1. Extent to which patients indicate that caregivers respect their life stance
2. Extent to which patients indicate that they have access to a counsellor for spiritual problems
3. Extent to which relatives indicate that the patient had access to a counsellor for spiritual problems
4. Extent to which relatives indicate that the patient received support with preparations for saying goodbye
5. Extent to which patients indicate that they feel that life is worthwhile
6. Percentage of relatives who indicate that the patient died peacefully
7. Percentage of relatives who indicate the patient had accepted her/his approaching death
8. Extent to which relatives indicate that there was attention and respect for the psychosocial and spiritual well-being of the patient.

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[42] Anna Schenck *et al.,* "The PEACE Project: Identification of Quality Measures for Hospice and Palliative Care," *Journal of Palliative Medicine* 13, no. 12 (2010): 1451-9.

[43] Susanne Claessen *et al.,* "A New Set of Quality Indicators for Palliative Care: Process and Results of the Development Trajectory," *Journal of Pain and Symptom Management* 42, no. 2 (2011): 169-182.

12. Evidence-Based Quality Indicators for Spiritual Care

Handzo and colleagues discuss some of the recommendations on evidence-based quality indicators by HealthCare Chaplaincy Network, with the aim of improving spiritual support and better meet the spiritual needs of patients, their relatives, and health care institutions in general.[44] Eighteen quality indicators were identified and divided into three categories: structural, process and outcomes indicators. Apart from these quality indicators, the panel also suggested a set of metrics which measure the present quality of SC and a number of evidence-based tools to measure these metrics, as described in the tables below:

Structural Indicators

Quality Indicator	Metric	Suggested Tools
1.A- Certified or credentialed spiritual care professional(s) are provided proportionate to the size and complexity of the unit served and officially recognised as integrated/embedded members of the clinical staff.	Institutional policy recognises chaplains as official members of the clinical team.	Policy Review
1.B- Dedicated sacred space is available for meditation, reflection and ritual.	Yes/No	
1.C- Information is provided about the availability of spiritual care services.	Percentage of patients who say they were informed that spiritual care was available	Client Satisfaction Survey
1.D- Professional education and development programs in spiritual care are provided for all disciplines on the team to improve their provision of generalist spiritual care.	All clinical staff receive regular spiritual care training appropriate to their scope of practice and to improve their practice.	List of programs, numbers of attendees, and feedback forms
1.E- Spiritual care quality measures are reported regularly as part of the organisation's overall quality program and are used to improve practice.	List of spiritual care quality measures reported.	Audit of organisational quality data and improvement initiatives

[44] George Handzo *et al.,* "What Is Quality Spiritual Care in Health Care and How Do You Measure It? Evidence-Based Quality Indicators for Spiritual Care" (2016), accessed February 19, 2019, http://www.healthcarechaplaincy.org/docs/research/quality_indicators_document_2_17_16.pdf.

Process Indicators

Quality Indicator	Metric	Suggested Tools
2.A- Specialists spiritual care is made available within a time frame appropriate to the nature of the referral.	Percentage of staff who made referrals to spiritual care and report the referral was responded to in a timely manner. Percentage of referrals responded within Chaplaincy Service guidelines	Survey of staff Chaplaincy data reports
2.B- All clients are offered the opportunity to have a discussion of religious/spiritual concerns.	Percentage of clients who say they were offered a discussion of religious/spiritual concerns	Client Survey
2.C- An assessment of religious, spiritual and existential concerns using a structured instrument is developed and documented, and the information obtained from the assessment is integrated into the overall care plan.	Percentage of clients assessed using established tools such as the FICA, HOPE, or Outcome Oriented models with a spiritual care plan as part of the overall plan of care	Chart Review
2.D- Spiritual, religious and cultural practices are facilitated for clients, the people important to them, and staff.	Referrals for spiritual practices	Referral logs, including disposition of referrals
2.E- Families are offered the opportunity to discuss spiritual issues during goals of care conferences.	Percentage of meeting reports in which it is noted that families are given the opportunity to discuss spiritual issues	Chart Audit
2.F- Spiritual care is provided in a culturally and linguistically appropriate manner. Clients' values and beliefs are integrated into plans of care.	Percentage of clients who say that they were provided care in a culturally and linguistically appropriate manner Percentage of documented plans of care that mention client beliefs and values	Client Survey Chart Audit
2.G- End of life and bereavement care is provided as appropriate to the population served.	Care plans for clients approaching end of life include document attention to end-of-life care A documented plan for bereavement care after all deaths	Chart Audit

Outcomes

Outcome	Metric	Suggested Tools
3.A- Clients' spiritual needs are met.	Client-reported spiritual needs documented before and after spiritual care	Spiritual Needs Assessment Inventory for Patients (SNAP) Spiritual needs Questionnaire (SpNQ)
3.B- Spiritual care increases client satisfaction	Client-reported satisfaction documented before and after spiritual care	Quality of SC Scale
3.C- Spiritual care reduces spiritual distress.	Client-reported spiritual distress documented before and after spiritual care	"Are you experiencing spiritual pain right now?"
3.D- Spiritual interventions increases clients' sense of peace	Client-reported peace measure documented before and after spiritual care	Functional assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-SP)- Peace Subscale "Are you at peace?"
3.E- Spiritual care facilitates meaning-making for clients and family members.	Client-reported measure of meaning documented before and after spiritual care	FACIT-SP-Meaning Subscale Religious Coping Activity Scales
3.F- Spiritual care increases spiritual well-being.	Client-reported spiritual well-being documented before and after spiritual care	FACIT-SP