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Exploring End-of-Life Issues and Determination of the Surrogacy Ladder in Malaysia

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Abstract

Clinicians face challenges managing patients at the end-of-life (EOL). A focus group discussion (FGD) of nine clinicians was conducted to explore their experiences. Verbatim was transcribed and thematically analysed based on grounded theory. 18 issues affecting EOL care decisions emerged and can be categorised into three categories: family-related issues, doctor-related issues and system-related issues. The findings suggest that the surrogacy ladder commonly used in decision-making for incapacitated patients in Malaysia is as follows: spouses followed by children, parents, and siblings. The results of this FGD can help policymakers develop guidelines on EOL decision-making suitable for use in the local context.

Keywords: surrogacy ladder, surrogate decision-maker, end-of-life decisions, advance care planning

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1.0 Introduction

When a patient has a terminal illness for which there is no known treatment, they may inevitably experience numerous clinical complications. This may include physical symptoms such as pain, breathlessness, fatigue, poor appetite, vomiting or constipation. They may also have psychological and spiritual issues such as anxiety, depression, anger or guilt. Additionally, their family or carers may need support in terms of training, finance, and purchase or loan of medical equipment to be able to care for patients. To help these patients and their families live life to their fullest within the limitation of their terminal illnesses, clinicians will adopt the palliative care approach to alleviate the sufferings that may arise. This approach addresses the physical, psychological, spiritual and social needs with an aim to improve the quality of life (QoL) of patients with an incurable disease and their families (Lim et al, 2022).

Patients at the end of life (EOL) may wish to be cared for according to their values and preferences (Martina et al., 2021). For example, knowing that they may have little chance of survival from their illness, terminally ill patients may opt to be cared for at home with their loved

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ones. They may not wish to have life-sustaining measures instituted upon them, such as being subjected to cardiopulmonary resuscitation (CPR), connected to a mechanical ventilator or being continuously fed with artificial nutrition and hydration despite their organs slowly ceasing to function. These wishes may be documented in a legal document called advance directives (AD), advance medical directives (AMD), or living wills, depending on the country's legal system (Alias et al., 2020; Martina et al., 2021). However, clinicians managing patients at the EOL may face challenges when the patient became incapacitated before making these decisions known to their family members or the managing doctors (Alias et al. 2020). Clinicians are then left to choose which one of the patient's family members or friends has the right and can make these important decisions on behalf of the patient, termed surrogate decision makers (SDMs) (DeMartino, 2017).

Alias et al, (2020) stated that "in Malaysia, Islam as the principal and official religion (as stated under article 3 of the Federal Constitution) accounts for 61.3%, Buddhism constitutes the second largest religion with 19.8%, while Christianity and Hinduism comprise 9.2% and 6.3%, respectively." As such, we feel it necessary to see if there are provisions in the Islamic 'shariah' law to guide Malaysian clinicians on whom to consult for these important medical decisions on behalf of an incapacitated Muslim patient. This will be done by conducting semi-structured interviews with subject matter experts in Islamic law and jurisprudence. However, to ascertain whether deciding on these SDMs is indeed considered a problem by Malaysian clinicians, there is a need to explore what issues they face when managing patients at the EOL. Subsequently, if they do consider it as a problem, what is their current practice in determining who these SDMs are?.

2.0 Literature Review

Literature from other countries highlights several issues concerning EOL care and Advance Care Planning (ACP) discussions. These include issues in communication skills, the decision-making process, and the roles of different healthcare professionals (Anderson et al., 2019; Michael et al., 2017). As far as we know, currently, there are no studies exploring EOL issues as experienced by Malaysian healthcare providers. EOL qualitative studies on Malaysian patients were mainly on suffering (Beng et al., 2014), and preferences and experiences of elderly adults in a Muslim-majority country (Abdullah et al., 2020).

There are also no local guidelines to assist healthcare providers in managing patients at the EOL (Alias & Kassim, 2021). However, the College of Anaesthesiologists, Academy of Medicine of Malaysia has published a consensus statement on "Withdrawal and Withholding of Life Support in the Critically Ill" to help guide local clinicians in the matter (Academy of Medicine of Malaysia, 2004).

The surrogacy ladder is a hierarchical priority list of individuals that acts as decision-makers on behalf of an incapacitated person (DeMartino, 2017). The names of these SDMs are usually recorded in a legal document that records treatment preferences, designates a durable power of attorney for health care, or both. Over the last two decades, healthcare professionals have fine-tuned the definition and advocated for using ACP. ACP is a continuous process of communication between doctors and their mentally competent adult patients that aims to establish a medical roadmap during severe and chronic illness. This roadmap must be consistent with the patient's values, goals, and preferences (Sudore, 2017). Fleuren et al. (2020) opinionated that this medical roadmap needs to address five underlying goals. These goals are: respecting individual patient autonomy, improving the quality of care, strengthening relationships, preparing for the end of life, and reducing overtreatment. However, this medical roadmap may or may not include decisions on ADs, AMDs, or SDMs.

In the local Malaysian context, Chan (2019) asserted that implementing ACPs or ADs may not be a priority in a nation with limited healthcare resources. Rather, its priority is on reducing mortality from chronic illnesses. This poor uptake is also influenced by other socio-cultural-religious factors, namely the lack of awareness of its importance among the public and healthcare workers, the societal inclination towards collective decision-making within family circles, having a paternalistic orientation to the doctor-patient relationship, and the influence of religious leaders (Alias et al., 2020; Chan, 2019; Chakraborty et al., 2017; Pereira-Salgado et al., 2017).

In most South-East-Asian countries with many Muslim residents, like Malaysia, Indonesia, and Singapore, the opinions of Muslim scholars are considered and respected in medical decision-making. Thus, physicians in those countries should be aware of the religious consensus rulings or 'fatwa' when discussing EOL care and deciding on an SDM with Muslim patients and their families (Alias et al., 2020). Alias, Kassim and Abdullah (2020) dissected the role of the guardian or 'wali' in Islam in patients who are incapable of making medical decisions with the emphasis on consulting the experts in the matter, in this case, doctors. In the context of guardianship hierarchy related to the property of the incapacitated, Islam follows the order of the individuals in the family most responsible for the overall welfare of family members. Suppose the guardian fails to act in the individual's best interest. In that case, the right will be transferred to the next designated guardian, and then to the next guardian and ultimately, to the ruler or in the modern context, the courts of law.

Before this study, the Institute of Islamic Understanding Malaysia conducted academic discourses and subsequently published a book on the Islamic bioethical perspective of AMD (Shaikh & Malek, 2017). However, the book did not have detail on the surrogacy ladder. Alias et al. (2020) quoted a fatwa by the Islamic Religious Council of Singapore (MUIS), which states there is no fixed hierarchy of guardianship or surrogate ladder to decide on behalf of incompetent patients. Therefore, there is a need to develop a local guideline to help doctors identify the most appropriate SDM, culturally congruent to a Muslim patient's faith.

3.0 Methodology

The development of this guideline is divided into three phases. The first phase is an extensive literature review. The second phase is this focus group discussion (FGD) to ascertain issues surrounding EOL care and the current practice of deciding an SDM for an incapacitated patient by their attending doctors. The last phase is an in-depth interview with subject matter experts to understand the Islamic rulings on matters related to AMD and SDM. This article will focus on phase 2 of the study. Results of phases 1 and 3, as well as the final guideline, will be published elsewhere.

An FGD of four critical care specialists and five palliative care physicians were conducted to explore their opinions on issues related to EOL care decisions and the most appropriate SDM according to local practice. The participants were chosen via convenient sampling. All are recognised medical specialists and leaders in the fields of anaesthesiology & critical care or palliative medicine in Malaysia. They have a minimum of five years of experience in their respective fields and are in active medical service in Peninsular Malaysia. All were involved in developing national-level policies and guidelines in their respective fields and have extensively managed patients at the EOL. We chose experts equally represented in terms of gender, place of work and experience to ensure that the views represent what is being practised in the field. Table 1 shows the demographics of the study participants.

Table 1. Demographics of the FGD participants

Code	Gender	Age	Ethnicity	Occupation	Workplace Setting,
I1	Male	44	Malay	Anaesthesiologist	MOH Hospital, Central
I2	Female	49	Malay	Anaesthesiologist	University Hospital, Central
I3	Female	50	Malay	Anaesthesiologist	MOH Hospital, Central
I4	Male	55	Malay	Anaesthesiologist	Private Hospital, Central
P1	Female	39	Malay	Palliative Physician	MOH Hospital, Northern
P2	Female	40	Chinese	Palliative Physician	MOH Hospital, Central
P3	Male	38	Chinese	Palliative Physician	MOH Hospital, Central
P4	Male	44	Chinese	Palliative Physician	University Hospital, Central
P5	Female	46	Malay	Palliative Physician	Private Hospital, Central

MOH = Ministry of Health; Central region = Perak, Selangor, Kuala Lumpur, Putrajaya, Negeri Sembilan; Northern region = Perlis, Penang, Kedah.

The FGD was recorded and transcribed verbatim, with notes taken on the verbal and physical responses of the participants. The transcript was then thematically analysed using an inductive method based on grounded theory. Two of the researchers conducted the analysis process independently, and themes emerging from each analysis were compared and consolidated into agreed categories (themes) and subcategories (subthemes).

3.0 Results

Eighteen issues (subthemes) emerged from the FGD when discussing issues surrounding EOL care for incapacitated patients, and these can be categorised into five themes: 1) the role of the family; 2) doctor's skills; 3) doctor-family disagreement/conflict of opinions; 4) availability of resources, and 5) awareness of AMD. These themes can be further categorised into family-related issues, doctor-related issues and system-related issues, with an overlap between the categories. Table 2 summarises the categories, themes and sub-themes of EOL discussions.

Table 2. Categories, themes and sub-themes of EOL discussions.

Categories	Themes	Subthemes
1. Family-related issues	1. Role of the family	1. Family's understanding of the medical futility of the situation 2. Family's familiarity with the patient's wishes and preferences 3. Family's autonomy vs. patient's autonomy 4. Family resources to fulfil patients' wishes and preferences
[Family & doctor-related issues]	2. Doctor-family disagreement/conflict of opinions	1. Conflicts usually arise when: - One or both parties have emotional distress. - There was a mismatched understanding concerning medical futility. 2. Doctors' paternalistic role in decision-making differs between family members and doctors. 3. Both parties needed time to reflect on what was discussed, and the meeting was rescheduled. But time may not be a commodity in the intensive care setting. 4. A third-party opinion would be encouraged
2. Doctor-related issues	3. Doctors' knowledge and skills	1. Ability to steer the conversation with the family into deciding what is best for the patient. 2. Doctors' communication skills differ from one doctor to another 3. Doctors of different teams should reach a consensus before speaking to the family. 4. Doctor's clinical acumen in disease trajectory and prognostication.
[Doctor & system-related issues]	4. Awareness of Advance Medical Directives	1. ACP discussion should be initiated early in the disease trajectory and not left till the late stage. 2. Some doctors are not aware, so discussions are not initiated. 3. Logistics on the document safekeeping because of the dynamic nature of disease progression.
3. System-related issues	5. Availability of resources	1. Treatment options depend on access and availability. 2. Patients may need to be triaged before being offered any limited treatment option. 3. It is essential to have trained counsellors or chaplains to support doctors, patients, and families.

Regarding consensus to determine the surrogacy ladder, the FGD participants agreed that the lack of legal provisions regulating any AD, AMD, or ACP documentation in Malaysia forces them to explore the patients' preferences and family dynamics. Experts agreed that the common local practice of a surrogacy ladder in decision-making for incapacitated patients is as follows: spouses followed by children, parents, and siblings. Issues that surface when deciding who the SDM should include are 1) culturally accepted hierarchy; 2) a spokesperson elected by family; 3) legal provisions, and 4) different family dynamics. Table 3 summarises the issues and examples of verbatims deciding the surrogacy ladder.

Table 3. Issues and Examples of Verbatim on Deciding the Surrogacy Ladder.

Issues	Examples of Verbatim
1. Culturally accepted hierarchy within families: spouses followed by children, parents, and siblings	I3: "I think in our society, it depends on family but (there is someone who is referred to more commonly than others) … usually. the spouse… " I2: "Spouse, usually spouse comes first" I3: "…the spouse, and then (children)" [other experts nodding] I2: "Parents" I3: "And then the family" I2: "Siblings" I3: "And then the siblings" [other experts nodding]
2. Spokesperson elected by the family	P4: "(If the) patient can talk, (we ask the) patient (who can help you decide); otherwise, we ask family members, who's the spokesperson, who's the one that makes the decision. So, it doesn't follow any pattern. You have to find out first."
3. Legal provisions for decision-making	I4: "Whoever is appointed as the legal power, attorney, or appointed as the independent capacity decision maker type person. So, (we need to) have that framework and (we) can follow that."
4. Different family dynamics.	I3: "But, basically (for example), the patient's 40-year-old, he's got his wife, his parents are still alive, and he may have adult children in their 20s. So, erm, the wife (would) feel she needs to consult (with his parents), and (also his) children, of course, consult (them all) …" I3: "commonly you will have a situation, with the elderly (patient), who sometimes has lots of children .and he's (living) with the youngest child…" I2: "... Yeah (agreed). So, which children (to consult)?" P3: "And. at the moment. the person with the loudest voice is the one who (speaks up for everyone)". I4: "But he shouldn't be the spokesperson". I2: "Yes". I1: (one patient had) three wives who don't talk to each other. I mean, we must bring them all together at the bedside at the end of his life, when you withdraw. So, it's not easy.

Phrases in brackets denote translation from the Malay language.

3.0 Discussions

EOL discussions, including the determination of an SDM, can be a complex and daunting task for healthcare providers (HCP). As reflected in the findings of this study, three broad categories of issues are discussed: family, doctor, and system-related problems. The issues highlighted in this study are like those in other countries (Anderson et al., 2019; Michael et al., 2017; Garner et al., 2010).

3.1 Family-related issues:

In Asia, end-of-life decisions by family members and physicians over the patient are recognized as a cultural feature (Alias et al., 2020). The family structure in Malaysia, as with many Southeast Asian countries, consists of extended families emphasising filial piety (Abdul Aziz & Yusoff, 2012). Therefore, it is not surprising that Malaysian informal caregivers may not be limited to the patients' respective spouses and children of the nuclear family but may include siblings and multiple families of polygamous marriages (Jawahir et al., 2021; Ismail 2021). Sibling positions are important in a Malaysian family (Mahmud et al., 2011); thus, after the parents, the eldest or the eldest male sibling is often regarded as having the most responsibilities and is the final decision-maker in most family affairs (Alias et al., 2020; Mahmud et al., 2011). However, these elder siblings may have difficulty communicating the patient's wishes and preferences if they are not the main carer of their sick parents. As is often observed, the role of the informal caregiver is commonly shouldered by the younger siblings or/and their respective spouses or the maids (domestic helpers) whose voices may or may not be considered when deciding on parental care. Furthermore, elderly patients may indicate care decisions that are not of their preference so as not to burden their children. (Alias et al., 2020; Anderson et al., 2010; Michael et al., 2017). Thus, determining the SDM and subsequently honouring the patient's actual wishes and preferences may be challenging for a Malaysian HCP.

Patients and caregivers may have poor knowledge and understanding of the concept of palliative care and ACP, making EOL decisions difficult. Two local studies on elderly patients and those with end-stage renal failure found that none or less than 5% of the study populations were aware of ACP respectively and recognised the need to appoint an SDM (Alias et al., 2020; Hing Wong et al., 2016). Further robust studies will need to be done to determine the prevalence of awareness of palliative care and ACP among the population.

3.2 Doctor-related issues:

Lack of awareness or knowledge on ACP and managing patients at the end of life are also prevalent among Malaysian doctors and nurses (Alias et al., 2020). Furthermore, the ability of a family to see and understand an apparent deterioration of a loved one's clinical status also depended on the knowledge and skill of the treating HCPs, including their communication skill (Anderson et al., 2010; Michael, 2017). This is even more important when conflicts in decision-making arise between the HCPs and SDMs or carers (Garner et al., 2010). Understanding the disease trajectories and managing the complex, multifaceted issues at the EOL, including good communication skills, require early exposure and continuous training. However, many studies have shown that medical graduates felt inadequately trained in palliative care during medical school (Melgaard & Neergaard, 2020; Ibrahim et al., 2020; Oliveira et al., 2020).

3.3 System-related issues:

For EOL care decisions to be carried out according to the patient's preferences, there must be a supportive environment with good resources. Data from the Malaysian Ministry of Health Ministry (2019) estimated that the number of people requiring palliative care in 2014 was 100,034 and that the number is projected to increase to 239,713 by 2030. However, based on local data from inpatient palliative care units and the not-for-profit community hospices, published in the Ministry of Health Malaysia’s ‘National Palliative Care Policy and Strategic Plan 2019-2030’, less than 10% of Malaysia's total palliative care needs are being met. This is not surprising as only 23 registered palliative care physicians and 30 active community hospices currently cater to 33.6 million Malaysians, according to the current Malaysian Hospice Council website and the Malaysian National Specialist Register. Spiritual support is an essential component of palliative care, with evidence showing positive effects on patients' quality of life reported across age groups and medical conditions (Gijsberts et al., 2019). Moreover, he also mentioned that the lack of spiritual support for patients and caregivers has adverse effects such as having more aggressive treatment resulting in increased costs, dissatisfaction with healthcare received less hospice service uptake, and reduced overall quality of life. In Malaysia, religion and spirituality are used interchangeably (Shariff & Lee, 2018) but may not necessarily subscribe to the international consensus definition of spirituality headed by Puchalski (2014). Currently, Malaysian hospitals and hospices may have religious officers to help patients with some aspects of religious rites and spiritual experiences. Still, from the authors' general observation, not many would have had the proper spiritual care training accredited by a professional body. Thus, there is a need to train more professionally recognised spiritual care providers or chaplains in healthcare.

This study is not without its limitations. The selection of experts was based on their recognised roles as leaders in their respective fields. However, there was no representative of experts practising in the southern and eastern regions of peninsular Malaysia and East Malaysia (the states of Sabah and Sarawak) in the FGD. Although the findings are like those from other countries, this limitation must be kept in mind, as mentioned.

4.0 Conclusions

Several issues arise when discussing EOL care. For both the family and HCP, there is a need to have specific knowledge and skills. Systems-related topics include access and availability of specific human, treatment, and logistic resources. Delivering high-quality care at the end of life depends on the harmonious interplay of these three domains and how information is communicated.

In a country with no legal framework to enforce the implementation of ADs and AMDs, ACP discussions may play an important role in ensuring patients receive the best possible care according to their wishes and preferences. If ACP discussions cannot be initiated early, having a culturally accepted guideline of a surrogacy ladder, which religious scholars support, may help ensure that terminally ill patients' wishes and preferences are upheld as best as possible. This guideline must consider the community's cultural norms in deciding on the SDM, which may be different from what is available in other parts of the world.

An in-depth interview of religious scholars on the surrogacy ladder would be beneficial to enhance knowledge in this matter. Furthermore, EOL care guidelines in different settings such as in the Emergency Department or nursing homes may also be beneficial for healthcare providers in the field. A feasibility study on the implementation of any ethical and legal framework of AMDs may be discussed further by the relevant authorities to anticipate the need to have such a framework in the future.

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Paper Contribution to Related Field of Study

This paper can give insight into future studies on AMD and ACP. The result of this study will also be used to develop a local guideline on decision-making at the end-of-life.

References

Abdullah R, Guo P, Harding R. Preferences and Experiences of Muslim Patients and Their Families in Muslim-Majority Countries for End-of-Life Care: A Systematic Review and Thematic Analysis. J Pain Symptom Manage. 2020 Dec;60(6):1223-1238.e4. . https://doi.org/10.1016/j.jpainsymman.2020.06.032

Abdul Aziz, R.; Yusooff, F. (2012). Intergenerational relationships and communication among the rural aged in Malaysia. Asian Social Science, 8(6). https://doi.org/10.5539/ass.v8n6p184

Alias, F., Jahn Kassim, P. N., & Abdullah, M. N. (2020). Dying Wishes: Understanding Advance Medical Directives from the Malaysian and Islamic Law Perspectives. Ulum Islamiyyah, 32, 18-39. https://doi.org/10.33102/uij.vol32no.174

Alias, F., Jahn Kassim, P. N., (2021) Legal aspects of End-of-Life Care in Malaysia. Malayan Law Journal, 2 (xxxiii). ISSN 0025-1283. http://irep.iium.edu.my/89416/

Anderson, R. J., Bloch, S., Armstrong, M., Stone, P. C., & Low, J. T. S. (2019). Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence. Palliative Medicine, 33(8), 926–941. https://doi.org/10.1177/0269216319852007

Beng TS, Guan NC, Seang LK, Pathmawathi S, Ming MF, Jane LE, Chin LE, Loong LC. The experiences of suffering of palliative care patients in Malaysia: a thematic analysis. Am J Hosp Palliat Care. 2014 Feb;31(1):45-56. https://doi.org/10.1177/1049909112458721

Consensus on Withdrawal and Withholding of Life Support in the Critically Ill. Academy of Medicine of Malaysia (AMM). (2004, June 1). Retrieved December 4, 2022, from https://www.acadmed.org.my/newsmaster.cfm?&menuid=3&action=view&retrieveid=8#Consensus_on_Withdrawal_and_Withholding_of_Life_Support_in_the_Critically_Ill

Chakraborty, R., El-Jawahri, A. R., Litzow, M. R., Syrjala, K. L., Parnes, A. D., & Hashmi, S. K. (2017). A systematic review of religious beliefs about major end-of-life issues in the five major world religions. Palliative & supportive care, 15(5), 609–622. https://doi.org/10.1017/S1478951516001061

Chan H. Y. (2019). Regulating advance decision-making: potential and challenges for Malaysia. Asian bioethics review, 11(1), 111–122. https://doi.org/10.1007/s41649-019-00078-2

DeMartino, E. S., Dudzinski, D. M., Doyle, C. K., Sperry, B. P., Gregory, S. E., Siegler, M., Sulmasy, D. P., Mueller, P. S., & Kramer, D. B. (2017). Who Decides When a Patient Can't? Statutes on Alternate Decision Makers. The New England journal of medicine, 376(15), 1478–1482. https://doi.org/10.1056/NEJMms1611497

Fleuren, N., Depla, M.F.I.A., Janssen, D.J.A. et al. Underlying goals of advance care planning (ACP): a qualitative analysis of the literature. BMC Palliat Care 19, 27 (2020). https://doi.org/10.1186/s12904-020-0535-1

Garner, K. K., Lefler, L. L., Kirshner, J. A. E., & Sullivan, D. H. (n.d.). Surrogate decision making: Medical and legal implications for healthcare providers. Consultant360. Retrieved October 10, 2022, from https://www.consultant360.com/articles/surrogate-decision-making-medical-and-legal-implications-healthcare-providers

Gijsberts, M.-J. H., Liefbroer, A. I., Otten, R., Olsman, E. (2019). Spiritual care in palliative care: A systematic review of the recent European literature. Medical Sciences, 7(2), 25. https://doi.org/10.3390/medsci7020025

Hing Wong, A., Chin, L. E., Ping, T. L., Peng, N. K.; Kun, L. S. (2016). Clinical impact of education provision on determining advance care planning decisions among end stage renal disease patients receiving regular hemodialysis in University Malaya Medical Centre. Indian Journal of Palliative Care, 22(4), 437. https://doi.org/10.4103/0973-1075.191788

Ibrahim, H., Lootah, S., Satish, K. P., Harhara, T. (2022). Medical student experiences and perceptions of palliative care in a Middle Eastern country. BMC Medical Education, 22(1). https://doi.org/10.1186/s12909-022-03448-x

Ismail, S. (2021, March 2). Fahami Urusan poligami demi Perkukuh Institusi keluarga. BH Online. Retrieved October 28, 2022, from https://www.bharian.com.my/wanita/keluarga/2021/03/791717/fahami-urusan-poligami-demi-perkukuh-institusi-keluarga

Jahn Kassim, P. N., Alias F (2015). End-Of-Life decisions in Malaysia: Adequacies of ethical codes and developing legal standards. J Law Med 2015;22:934–50.http://irep.iium.edu.my/42098/

Jawahir, S., Tan, E. H., Tan, Y. R., Mohd Noh, S. N., & Ab Rahim, I. (2021). The impacts of caregiving intensity on informal caregivers in Malaysia: Findings from a national survey. BMC Health Services Research, 21(1). https://doi.org/10.1186/s12913-021-06412-5

Lim, R. B. L., Lam, C. L., Ahmad, F., Khoo, C. S. Y., Lee, C. C., Teoh, C. C. O., Hiew, A. W. H., Abdul Hassan Chin, A., Chng, G. S., Chong, L. A., Katiman, D., Hamzah, E., Taib, F., Khalid, F., Loh, F. Y. Y., Yaakup, H., Jamaluddin, J., Sharmini, J., Liew, J., Yeat, C. L. (n.d.). National Palliative Care Policy and Strategic Plan 2019-2030. Retrieved October 28, 2022, from https://www2.moh.gov.my/moh/resources/Polisi/BUKU_NATIONAL_PALLIATIVE_CARE_POLICY_AND_STRATEGY_PLAN_2019-2030.pdf

Mahmud, Z., Ibrahim, H., Amat, S., Salleh, A. (2011). Family Communication, Sibling Position and Adolescents' Sense of Responsibility. World Applied Sciences Journal, 74–80. Retrieved October 10, 2022, from https://www.idosi.org/wasj/wasj14(LIDDL)11/12.pdf.

Martina, D., Lin, C. P., Kristanti, M. S., Bramer, W. M., Mori, M., Korfage, I. J., van der Heide, A., van der Rijt, C., & Rietjens, J. (2021). Advance Care Planning in Asia: A Systematic Narrative Review of Healthcare Professionals' Knowledge, Attitude, and Experience. Journal of the American Medical Directors Association, 22(2), 349.e1–349.e28. https://doi.org/10.1016/j.jamda.2020.12.018

Melgaard, S. K., Neergaard, M. A. (2019). Medical students do not feel confident in managing palliative care as future doctors. Progress in Palliative Care, 28(3), 201–206. https://doi.org/10.1080/09699260.2019.1696007

MHC Member Hospices. Malaysian Hospice Council. (n.d.). Retrieved October 12, 2022, from https://www.malaysianhospicecouncil.com/hospice-in-malaysia

Michael, N., O'Callaghan, C. Sayers, E. (2017). Managing 'shades of grey': A focus group study exploring community-dwellers' views on advance care planning in older people. BMC Palliative Care, 16(1). https://doi.org/10.1186/s12904-016-0175-7

Oliveira, S., Santiago, L. M., & Dourado, M. (2020). Conhecimento sobre Cuidados Paliativos em Estudantes de Medicina da Universidade de Coimbra [Knowledge of Palliative Care Among Medical Students of the University of Coimbra]. Acta medica portuguesa, 10.20344/amp.12590. Advance online publication. https://doi.org/10.20344/amp.12590

Shaikh Mohd Salleh, S. M. S., & Malek, M. M. (Eds.). (2017). Arahan Perubatan Awal Perspektif Bioetika Islami. Institut Kefahaman Islam Malaysia.

Shariff, N. M., & Pien, L. S. (2018). The Need to Particularise the Concept of Spirituality within Mental Health Services in Malaysia. INTERNATIONAL JOURNAL OF CARE SCHOLARS, 1(1), 44–49. https://doi.org/10.31436/ijcs.v1i1.45

Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z., Matlock, D. D., Rietjens, J., Korfage, I. J., Ritchie, C. S., Kutner, J. S., Teno, J. M., Thomas, J., McMahan, R. D., & Heyland, D. K. (2017). Defining Advance Care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel. Journal of pain and symptom management, 53(5), 821–832.e1. https://doi.org/10.1016/j.jpainsymman.2016.12.331

Pereira-Salgado, A., Mader, P., O'Callaghan, C., Boyd, L.; Staples, M. (2017). Religious leaders' perceptions of advance care planning: A secondary analysis of interviews with Buddhist, Christian, Hindu, Islamic, Jewish, Sikh and bahá'í leaders. BMC Palliative Care, 16(1). https://doi.org/10.1186/s12904-017-0239-3

Puchalski, C. M., Vitillo, R., Hull, S. K., & Reller, N. (2014). Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus. Journal of Palliative Medicine, 17(6), 642–656. https://doi.org/10.1089/jpm.2014.9427