ORIGINAL ARTICLE

"My Soul is Empty...": The Intensive Care Patients' and Their Family Members' Experience of Spiritual Care

Ayuni Asma' Baharudin[1], Mohd. Said Nurumal[2]

[1] Department of Medical-Surgical Nursing, Kulliyyah of Nursing, International Islamic University, Jalan Sultan Ahmad Shah, Indera Mahkota, 25200 Kuantan, Pahang, Malaysia
[2] Department of Critical Care Nursing, Kulliyyah of Nursing, International Islamic University, Jalan Sultan Ahmad Shah, Indera Mahkota, 25200 Kuantan, Pahang, Malaysia

ABSTRACT

Introduction: The intensive care environment may seem intimidating, too focused on the patient survival 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 findings, critically ill patients of the intensive care unit (ICU) need psycho-emotional and spiritual care. In addition, these cares are also vital for their family members. This study was conducted to explore patients' and family members experience in receiving spiritual care in the ICU. **Methods:** Interviews with patients and their family members were conducted in the ICUs of three government hospitals in Johor. Data from the interviews were recorded, anonymised, and transcribed. Codes and themes were generated using Braun and Clarke's thematic analysis. **Results:** A total of 25 patients and family members were included in this study. The central theme was Faith-based Care. Based on the narratives of the participant's experience, nine categories of spiritual needs were identified emerging through four themes: 1) Having Faith, 2) Giving-receiving All, 3) Being There, and 4) Letting Go. **Conclusion:** The intensive care patients and their family members valued the provision of spiritual care from ICU clinicians. Their experience of spiritual care in the ICU can be improved with a model of ICU spirituality. Further research is needed to seek the clinicians' view on spirituality and to further improve its provision in the ICU settings.
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Corresponding Author:
Ayuni Asma' Baharudin, Ph.D
Email: ayuniasma@iium.edu.my
Tel: +6017-6987846

INTRODUCTION

An intensive care unit (ICU) is a structured system for providing care to critically ill patients, comprising specialised and intensive nursing and medical care, improved monitoring capacity, and several support modalities for physiologic organs in order to sustain life in a period of acute organ system insufficiency (1). Critically ill patients who are admitted to the ICU are dependent on clinicians, especially intensive care nurses for their self-care and disease management. Physicians in the ICU usually specialises in anaesthesiology. Critically ill patients admitted to the ICU are haemodynamically unstable, necessitate require continuous monitoring and usually require mechanical ventilation (2). The acuity of the patients' illnesses in the ICU necessitate that clinicians are immediately available to manage emergencies (1). Some ICUs also apply restricted access and visitation policy to control the privacy of clinical care and risk of infection (3). Ultimately, intensive care is a highly specialised unit that focuses on the treatment and close monitoring for seriously ill patients with highly skilled nurses and physicians available at all times.

However, previous studies revealed that the provision of spiritual care in the ICU is fragmented. Symbolic interactionism paradigm was used in the context of this study as the patients and family members are cared for as the social world where they have to be is in constant interaction with each other (4,5). They also interact with the clinicians in ICUs expecting care that

reciprocates their own experiences and meaningful in nature. 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 with an intentional interpersonal processes that is highly dynamic and interactive with mutual recognition of that individual's values and experiences (6,7). Research conducted by Rajamani and colleagues showed that spiritual care was not offered in 40% of the family members who have their loved ones in the ICU (8). Family members demonstrated a high prevalence of psychologic symptoms after death in the ICU and they also reported that spiritual care would have helped them then (9,10). Ernecoff and colleagues reported that family members raised spiritual expression during discussions with the ICU professionals, but these expressions were not appropriately replied to (11). In a scoping review, spiritual distress was found to be prevalent in the patient population that was dying (29.6%) and many more dying with spiritual suffering (12). Spiritual distress is described as the sense of suffering that occurs when an individual's sense of spirituality is challenged or becomes vulnerable, which might be a response to emotional, physical and psychological suffering. Individuals with spiritual distress may benefit from spiritual supports or religious-specific activities such as prayer, while spiritual expressions are discourse around meaning and purpose, counselling to enable reflection, hope and reconciliation, emotional support through empathy and comfort, or advocacy around ways to meet patients' and their families' needs (13). In Malaysia, the Ibadah-friendly initiative was implemented in 2014 to help the Muslim patients in performing their religious rituals (14), however, it is beyond this initiative to provide spiritual care for patients and family members from different faiths. ICU patients who have survived critical illness were interviewed by Kang & Jeong (2018) stated that they were overwhelmed and exhausted by repeated crises and often driven to mental and physical suffering. This evidence indicated that spiritual care is important for ICU patients and their family members. Hence, this study explored the experience of intensive care patients and family members on spiritual care that they have received in the ICU.

MATERIALS AND METHODS

A qualitative study was conducted in three government hospitals in Johor, a southern state of Malaysia. Purposive sampling was used to select the patients and family members from different ethnic groups. A gatekeeper from each ICU assisted in identifying the patients and the family members to be included as the study participants. The patients were selected in the ICU based on the following criteria; aged 18 years and above, Malaysian citizen, able to understand and speak Malay or English language, physically and psychologically stable. Patients on ventilation, sedation, severely ill and not fluent in Malay or English were excluded from the study. The family members were invited to participate in the study if they have an adult relative in the ICU, consent to participate and are able to communicate in either Malay or English language.

The study was registered in the National Medical Research Registry (NMRR-18-3951-45429). The Malaysia Medical Research Ethical Committee (MREC) approval was obtained on 9 October 2019 and the University Ethics Committee was notified upon the MREC approval.

The study started in September 2019 and ended in March 2020 when the data was saturated. Data saturation was determined as the point where the researcher no longer finds new data that adds to the insight of the studied phenomenon (16). Maximum effort was used to ensure participation of patients and family members from different religions. The patients and family members who agreed to participate were given the information sheet before the interview. Written consent was attached to the information sheet and was signed individually. The interviews were conducted either at the bedside or in the ICU conference room. The sessions were recorded with an audio recorder. Pseudonyms were used to protect the participants' identities.

The flow of the study was described in detail in the field notes, which allowed audit trail and to ensure the study rigour. Member checking was applied by providing the coded transcripts to the key informants and allowing the interviewees to reflect their views. This procedure is important to establish that the researcher has made correct interpretations of the participants' narrations. Confirmability was achieved by transcribing the verbal accounts in the verbatim form to illustrate the themes and subthemes. Trustworthiness was established as the researcher kept a research diary to reflect on personal experiences and thoughts about their interests in spiritual care throughout the research process. Reflexivity, also known as researcher's positionality, is the awareness of how the researcher's background and knowledge could affect the research process (17). The research team held meetings regularly to discuss the codes and themes. All of these procedures were applied based on the set of criteria identified by Lincoln and Guba (1985) to ensure the study's trustworthiness.

RESULT

Transcribed conversations were analysed by applying thematic analysis using the six-step approach described by Braun, Clarke, Hayfield and Terry (19). The steps comprised data familiarisation, codes generation, themes construction, themes revision, themes definition, and generating the report. Participants' interviews were audio-recorded and transcribed verbatim. Then, the researcher read the transcripts repeatedly to become immersed and familiarised with the data. The

Table I The demographic data of the participants

Demographic characteristics	Patient (%)	Family members (%)
Gender		
Male	5 (20)	4 (16)
Female	1 (4)	15 (60)
Age		
20-39 years old	3 (12)	5 (20)
40-59 years old	3 (12)	9 (36)
60 years old and above	0 (0)	5 (20)
Education		
Primary	1 (4)	3 (12)
Secondary	4 (16)	14 (56)
Tertiary	1 (4)	2 (8)
Race		
Malay	3 (12)	11 (44)
Chinese	1 (4)	3 (12)
India	2 (8)	5 (20)
Religion		
Islam	3 (12)	11 (44)
Buddhist	1 (4)	3 (12)
Hindu	2 (8)	5 (20)
Diagnosis		(Of the relative who was in the ICU)
Head injury	0 (0)	4 (16)
Trauma	2 (8)	3 (12)
Cancer	1 (4)	1 (4)
Neurology	1 (4)	3 (12)
Pulmonary	1 (4)	5 (20)
Renal	1 (4)	2 (8)
Dengue	0 (0)	1 (4)
TOTAL (%)	6 (24)	19 (76)

meaningful sentences were then labelled with codes. Codes with similar meanings were clustered under the same theme. Themes were revised a few times and given definitions. During the discussions, the final four themes that emerged was based on the consensus of the research team members' decision. Finally, the findings were written in the form of a thesis and manuscripts for publication.

This study involved six patients and 19 family members, thus amounting to a total of 25 participants. Table 1 shows the participants' demographic information. Concerning religion, 14 referred as Muslims, four as Buddhists and seven of whom indicated Hinduism as their religion. Four themes, namely, "Having Faith", "Giving-receiving All", "Being There", and "Letting Go", established the central theme of this study, which is "Faith-based Care" (Table II). This central theme reflects the patients' and their family members' desire to partake in their care, and their reverence for spirituality in the process of care.

Table II Faith-based Care - Themes, Subthemes, and Categories

Central Theme	Main themes	Subthemes	Categories
Faith-based Care	Having Faith	Interpretative need	Inner part
			Submission to God
		Ritual need	Prayer
			Recitals
			Holy water
			Charity
	Giving-receiving All	Informative need	Honest and consistent
			Understanding
			Spiritual discourse
		Carative need	Knowledge
			Attitude
			Practice
		Procedural need	Disease process
			Decision and consent
			Intensive care syndrome
			Transition
	Being There	Psycho-emotional need	Worry
			Sad
			Helplessness
			Acceptance
		Proximity	Family presence
			Environment
	Letting Go	Time	Limited
			Prolonged
		Rites	Symptom management
			Privacy
			Last words

Having Faith

This theme refers to expressions used by the participants to indicate their spiritual side. Two subthemes further emerged from Having Faith; 1) interpretative need, and 2) ritual need. The patients and family members mostly agreed that spirituality is an important aspect of a person, specifically related to health and illness. They related the importance of spirituality, in this case, having faith in their current recovery state or having loved ones in critically ill conditions. The most common term stated was dalaman [inner, inside], constituting the first category. Participants related this inner aspect as their soul and source of strength.

"Our inside *lah*… A person's strength too" F2

"Not really [spiritual], but strength is inside ourselves…" F12
"It is like spiritual strength, it is for ourselves *lah*…I don't really know how to say it… the first day I came in [ICU], I felt like myself was empty…empty soul…looking at my husband like that. Like my soul is empty, no will at all." F3

The participants articulated that this inner side submits to God, hence, being ill and also having family members who are critically ill is a spiritual test from God.
"He [God] has… We believe him. This is all his game. Like our karma. Our lives have these… will happen. That is something no one can stand, can't stop it." P6
"Spiritual is like we actually… we know Allah is more kan but at that point of time, we do ikhtiar [make efforts], we surrender/succumb. Since we are all loans [from God], whatever it is, it is still borrowed. The most important is his life but we have done everything we could, *inshaa Allah.*" F19

Several categories such as prayers, recitals, holy water and charity were identified in the other subtheme, ritual need. These needs are the participants' practices while in the ICU to help them cope with the critical illness. Prayers for Muslims are called solat. Obligatory Solat is performed five times daily. One of the participants related her father's personal habits (the patient) who used to, not only performed the obligatory prayers, but also the supererogatory prayers such as solat dhuha and solat tahajud. For participants from other faiths, they preferred to do it on their own preferences.
"He never misses his solat dhuha, and he always performs charity. That is why people from our neighbourhood still do *solat hajat* [religious rituals], Yasin recitation for my father. He always wakes between 3 to 4 am in the early morning to perform *solat tahajud*. He never misses them." F2
"I used to perform solat and I maintained the five daily obligatory prayers, that is all… but for now, I miss them sometimes because of our condition. Sometimes we feel weak, we can't pray at the right time but we *qada* [replace]." P5
"We pray ourselves, that is our son. We must pray on our own, which is better and not rely on other people." F4

Muslim participants prefer to recite zikir and verses from the Holy Quran as their spiritual practice. Sometimes, the nurses play the audio records of Quranic verses for the patients. This practice is considered a positive initiative and appreciated by the family.
"I always do *du'a* [pray] and zikr, so he may recover. I never give up, always reciting *Yasin* for him, asking for his recovery. If it is destined by Allah and His Will, then I accept." F12
"Although I can't really play [audio records] in Tamil Hindu, the nurse would still do... but I just allow them as long as the intention is good." F5

The use of water that was recited upon with Quranic verses or prayers could also be used to improve the participants' state of spirituality. For Muslims, Zam-zam water that is originated from a well in Mecca is also considered to be beneficial for physical and spiritual health.
"I asked for water to improve my strength, ask water from my father. I pray to God to please let me be strong to face everything… Feels like I am stronger, if not, I become weak." F3
"Early in the morning, he will be restrained because he could not… He struggled to pull the wires but since the application of *Zam-Zam* water, he wakes up calmly, *Alhamdulillah* [All praise to Allah]. He listens to us [calmly]…He sits quietly. No need to restrain" F10

Charity is one of the spiritual practices applied by the participants. For some patients and family members, this practice was a habit that has been practised even before the episode of illness. Despite some of the participants were from other faiths, they accepted the *Zam-zam* water and dates donated by the Muslim volunteers who regularly come to the hospital to visit the patients and their families as an act of appreciation.
"He [the surgeon] told me. I have to do a lot of charity for the patient. The ones who are not sick [the family] can perform the charity on behalf of him [the patient]. So, I went back quickly and did the charity. I did the easy ones such as giving away rice, sugar, flour… We do it before the doctor advice. Encik Abu [the husband/patient] is someone who always loves to do charity since he was young until he got married and has a family. He engaged in doing charity since he was healthy until he became sick..." F17
"Give away all the Zam-zam water. He [referring to non-government individuals] gave Zam-zam water in small cups. Malay families took more, but my friend has plenty. I don't mind, I can have them [*Zam-zam* water]." F18

Giving-receiving All

Giving-receiving all is the theme that describes the exchange of provision and acceptance of care from ICU clinicians to the patients and family members. During the interviews, the patients and family members were asked to describe the supports that they received in the ICU, how they expressed their needs, and how it was provided. Three subthemes emerged from this theme; 1) Informative need, 2) Carative need, and 3) Procedural need. These needs were those that were expressed explicitly. The participants highly valued the information that was regularly provided to them by the doctors and nurses. Inconsistencies and misunderstandings in the process of communicating the information would cause distress to the family members.

"Even if I could not see the doctor, I will ask [her father/patient's condition] from the nurse. Like when I swap places with my sister, I'll ask the nurse about my father's

condition." F2
"Because these things (information) keep changing. When admitted, he had an infection and he underwent laser, for whatever reason. Then at last, currently, the kidneys… So, we don't know what really is the problem. We were only told that he has an infection. That's it." F14
"I didn't really understand. When he was (husband) admitted, I was confused. I thought my husband is like this, like that, like really dreadful thoughts." F3

This information needs to also include the spiritual discourse between the ICU clinicians, the patients, and their family members. Most of the advice was given by the clinicians to the participants to cope with the situation.
"They (the nurses and doctors) help a lot. They say if we make du'a (pray), maybe we can get well better." P2
"When my husband was brought to the operation theatre at 11 am, the surgeon suggested to (the family) ask for each other's forgiveness. He advised us to pray extensively and stated he was just helping. Ask from Allah, he said." F17
Furthermore, the patients and family members appreciate the good knowledge, attitude and practices demonstrated by the ICU clinicians, thereby signifying the carative dimension of this theme. Most family members reported that the ICU clinicians provided satisfying answers to their questions about their loved ones' conditions. The clinicians were perceived to be cooperative as they work diligently to meet the patient and family needs. However, there was an instance when a family member reported that he received an inappropriate response to his inquiry on his father's condition in the ICU. This example of poor attitude may lead to emotional distress on the family's side.

"All my questions were answered nicely. All the answers were very satisfying." F16
"I see the doctors and nurses work so hard and give support to my husband. For example, when he comes in, Encik K open your eyes, see your wife is here. Alhamdulillah, all the doctors are very good. They are highly cooperative." F3
"Don't say 'I don't know, ask the doctor to explain to you', like you don't care! Riled us up… Important [spiritual care]. We think about him (our father/patient) all the time, how would he be treated, what if he got uncaring treatment, with all the 'attitudes', are we not supposed to be upset?" F14

In procedural need, the family members expressed for more counsel and support to understand the disease course, decision making, and how to cope with intensive care syndrome, and when they will be discharged from the ICU (ICU-ward transition).
"Sometimes I feel like it (the amputated lower limb) is still there. Sometimes I ask my wife to lift it up. Then she would say redha, it's gone already… Then, I was aggressive, very aggressive. I understand my condition at that time was bad. I was really aggressive, like really bad.… Because of the nightmares." P5
"I was unconscious for 18 days. I sit and sleep all the time…I tell you, to get up like this (showing his current sitting position) was very difficult. I couldn't really talk and couldn't get up…. Oh! Getting up was difficult!" P4
"True, because I know he (husband/patient) is being cared for here (in ICU), After this, in the ward, all will be on us. He would be transferred to the ward soon. So, I have to be ready..." F19

Being There
This theme means indicate the need for the family members to be close to the relative who is being ill; physically and emotionally. Two sub-themes were identified from this theme; 1) Psycho-emotional needs and, 2) Proximity. The first sub-theme is the emotional expressions that indicate their psychological states may be of concern. It was most frequently noted during the early stage of critical illness, where the family members feel anxious, sad, and helpless. With time and supports from their relatives, as well as the clinicians, they embraced the reality and be at peace.
"I can't cry because I don't want to be weak. I can't even swallow a drop of water. I won't go anywhere, only here. Ya Allah, oh my God, hasten the visiting hour. Ya Allah, please give me strength to see my husband… when it is12.30 (pm), I dashed in straightaway." F12
"I went in and saw her; I am really sad. I am her closest sister… When she was awake, she pulled my hand and signalled to take off her tube. I feel so sad…When she (sister/patient) was awake, she pulled my hand, ask for water. I feel like I could not do anything, we were in the hospital, still in treatment but I felt helpless. Can't say I am not sad… I felt like my heart is crushed. Not really broken because it is will from God. I accept that my sister is tested by Allah." F9

The immediate family member, especially the wife, is expected to be physically present at all times while the husband is ill in the ICU. The facilities for them to be present were the ICU waiting areas and the ICU visiting hours. They also expressed frustration when this proximity need was curbed due to the visitation policy. Besides, the participant also valued the presence of the nurses and the ambient nature of the ICU.
Yes. My wife, my sister, they are too… The Indians believe in thali tau, which will save the husband. This is our belief." P6
"The ward here is like average. The ICU is cleaner. If you have pain or anything, the nurse is always there. Here, no… anything you need, you have to call, then they come." P2

Letting Go
There is a special need for end-of-life care. This theme represents the family members' need for time and privacy to perform their final rites, hence the subthemes, 1)

Time, and, 2) Rites. All family members were allowed to be close to the patient during this time. It is a distressing moment, not only to the patient's family but also to patients and family members of the neighbouring beds. This was brought forth during an interview with one of the family members who witness the neighbouring patient and their family at the time of death.

More than 10 visitors surrounded the patient's bedside while some of them were crying. The nurse sits back at her station, quiet and head bent down, eyes focus on the notes. (Field note 24102019)

"Wide-area…all (patients) are sick too. We understand. I saw a mother cried… talked to his son (another patient). So, he (nephew/patient) cried too. A bit bothering too." F6

During this time, ICU clinicians especially nurses, would clean the patients and provide analgesics to ensure that their loved ones were comfortable at their last moments. Nurses would distance themselves from the area but would be ready for comfort management whenever it was required.

"Why does she keep drooling? Can I wipe it? I think it's not so hygienic…all the germs around her… I just worry..." F1

The nurse in the background performs suctioning because the patient appears to have a lot of secretion. Also, the nurse adjusts the analgesic infusion (Field note 24102019)

DISCUSSION

This study identified faith-based care as the core of spiritual nursing care in the ICU. It signified that compassionate and values-driven care during the hard times of being critically ill or having family members with critical illness is highly needed. Spirituality is a significant dimension that needs constant sustenance in each person; patient and their family, irrespective of their religious beliefs. In this regard, ICU clinicians have to integrate spiritual care into the current management of critically ill patients and their family members. Considering the multicultural background of the clinicians, patients and families in Malaysia, interfaith spiritual care could be considered. A review that discussed interfaith spiritual care indicated that this is a condition in which the patients and spiritual care providers have different spiritual or religious worldviews (20). As stated by comparative religion experts, positive inter-religious dialogue should be actively practised because it can foster meaningful engagement between different people from different ethnic and religious backgrounds (21). Hence the implementation of interfaith spiritual care could potentially improve the current Ibadah-friendly initiative, increase satisfaction with care among the hospital clients, leading to harmonious connection and understanding between the multicultural communities in Malaysia.

In the first theme, the participants in this study viewed spirituality as the inner part of themselves that submits to God and considered critical illness as God's test for them. It is parallel with the Islamic view on the duality of human nature; physical and spiritual. The physical side is the body, while the spiritual side is al-ruh (spirit) or ruhaniah (spirituality); both are Quranic terms which Imam al-Ghazzali defined as the essence of human being (haqiqah al-insan) that drives and moves the body. Human spirit is commanded by God and will be judged accordingly to its deeds (22). In comparison, this view is unique and slightly different from the definition of spirituality from the international consensus which define spirituality as:

"Spirituality is 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. Spirituality is expressed through beliefs, values, traditions, and practices." (23 p. 646).

Despite this marked difference, the finding provides further evidence that spirituality is an abstract term. The international consensus recognised this, thus aimed to generate a more robust and inclusive definition of spirituality. Given that this study was conducted to understand the experience of ICU spiritual care, the findings also signified the specific nature of spirituality. The participants' psychospiritual nature not only relating to God but also seen in their emphasis on family bonding and presence. The hospitals included in this study has different visitation policies, hence the various participants' expressions in this regard.

Our study also calls for a more holistic care in the ICU. The second theme emphasized on the clinicians' conduct and the dynamics of ICU treatment. It further underscores the importance of information and the discourse surrounding it. Similar to other studies (24–27), the family members are in need of information regarding their loved ones conditions, and this calls for a better communication skills among the ICU clinicians especially in explaining the disease process and the treatment course. Previous studies also highlighted the need to humanize the ICU environment because of the stressful nature it emits (28,29). In our study, patients and family members expressed the need to be close and support each other during the critical illness. Understanding the need for family presence, flexible visitations and allowing personal momentos are among the strategies that the clinicians should consider in the ICU in order to support the patients and their family members spiritually.

The study is limited by the setting and the sampling strategy. Firstly, it has to be acknowledged that the study was conducted in the ICU of government hospitals in the southern state of Malaysia. It might be that ICU patients and families who lived in other states or private hospitals have different experiences. Secondly, the interviews

were conducted soon after the patients were discharged from ICU. It could be that the patients were still having ICU syndrome. There is a need for further longitudinal research into the patients and family experiences to examine the change of their experiences and spiritual needs over time. The strength of this study lies in the multi-ethnic background of the participants that is unique to the Malaysian population. Conflicts often arise in multi-ethnic study population (25), but this was not the case in our study, possibly because Malaysians are more accepting of different cultures. Consequently, a study to develop an interfaith model of spiritual care should be considered in the future.

CONCLUSION

The findings highlighted that the patients and the family members in this study thought of spirituality as part of themselves and they valued the spiritual care given to them. Additionally, ICU clinicians need to allocate special attention to patients' and family members' spiritual needs in the ICU to improve the quality of life, quality of care, and quality of death. Future research should focus on the course of patients' and family members' ICU experience over time, and also ultimately on the development of a model of ICU spiritual care to better integrate it into the current management of intensive care. This model could benefit from inter-religious dialogue and the perspectives of ICU clinicians on spirituality and their own and current initiatives in providing spiritual care.

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