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PERSPECTIVES AND EXPERIENCES OF SPIRITUALITY, SPIRITUAL NEEDS, AND SPIRITUAL CARE AMONG INTENSIVE CARE PATIENTS, FAMILY MEMBERS, AND CLINICIANS: A GROUNDED THEORY INVESTIGATION IN THE JOHOR STATE OF MALAYSIA

BY

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A thesis submitted in fulfilment of the requirement for the degree of Doctor of Philosophy in Nursing

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ABSTRACT

The intensive care environment is intimidating, too focused on the disease management and causing stress to the patients and the family members. As more patients survive critical illnesses, experts began to shift treatment focus towards survivorships. Based on previous literatures, critically ill patients of the intensive care unit (ICU) need psycho-emotional and spiritual care. These cares are also vital for their family members as they are also under distress with their loved ones being ill. However, clinicians were reported to be unprepared to provide spiritual care in the ICU because of poor knowledge, attitude and communication skills leading to inconsistent practice. This study sought to develop a model of spiritual care to guide ICU clinicians in providing spiritual care to their patients and family members in the intensive care unit (ICU) by utilizing grounded theory methodology. Interview guides were developed for the data collection. The researcher also conducted participatory observation and used field notes while conducting fieldwork in three ICUs in Johor, Malaysia. The study was commenced in October 2019 until June 2020, starting with the exploration of the experience and the spiritual needs of patients admitted in the ICUs and their family members. Another focus of this study was to explore the perceptions of the ICU clinicians on spirituality and the spiritual care that they provide for the patients and their families. A panel of six experts were invited to establish the usability and applicability of the model. A total of 47 patients, family members, ICU nurses and physicians were interviewed. The interviews and field notes were recorded, anonymized, transcribed. Data analysis was performed using grounded theory analysis in Atlas.ti software. The findings indicated there are nine dimensions of spiritual needs of ICU patients and family members consolidated upon four concepts. These concepts later become the foundational parts in the Interfaith Spiritual Care Model for ICU Patients and Their Family Members. There are also multiple barriers to spiritual care as discussed by the ICU clinicians; nurses and physicians in this study. Further involvement of ICU stakeholders, education, training and research are needed to apply this spiritual care model in the management of critically ill patients and the family members.

خلاصة البحث

من الملاحظ أن البيئة للعناية المركزة مخوِّفة، حيث إنها تركز بشكل كبير على إدارة المرضى وتسبب الإجهاد للمرضى وأفراد الأسرة .مع تزايد عدد المرضى الذين يتمكنون من التغلب على الأمراض الحرجة، فيبدأ الخبراء بتحويل تركيز العلاج نحو المرضى على قيد الحياة/ البقاء .بناءً على الدراسات السابقة، يتضح أن المرضى المصابين بأمراض خطيرة في وحدة العناية المركزة يحتاجون إلى رعاية نفسية عاطفية وروحانية .وكذلك أن هذه العناية ضرورية لأفراد أسرتهم لأنهم أيضًا يعانون من الإجهاد الذي ينبثق من مرض أحبائهم .ومع ذلك، تم الإبلاغ عن أن المعالجين السريريين غير مستعدين لتقديم الرعاية الروحانية في وحدة العناية المركزة بسبب .ضعف المعرفة، والسلوك، ومهارات الاتصال، مما يؤدي إلى ممارسة غير متسقة سعت هذه الدراسة إلى تطوير نموذج للرعاية الروحانية في توجيه المعالجين السريرين من الأطباء والممرضين بوحدة العناية المركزة في سبيل توفير الرعاية الروحانية للمرضى وأفراد أسرتهم الذين كانوا في وحدة العناية المركزة، ويتم ذلك من خلال تطبيق منهج النظرية المجذرة .وبنت الدراسة أدلة للمقابلات من أجل جمع البيانات .ومن ناحية أخرى، أجرت الباحثة الملاحظة التشاركية واستخدمت المذكرات ،الميدانية أثناء القيام بالعمل الميداني في ثلاث وحدات للعناية المركزة بولاية جوهور ماليزيا .بدأت الدراسة في أكتوبر 2019 حتى يونيو 2020 باستكشاف التجربة والاحتياجات الروحانية للمرضى المسجَّلين وأفراد أسرتهم في وحدات العناية المركزة .كان التركيز الآخر لهذه الدراسة هو استكشاف تصورات المعالجين السريرين بوحدة العناية المركزة في موضوع الروحانية والرعاية الروحانية التي يقدمونها للمرضى وعائلاتهم .كانت جماعة من ستة خبراء يتعينون لتحديد قابلية النموذج للاستخدام والتطبيق .وتمت المقابلة مع 47 سخصاً وهم المرضى، وأفراد الأسرة، والممرضات والأطباء من وحدة العناية المركزة .وتم تسجيل المقابلات والملاحظات الميدانية، وعدم الكشف عن هويتها ونسخها .وتبنت الدراسة النظرية في تحليل البيانات .وأشارت النتائج إلى أن Atlas.ti المجذرة المتوفرة في برنامج هناك تسعة أبعاد للاحتياجات الروحانية لمرضى وحدة العناية المركزة وأفراد الأسرة مدمجة على أربعة مفاهيم .وأصبحت هذه المفاهيم فيما بعد الأجزاء الأساسية في نموذج الرعاية الروحانية بين الأديان للمرضى وأفراد أسرتهم في وحدة العناية المركزة .ومن خلال ذلك، اكتشفت أيضًا حواجز متعددة عند الرعاية الروحانية كما ناقشها المعالجون السريريون بوحدة العناية المركزة؛ وهم الممرضون والأطباء في هذه الدراسة .ويفترض على أن تكون هناك حاجة إلى مزيد من مشاركة أصحاب المصلحة في وحدة العناية المركزة، والتعليم، والتدريب، والبحث لتطبيق هذا نموذج الرعاية الروحانية في إدارة .المرضى المصابين بأمراض خطيرة وأفراد الأسرة.

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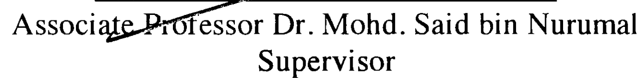

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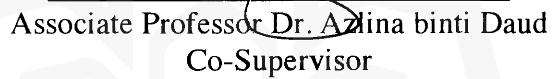

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DECLARATION

I hereby declare that this thesis is the result of my own investigations, except where otherwise stated. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at IIUM or other institutions.

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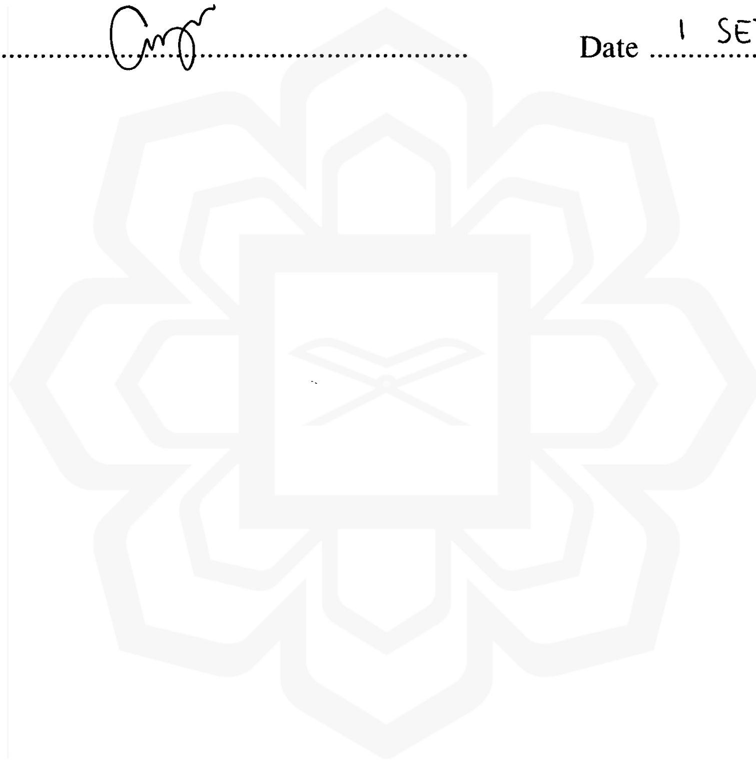

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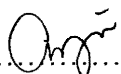

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"He gives wisdom to whom He wills, and whoever has been given wisdom has certainly been given much good. And none will remember except those of understanding" (Quran 2:269).

All praise be to Allah The All-Knowing, The Most Wise. There is no god but Him and to Him I surely return. Alhamdulillah indeed for the completion of this journey and I will treasure its lessons forever, if He Wills.

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"O youth, the advice is easy, the difficulty is accepting it... Do not be bankrupt of works, nor empty of states; be assured that knowledge alone does not strengthen the hand... Though a man read a hundred thousand scientific questions and understood them or learned them, but did not work with them—they do not benefit him except by working...Knowledge is tree, and working is its fruit; and though you study a hundred years and assembled a thousand books, you would not be prepared for the mercy of All the Exalted except by working."

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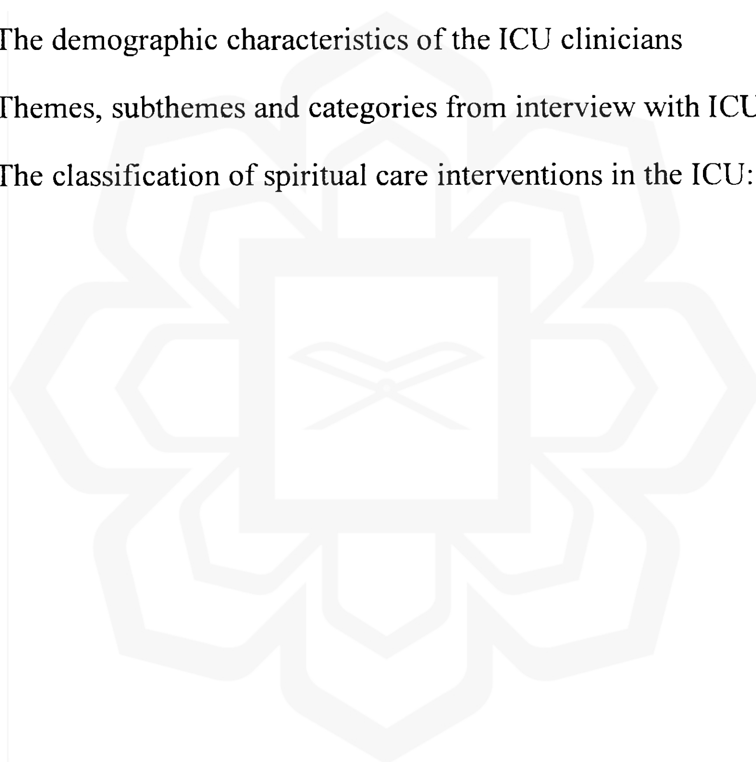

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CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND OF THE STUDY

The advances in healthcare contributes to the longevity of human lives and evidence-based clinical treatments. The concept of intensive care medicine is one of the results of this evolutionary healthcare. The intensive care environment is packed with life-support machines such as cardiovascular monitor, mechanical ventilator, renal replacement, and intraaortic balloon pump among many others. According the World Federation of Societies of Intensive and Critical Care Medicine, an intensive care unit (ICU) is defined as "...an organized system for the provision of care to critically ill patients that provides intensive and specialized medical and nursing care, an enhanced capacity for monitoring, and multiple modalities of physiologic organ support to sustain life during a period of acute organ system insufficiency." (p. 274, Marshall et al., 2017). Critically ill patients in the intensive care units (ICUs) are dependent on the clinicians, especially intensive care nurses for their self-care and disease management. Physicians in the ICUs usually specialises in anaesthesiology. Critically ill patients admitted to the ICUs are haemodynamically unstable, necessitate continuous monitoring, and usually require mechanical ventilation (Malaysian Society of Intensive Care, 2012). Acuity of the patients' illnesses in the ICUs necessitates that clinicians be immediately available to manage emergencies (Marshall et al., 2017). Some ICUs also have restricted access and /visitation policy to control the privacy of clinical care and risk of infection (Rippin, 2016). Ultimately, intensive care is a highly specialised unit that is fast-paced and focused on the treatment and close monitoring for the seriously ill patients with highly skilled nurses and physicians available at all times.

Accordingly, the ICU environment may seem intimidating, too focused on patient survival, and cause stress to patients and family members. As more and more patients survived critical illnesses, the experts began to shift the focus of their treatment towards the survivorships. There have been many studies conducted to explore the

outcomes of intensive care and the experiences of intensive care patients and their family members in the ICUs. The patients who were discharged from the ICU recall many memories of stressors during their stay, which include the fear, inability to communicate, isolation, procedures, noises, thirst, inability to sleep, nightmares, immobility, and family worries (Alasad, Abu Tabar, & Ahmad, 2015; Burry et al., 2015; Khalaila et al., 2011; Kim et al., 2014; Rose, Nonoyama, Rezaie, & Fraser, 2014). More than one third of the patients in a study felt that the unit was too noisy (Alasad et al., 2015). Trouble with communication was rated as the most bothersome experience in ICUs (Rose et al., 2014), and it is related to moderate to high level of psycho-emotional distress among ICU patients (Khalaila et al., 2011). It was reported that spiritual distress is prevalent in the patient population that is dying (29.6%) and many more dying with spiritual suffering (Roze des Ordons, Sinuff, Stelfox, Kondejewski, & Sinclair, 2018). In a study conducted by Rajamani et al. (2015), it was found that emotional/spiritual support was not offered in 39.1% of the cases. ICU survivors were interviewed in another study by Kang and Jeong (2018). They reported that the survivors were overwhelmed and exhausted by repeated crises, which often driven them to mental and physical suffering. The ICU treatments did not only affect the patients, but also their family. Family members, with their loved ones being ill in ICU, also had mental and psycho-emotional sufferings (Kiwanuka, Imanipour, Akhavan Rad, Masaba, & Alemayehu, 2019; Wetzig & Mitchell, 2017). Based on the reports from these past studies, the critically ill patients of ICUs need psycho-emotional and spiritual supports along with the physical care and treatment. These are vital for their family members too.

Spiritual care is the attention given to spiritual and/or religious needs that arise with illness, grief, loss, or pain with an effort to touch the spirit of another individual. It involves intentional interpersonal processes that are dynamic and interactive with mutual recognition of that individual's values and experiences (Ho, Nguyen, Lopes, Ezeji-okoye, & Kuschner, 2018; Ramezani, Ahmadi, Mohammadi, & Kazemnejad, 2014). In the United States, a family-centred intensive care guideline was developed by the American Society of Critical Care Medicine (SCCM), in which they endorsed spiritual care provision. In this guideline, it was stated that the patient has a right for spiritual support, hence spiritual care should be offered to the family. This is

recommended based on the evidence that showed favourable outcomes in terms of the value of spiritual support to the family and its association with increased satisfaction (Davidson et al., 2016; Johnson et al., 2014). Development of a spiritual care model has been conducted in many other countries to support patients and family members in the hospitals, but limited studies were conducted involving intensive care units. Following the implementation of a Dutch multidisciplinary spiritual care guideline, there were increased quality of chaplaincy profile, increased healthcare providers competencies, and reduced barriers (Geer et al., 2018). In our neighbouring country, Indonesia, an Islamic-based caring model was developed and implemented resulting in harmonious life for the critically ill patients (Ismail & Hatthakit, 2018). In 2019, the Malaysia Ministry of Health (MOH) acknowledged the need for spiritual guidance in order to improve psycho-emotional health support for the patients and their family members. However, the current *Ibadah*-friendly policy is still not widely implemented, does not support multicultural, multi-religious spiritual needs of the patients' population, and the proper training and employment for those spiritual guidance officers are still pending (Dzulkefly Ahmad, 2019). Proper implementation of spiritual model of care and continuous training for the clinicians, especially in ICUs are crucially needed to ensure the patients and family members do not suffer the consequences of suboptimal spiritual care in ICUs.

From the above descriptions, critical illness is a great stressor that consequently affects both the patients and their family resulting in post-traumatic stress disorder (PTSD) (Wade, Hardy, Howell, 2013). PTSD is defined as "anxiety disorder that often follows exposure to an extreme stressor that causes injury, threatens life, or physical integrity" in DSM-IV and later on updated in DSM-5. It is to be marked by intense psychological distress, intrusive symptoms of re-experiencing of the trauma, including thoughts, flashbacks, or nightmares, avoidance of trauma reminders, negative alterations in mood and cognition, and hypervigilance or elevated trauma-related reactivity (American Psychiatric Association, 2013; Birk et al., 2019). At least one in five patients suffered from PTSD after ICU discharge and has lower quality of life due to this disorder (Wade et al., 2013). Empirical evidence showed that PTSD symptoms occurred in ICU survivors up until one year after ICU discharge. They were discharged with higher risk for those who had comorbid psychopathology, given benzodiazepines, and had early

memories of stressful ICU experiences (Parker et al., 2015). Approximately one-third of ICU survivors were reported to have anxiety and depression and this trend is persistent up until one year after critical illness (Nikayin et al., 2016; Rabiee et al., 2016). As stated before, the family is also affected by critical illness. The prevalence of psychological outcomes in family members of ICU patients ranged from 4% to 94% for depression, 2% to 80% for anxiety, and 3% to 62% for PTSD (Johnson et al., 2019). In a Malaysian study, 35% and 37% of the family members of ICU patients had severe depression and anxiety, respectively (Dharmalingam, Kamaluddin, Nadarajan, et al., 2016). The risk for psychological symptoms is higher for family members who suffered loss of their loved ones to critical illness (Kross et al., 2011). The family members bereaved after a loss due to critical illness until one year after the death in ICU (Jones, Puntillo, Donesky, & McAdam, 2018). The family members with psychological symptoms reported that if spiritual support was given while they were in the ICU, it would have helped them through it (Gries et al., 2010; Wall, Engelberg, Gries, Glavan, & Curtis, 2007). Then, the term post-intensive care syndrome (PICS) and post-intensive care syndrome (family) (PICS-F) started to be used in the literatures to show that critical illness treatments have moved from patient survival towards survivorship, which include the patient and their family members (Davidson, Jones, & Bienvenu, 2012; Needham et al., 2012). A consensus statement from intensive care experts' discussion designated PICS as the term used to describe new or worsening impairments in physical, cognitive, or mental health status happening after critical illness and continuing even after acute care hospitalisation (Needham et al., 2012). As survivors of PICS and PICS-F have been physically, mentally, and cognitively impaired, this transition has been clearly expressed through various causal or contextual conditions, such as ICU treatment, environment, as well as clinician and family support. These evidences signify the need of patient and family in term of their psychospiritual support worth to be further researched to enhance their physical, cognitive, and mental health status, and further reduced the effects of PICS and PICS-F. Given the many evidences put forward by the literature, more efforts should be made towards understanding the mechanisms of psychospiritual support during critical illness. The current practice of providing spiritual care in the ICUs by the clinicians in the multicultural and diverse religious community needs to be fully comprehended. While there are not so many studies addressing this

issue in the local context, the international studies which did find that spiritual care that is in place has been suboptimal, thus needs more research.

1.2 STATEMENT OF THE PROBLEM

Patients admitted to the ICU are at risk of developing PICS and delirium due to their illnesses and the use of sedation (Hipp & Ely, 2012; Pandharipande et al., 2013). The use of high-end technological equipment in the ICU can be dehumanising to the patients (Ismail & Hatthakit, 2018). The maintenance of human lives through the equipment shifts the focus of care through the signals that the machine emits rather than the beings that are attached to it. This phenomenon is called high-tech low-touch care (Eschiti, 2007). While these factors cannot be avoided in the development of PICS, there are other modifiable factors that have become an issue. PICS and PICS-F signify that the long-term impact ICU has on the patients and their family members can be debilitating. More humane and caring attitudes of clinicians that pay attention to the patient's physical body and spiritual body are highly needed.

Although previous studies that investigated on the ICU spiritual care activities did not signify their impact on physical and psychospiritual status, it did show an association with ICU family satisfaction. Yet, the program was not specifically designed to meet the spiritual needs of a diverse community that offers culturally-sensitive emotional and spiritual support to patients, families, and staff, regardless of religious, faith, or spiritual tradition. Some families may have been reluctant to engage or accept spiritual care providers' services if they felt that their own religious traditions may not be addressed (Johnson et al., 2014). In many countries, spiritual support is given through chaplaincy services. However, this service is underutilised and spiritual care remains suboptimal despite many beneficial outcomes from spiritual care activities have been supported by medical literature.

With regards to knowledge, ICU clinicians, especially nurses perceived that they were unprepared and in need for more education and training about multicultural considerations in supporting the psychospiritual needs of their patients and the family

members (Balboni et al., 2013; Canfield et al., 2016; Kim, Bauck, Monroe, Mallory, & Aslakson, 2017). In two studies conducted on examining spirituality and spiritual care of the nurses, both found that nurses had insufficient knowledge on spirituality and spiritual care. In one of the studies, more than half of the nurses (55.2%) had no knowledge on spiritual care (Bakir, Samancioglu, & Kilic, 2017) while the other study highlighted the fact that nurses had difficulty distinguishing between spirituality and religiosity (Mohd Arif et al., 2019). This statement signifies that one of the factors that may affect spiritual care provision in the ICUs is due to the lack of knowledge of ICU clinicians on spirituality.

Another factor for the suboptimal spiritual care in the ICUs is the clinicians' attitude. In a previous review, it was shown that the some of the clinicians were guarded towards spiritual care and spirituality, while some others rejected; claiming that it was not their responsibility to address spirituality (Appleby, Wilson, & Swinton, 2018). In an ICU survey, one of the barriers that predicted less frequent spiritual care by the clinicians was their claim on that it was not their professional role to address spiritual aspect of patients care (Balboni et al., 2014). Both clinicians; nurses and physicians predicted that lack of desire for spiritual care training was due to lower sense of spirituality (Balboni et al., 2014). Moreover, their increasing responsibilities and workload kept them busy in the ICUs causing limited time and space for them to provide spiritual care for the patients and their family members (Balboni et al., 2014; Bone, Swinton, Hoad, Toledo, & Cook, 2018; Canfield et al., 2016). In a local survey among the nurses in Malaysia, Mohd Arif et al. (2019) found that they mostly avoided spiritual discussions with their patients although they agreed that supporting and respecting the culture and beliefs of the individual patient is a way to integrate spiritual care to their routine nursing care. For some physicians, spiritual discussion may invoke emotional connection with the patients and their family members, thus explained the reason for their ambivalent and avoidant attitudes (Choi, Curlin, & Cox, 2018; Zambrano, Chur-Hansen, & Crawford, 2012). In the ICU practice, discussions of spirituality are usually very significant at the end of life. In a multicentre observational study involving ICU clinicians, a paternalistic pattern could be seen in the decision to withdraw life-sustaining treatment. This was because the clinicians tend to perceive the family members as uneducated (Ntantana et al., 2017). Nurses also felt that they were unable

to safely voice out their concerns regarding end-of-life care possibly due to the feeling of inferiority and fear of criticism (Festic, Wilson, Gajic, Divertie, & Rabatin, 2012). In addition to these problematic attitude and practice, another study found that ICU nurses with lower sense of spirituality were vulnerable to burnout (Kim & Yeom, 2018). One of the ways around this issue is to address the clinicians' awareness on the importance of spirituality in which it is a dimension of a person that can give beneficial impacts on the patients and their family members, as well as the clinicians themselves.

Furthermore, spiritual care in the ICUs is also challenged by communication discordance among the clinicians, other professionals, and the family members too. In a study to investigate spiritual concerns during ICU discussions between the clinicians and the surrogate decision-makers, it was found that the former often failed to respond when the family made spiritual statements (Ernecoff, Curlin, Buddadhumaruk, & White, 2015). In a different study, discordance between the physicians and surrogates in the communication of expected prognosis was reported as a result of the differences in their beliefs (White et al., 2016). It was narrated by the surrogates that bedsides discussions, as well as the use of vague estimates and laymen terms were not helpful during the communication of prognosis (Anderson et al., 2015). Other than that, the disagreements between ICU professionals regarding spiritual issues could be seen in the previous study where the nurses perceived that the communication of physicians did not improve quality of death for their patients due to the lack of spiritual address (Ramos et al., 2016). Discrepancies can be further seen as ICU nurses were more likely to consult chaplains as compared to the physicians. This is because the physicians found that the chaplains were less helpful in challenging ICU meetings (Choi, Chow, Curlin, & Cox, 2019). Choi's study also discovered that the ICU physicians rarely read chaplains' notes (Choi, Curlin, & Cox, 2015). All of these evidences underlined the problem of communication between professionals and the family members, which can lead to suboptimal spiritual care in ICUs and the need for solutions in this matter.

In summary, the irregularities in the provision of spiritual care in the ICUs is because of the clinicians, especially physicians and nurses who have poor knowledge, attitude, and communication. This leads to inconsistent practices and suboptimal spiritual care. All of these factors that contribute to the problems in ICU spiritual care

highlight continued gaps in the provision of spiritual care for ICU patients and their family members. Further work should be aimed at bridging the gap between clinicians' self-perceived role, the patients' and family members' perspectives, and actual clinical practices so that high-quality spiritual care can be provided to all ICU patients regardless of their cultural and religious background. Further inquiry is required to link the apparent disconnection between the experiences of patients and family members, the self-initiated spiritual care activities of the clinicians, and actual practices which therefore inform a targeted solution. In this study, a working model that extends the current *Ibadah*-friendly hospital initiative to embrace the broader sense of spirituality is necessary to create the space for these issues to be addressed.

1.3 PURPOSE OF THE STUDY

This study was conducted with the aim to develop a model of spiritual care in the ICUs for the patients and their family members.

1.3.1 Specific Research Objectives

The objectives of this study are:

1. To explore the experience of ICU patients and their family members in receiving spiritual care in the ICUs that includes their views on spirituality, their spiritual needs, and supports that they received while they were in the ICUs.
2. To explore the views of ICU clinicians on spirituality and the spiritual care that they provide for the patients and their family members.
3. To develop a model of spirituality and spiritual care for the ICU patients and their family members.
4. To establish the usability and applicability of the developed model of spirituality and spiritual care for the ICU patients and their family members.

1.3.2 **Research questions**

1. What are the experiences of ICU patients and their family members in receiving spiritual care in the ICUs?
2. How do ICU clinicians provide spiritual care for the patients and their family members in the ICUs?
3. How can a model be developed to incorporate spiritual care for ICU patients and their family members?
4. Is this model of spirituality and spiritual care for the patients and their family members usable and applicable in the ICUs?

1.4 SIGNIFICANCE OF THE STUDY

The findings of the present study are significant to the patients and their family members in the ICUs, the nursing and health care practices, healthcare organisations, and body of knowledge.

1.4.1 **Contributions to nursing and healthcare practices**

This thesis would be a valuable reference to healthcare professionals in providing spiritual care for patients in hospitals, particularly in ICU settings. ICU clinicians, specifically nurses, perceived chaplains as helpful during ICU family meetings and rounds. A misconception generally arises among ICU clinicians when they only refer to chaplains for end-of-life care for the critically ill patients (Choi et al., 2019, 2015). Integrating spiritual care in the ICU management of critically ill patients is preferred, but difficult to achieve as the ICU clinicians, especially the non-Muslims have different understanding and perspectives on spirituality (Suzan Willemse, Smeets, van Leeuwen, Janssen, & Foudraine, 2018). However, their positive attitudes towards spiritual care and inclination for referral to spiritual guidance officers are proven to be a strength for implementing a framework of spiritual care in ICUs.