

Needs Analysis for The Development of a Manual in Palliative Care for Malaysia Based on the Islamic Psychospiritual Approach

This Accepted Manuscript (AM) is a PDF file of the manuscript accepted for publication after peer review, when applicable, but does not reflect post-acceptance improvements, or any corrections. Use of this AM is subject to the publisher's embargo period and AM terms of use. Under no circumstances may this AM be shared or distributed under a Creative Commons or other form of open access license, nor may it be reformatted or enhanced, whether by the Author or third parties. By using this AM (for example, by accessing or downloading) you agree to abide by Springer Nature's terms of use for AM versions of subscription articles: <https://www.springernature.com/gp/open-research/policies/accepted-manuscript-terms>

The Version of Record (VOR) of this article, as published and maintained by the publisher, is available online at: <https://doi.org/10.1007/s10943-024-02073-w>. The VOR is the version of the article after copy-editing and typesetting, and connected to open research data, open protocols, and open code where available. Any supplementary information can be found on the journal website, connected to the VOR.

For research integrity purposes it is best practice to cite the published Version of Record (VOR), where available (for example, see ICMJE's guidelines on overlapping publications). Where users do not have access to the VOR, any citation must clearly indicate that the reference is to an Accepted Manuscript (AM) version.

Needs Analysis for The Development of a Manual in Palliative Care for Malaysia Based on the Islamic Psychospiritual Approach.

Che Zarrina Sa'ari^{1#}. Hasimah Chik². Sharifah Basirah Syed Muhsin³. Sheriza Izwa Zainuddin⁴. Nor Azah Abdul Aziz⁵. Khairul Hamimah Mohammad Jodi⁶. Che Zuhaida Saari⁷. Abdul Salam bin Muhamad Shukri⁸. Salmah Karman⁹. Abdul Ghafar Bin Surip¹⁰

The authors of this article were led by professor from Universiti Malaya and followed by other authors consisting of master's degree and Doctor of Philosophy holders which experts in Islamic psychospiritual, palliative care, law and designing. The authors come from various backgrounds and different institutes that are Universiti Malaya, Sultan Idris University of Education (UPSI), International Islamic University Malaysia (IIUM) and Department of Islamic Development Malaysia (JAKIM). This article entitled Needs Analysis for the Development of a Manual in Palliative Care for Malaysia Based on the Islamic Psychospiritual Approach is the output of research related to designing the guideline for terminal patients.

Needs Analysis for the Development of a Manual of Palliative Care for Malaysia Based on the Islamic Psychospiritual Approach

[#]Department of Aqidah & Islamic Thought, Academy of Islamic Studies, Universiti Malaya, 50603 Kuala Lumpur, Malaysia
Telephone number: +603-79676098
Fax number: +603-7956 0705
Email: zarrina@um.edu.my

¹Department of Aqidah & Islamic Thought, Academy of Islamic Studies, Universiti Malaya, 50603 Kuala Lumpur, Malaysia.

²Department of Aqidah & Islamic Thought, Academy of Islamic Studies, Universiti Malaya, 50603 Kuala Lumpur, Malaysia.

³Department of Aqidah & Islamic Thought, Academy of Islamic Studies, Universiti Malaya, 50603 Kuala Lumpur, Malaysia.

⁴Department of Medicine, Faculty of Medicine, Universiti Malaya, 50603 Kuala Lumpur, Malaysia

⁵Faculty of Art, Computing and Creative Industries, Universiti Pendidikan Sultan Idris (UPSI), Tanjung Malim, 35900 Perak, Malaysia

⁶Cluster of Education and Social Sciences, Open University Malaysia, 47301 Petaling Jaya, Selangor, Malaysia

⁷Faculty of Syariah and Law, Universiti Sains Islam Malaysia, 71800 Nilai, Negeri Sembilan, Malaysia

⁸Kulliyah Of Islamic Revealed Knowledge and Human Sciences, International Islamic University Malaysia (IIUM), 50728 Kuala Lumpur, Malaysia

⁹Department of Biomedical Engineering Faculty of Engineering, Universiti Malaya, 50603 Kuala Lumpur, Malaysia

¹⁰Division of Research, Department of Islamic Development Malaysia (JAKIM), Kompleks Islam Putrajaya, Presint 3, 62100 Putrajaya, Malaysia

Abstract

This study **explicates** an Islamic approach to palliative care based on the results of a needs analysis **regarding the development of** an Islamic psychospiritual manual of palliative care **alongside** related elements. This article **represents** the first phase of a three-phase study using the Design and Development Research (DDR) approach developed by Richey and Klein **to study for design and development of manual either needed or otherwise**. This **project** is a quantitative study **that uses purposive sampling through** a questionnaire instrument **to investigate** 210 participants from the general population in Malaysia **that have experience in taking care of terminally ill patients**. The findings of the study indicated that the majority **of participants** agreed with the development of **an** Islamic psychospiritual manual with mean values (\bar{x}) **of** 4.57 and 4.66. Concurrently, the findings showed that the hierarchy of emphasis in terms of the elements to be included in the manual starts with emotional support, **which exhibited** the highest mean rate (\bar{x}), followed by faith in God, spiritual and religious support, self and physical management, trauma management **and** social support. The correlations indicated that all the elements to be included in the manual **were significant**.

Keywords: *needs analysis, manual, Islamic psychospiritual, care, palliative, Malaysia*

i. Introduction

Islam emphasizes well-being by focusing on a healthy and positive lifestyle regardless of gender, race and religion (Badri, 2018). The World Health **Organization** defines health as 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' (World Health Organization, 2022). This **definition** is, however, contested, and there **have been calls** for a biopsychosocial-spiritual model of

well-being that includes spirituality and spiritual care, which is more holistic (Vermette & Doolittle, 2022). Modules of care have been found to be helpful, especially for those who need care in a holistic sense, to ensure that individuals experience the best quality of life (Ross et al., 2017).

It has been demonstrated that the Islamic psychospiritual approach can mitigate mental issues efficiently (Othman et al., 2020; Sabki et al., 2019). Spiritual means the 'search for the scared' as articulated by Pargement (McGhee, 2015), and within the Islamic framework refers to the array of tools, techniques, rituals and behaviour as transmitted by the Qur'an and operationalised by the Prophet of Islam. This ranges from prayers, meditation (dhikr), intermittent and prolonged fasting, charity to modelling the virtues and values to combat the various vices.

The rationale of merging of the two constructs, that is, psychological and spiritual, is premised on the evidence-based field of psychology informing and enhancing the spiritual practices within the framework of Islam. This type of fusion of the psychospiritual is not new and as a matter of fact, was championed by Abu Zayd al-Balkhi, whose 9th century manuscript outlines a form of cognitive behaviours therapy (Badri, 2013;1-71). Islamic spiritual framework also has been integrated to treat variety of psychological problem (Ali et al., 2020).

This research examines the literature concerning palliative care within the framework of the Islamic psychospiritual approach within a health care setting based on priority needs. This approach is adopted to appropriately develop a manual alongside related guidelines. Based on the data generated, an analysis is performed, and the results are discussed to draw relevant conclusions. While pursuing the main aim of this study, evidence is presented concerning the efficacy of Islamic psychospiritual therapy with

respect to caring for terminally ill patients, especially in the context of controlling anxiety and uneasy feelings.

Palliative Care Based on the Islamic Psychospiritual Approach

Palliative care is an approach to the task of improving the quality of life of patients facing life-threatening disease-related problems as well as that of their families. This task generally accomplished by reducing suffering through early identification, comprehensive assessment, and treatment of diseases relating to physical, psychological, social and spiritual aspects (World Health Organization, 2020). Islamic psychospiritual knowledge is a combination of thought and study concerning mental and spiritual processes that uses Islamic approaches and methods (Saged et al., 2022). Malik Badri (2018) emphasized that Islamic psychospiritual knowledge pertains to many aspects of life, including its physical, psychological, spiritual and social dimensions. This approach, then, is similar to the biopsychosocial model of Sulmasy (2002), although it exhibits certain differences from that model since this manual is framed within the context and concepts of Islam.

Studies have been conducted to ensure the best results for patients receiving palliative care with respect to their quality of life as well as their ability to achieve a good death via palliative care planning (Lin & Bauer-Wu, 2003; Pollock & Seymour, 2018). The notion of a good death has been understood in various ways by different scholars of religion as well as from patients' perspectives (Krikorian et al., 2020). For example, a good death requires a lack of feelings of fear, loneliness, despair, negligence and being condemned to a lonely death (Aghabarary & Nayeri, 2016). The characteristics of a good death also pertain to the control of pain and symptoms, unambiguous decision-making, a sense of closure, being seen and perceived as a person, preparing for death, and

continuing ability to give something to others (Krikorian, A., Maldonado, C. & Pastrana, T, 2020).

Muslim scholars interpret a good death by **reference to** a specific term, that is, *ḥusn al-khātimah* or a good ending, **which includes** well-being and happiness in this life and in the hereafter, which is the dream of every Muslim (Al-Ghazali, 2020). This study emphasized **this** psychospiritual element based on **the results of** previous studies **that have** demonstrated that spiritual resiliency can help an individual **obtain** a better quality of life and make **their thinking** more positive (Manning, Ferris, Narvaez Rosario, Prues, & Bouchard, 2019). Spiritual resilience **refers to** the ability to cope with life after having experienced loss and grief or having **undergone the** trials and tribulations of life, **and it is associated with** an increase in the meaning of life, which tends to result in increased levels of happiness, well-being and **life satisfaction among patients and their family members** (Connolly, M. & Timmins, F., 2022; Manning et al., 2019). Having a worldview that **includes the** meaning for life or earthly existence is one spiritual element that **can** help an individual achieve a good death or end his or her life peacefully (Hasimah Chik, Che Zarrina Sa'ari, & Loh Ee Chin, 2017).

The Islamic spiritual approach **claims** that everything is **given by** God, **such that** life is a process of learning and adapting and **is related to an** afterlife in which **individuals' lives** will be **measured** and **they will then be** rewarded for good actions and **reprimanded** for bad actions. Spiritual values include patience (*sabr*), **contentment** (*rida*), trusting in God (*tawakal*), **hopefulness** (*amal*) and **gratefulness** (*shukr*), which **have been** utilized by groups as coping mechanisms **in** difficult circumstances (Munsoor, 2021) This type of spiritual approach **has been highlighted** by a detailed case study **of** drug addicts and HIV patients, who were able to transform their lives and manage their negative emotions **via the** approach underlined by these spiritual values,

according to which the participants in the study set targets for themselves and actively practised the virtues (Munsoor, 2021; Sa'ari et al., 2020).

For example, with regards to the concepts of hopelessness and despair, the members of this spiritual order experienced due to being abandonment by their families and their struggle with drug addiction as well as dealing with their HIV; the spiritual concepts of patience (sabr), gratitude (shukur), divine mercy (ar-raheem) and contentment with what we have (rida), were utilised by them to cultivated these practices, in combination with other practices, which was used as a basis for their transformation (Munsoor, 2021: 186-192). In this sense, the Islamic psychospiritual approach encourages people to practice their Islamic lifestyle to achieve holistic health, including spiritual, physical, mental and social well-being (Mohd et al., 2016).

Important of Islamic-based Manual Development

In this context, support and guidance are very important to help individuals, especially carers, find solutions when facing impasses and implement the best solutions for patient welfare. The existing manual used in Malaysia to help care for patients is more closely related to the practice of worship, such as the guidelines for prayer during illness (JAKIM, 2017). Caregiver's Guidelines also exist, which are specific to carers (Cleland et al., 2013). In Malaysia, guidelines concerning palliative care have been developed by a few palliative experts to produce the *Handbook of Palliative Medicine in Malaysia*. All these handbooks and guidelines have mostly focused on the treatment of pathological conditions and have discussed spirituality only in general.

In light of this situation, this study explored the need for the development of a manual that includes guidelines based on the Islamic psychospiritual perspective. A literature review concerning needs analysis found that the aim of developing such a

health care manual had not been widely achieved in the case of Malaysia, such that only recommendations for building such a manual or model had been proposed to strengthen palliative care services both within and outside the country (Lim & Katiman, 2015).

This manual and the proposal of the necessary elements of care have already been discussed widely by scholars, especially in terms of aspects pertaining to spiritual care, religious elements, psychology, emotions and social roles (Ilyas et al., 2020; Vermette & Doolittle, 2022), and the importance of physical care by experts has also been a central element (Ferguson & Barham, 2020). Due to the necessity of and lack of study concerning this specific topic, namely, from an Islamic psychospiritual perspective, researchers have highlighted the fact that this project must be mapped out and responsibility must be taken to explore the aspects of care needs in further detail to assist the health care system in a holistic manner.

ii. Materials and Methods

This study was based on the needs analysis model developed by McKillip (2001), which involves five main steps to conduct a needs analysis in developing an Islamic psychospiritual manual for palliative care alongside related elements either needed or otherwise. The first step is to identify users; the second is to describe the target population and service environment; the third is to identify needs; the fourth is to assess the importance of those needs; and the fifth is to submit a report (Mohd Jamil & Mat Noh, 2020). Needs analysis is an important aspect of the Design and Development Research (DDR) approach developed by Richey and Klein (Mohd Jamil & Mat Noh, 2020; Richey & Klein, 2007).

The study employed a quantitative approach by purposive sampling. The instrument used was a questionnaire survey including 210 participants consisting of

health care providers, carers and the general population that have experience in taking care of terminally ill patients. The questionnaire, which had been validated by experts, was divided into three parts. Part A pertained to demographic information. Part B was a closed-ended questionnaire to investigate the participants' opinions of and levels of agreement with the manual to be developed. Part C was a questionnaire based on a Likert scale that used open-ended questions to solicit opinions and suggestions for appropriate items.

The seven-point Likert scale used in the third section included the following options: (1) Strongly Disagree; (2) Disagree; (3) Somewhat Disagree; (4) Uncertain; (5) Somewhat Agree; (6) Agree; and (7) Strongly Agree (Barnette, 2012). Each section left room for comments and suggestions. Data collected were analysed using Statistical Package for Social Science (SPSS) Version 25 software. The findings were analysed in terms of Cronbach's alpha, frequency, descriptive, and correlation.

The items concerning the necessary elements in the questionnaire were constructed based on a literature review. The main element included was spirituality, which was separated into two items, namely, faith in God and spiritual and religious support (Abbas et al., 2022; Vermette & Doolittle, 2022; Paiva et al., 2015). Emotional support was the second important factor because this element has been experienced acutely by terminally ill patients (Green, 2018; Paiva et al., 2015). Other elements noted in the literature include trauma management (Hoelterhoff & Chung, 2013; Kucharska, 2020), self-management (Ilyas et al., 2020; Amanda L Roze des Ordon et al., 2015), daily routine (Ilyas et al., 2020; van Riet Paap et al., 2015) and social activities (Ilyas et al., 2020; Wang et al., 2020). All of these elements are important with respect to improving the quality of life of patients.

iii. Data Analysis and Results

a. Data Analysis

This study used a questionnaire consisting of three parts: A, B and C. Part A collected the participants' demographic information, and Part B solicited their opinions of and levels of agreement concerning the manual to be developed. Part C included open-ended questions to collect opinions and suggestions for appropriate items to be included in the manual, as noted in the methodology section. Cronbach's alpha value was one of the indicators used for internal reliability testing (Pallant, 2016). A five-point likert scale ranging from "strongly disagree" (1) to "strongly agree" (5) was employed in the questionnaire to allow respondents to give their response to each item. The survey was piloted with 30 respondents at university hospital to establish test reliability the instrument. If Cronbach's alpha value is between 0.6 and 0.7, the item can be considered acceptable (Bond et al., 2020; Bond & Fox, 2015). In this study, the overall Cronbach's alpha value for Part B of the questionnaire was 0.599. This value of 0.599 was low but nevertheless significant because it was affected by question 1, which asked about the participants' knowledge of existing Palliative Care Manual based on the Islamic psychospiritual approach. Most participants responded negatively to this question, thus lead to a low Cronbach's alpha value. This question was very important as a foundation to indicate that the notion of a manual for palliative care based on the Islamic psychospiritual approach remains largely unknown or unavailable. Part C of the questionnaire used a Likert scale to study the necessary elements to be included the manual, and Cronbach's alpha value for this section was 0.99. Therefore, all items included in this questionnaire were reliable and suitable for use in the manual under development.

b. Demographics

A total of 210 online survey responses were completed over an 8-week data collection period ranging from 1 April 2020 to 30 May 2020. Table 1 shows the demographics of the study participants. Approximately 63.8% of these participants were involved in care, including as family, health care providers, friends, volunteers and others who played multiple roles in care. The highest percentages among the participants were for the adult population (90.5%), female participants (77.6%), participants of the Malay ethnicity (92.9%), participants from urban areas (64.8%) and participants with higher levels of academic achievement (72.4%).

[Place Table 1 about here]

c. Need for the Design and Development of a Palliative Care Manual based on the Islamic Psychospiritual Approach

The development of an Islamic psychospiritual manual of palliative care requires a process based on current needs so that the manual can be framed contextually. Based on the responses to the questionnaire, the mean value indicated that the majority of the participants agreed that such a palliative care manual was necessary and its guidelines should be based on the Islamic psychospiritual approach, with mean values (\bar{x}) of 4.57 and 4.66 based on Table 2. Table 3 and Table 4 show that the category of study participants from the general population were individuals who played multiple roles in caring for patients, especially patients' family members, and that most patients receiving care were senior citizens who were most likely family members of those participants. The other categories in Table 3 refer to persons who played a few roles in

caring for patients, whether as family members, health care providers, friends or NGO workers and volunteers. The other categories included in Table 4 refer to a few categories of persons receiving care.

[Place Table 2 about here]

[Place Table 3 about here]

[Place Table 4 about here]

d. **Necessary Elements of Palliative Care Based on the Islamic Psychospiritual Approach**

Means (\bar{x}) and standard deviations (SD) were used to examine the level of participants' needs in the context of care based on a Likert scale. The findings of the study included in this section indicate the level of agreement concerning the elements of care on a scale ranging from 1 to 5. The mean scores for each element are compared. Table 5 shows the average mean values pertaining to these necessary elements.

[Place Table 5 about here]

The results showed that participants agreed with emphasizing the emotional support element in the proposed manual, which exhibited the highest mean rate of 4.57, followed by the element pertaining to faith in God, which was 4.56. Spiritual and religious support recorded average means of 4.53 and 4.48 for self and physical management, respectively. This factor was followed by trauma management and social activities, which exhibited the same mean of 4.42.

In terms of the family, the mean of emotional support exhibited the highest mean value, 4.64, indicating that families require more emotional support when carrying out their duties and responsibilities. The element pertaining to faith in God indicated a similar mean value for patients and family members, 4.59. The other elements exhibited the same trend, receiving a higher mean rate in the context of family member items compared to other items, namely, spiritual and religious support of 4.57, self and physical management of 4.61, and 4.47 for social activities. The element of trauma management support received the highest mean from medical practitioners, with a value of 4.54. This situation may be due to the fact that medical practitioners frequently encounter struggles and traumatic events with patients, for example, death or the responses of patients' family members to medical results.

The results of the correlation analysis illustrated in Table 6 show that the relationship between need analysis for the development of the manual and the users of the manual, including patients, carers and others, was below 0.05 ($p \leq 0.05$). The correlation coefficient value showed that the correlations among the data were significantly positive. Every person involved in care requires guidance to address the challenges of palliative care.

[Place Table 6 about here]

Pearson correlation analysis was used to identify the requirements of an Islamic psychospiritual knowledge-based manual of caring for terminal patients, and correlation analysis was conducted by reference to Pearson (r) values. In addition, the significance of the null hypothesis was tested by reference to the interpretation of the strength of the value of the correlation coefficient based on the rating scale (Baba, 1999).

The results of the Pearson correlation between the needs analysis for the development of the manual and the necessary elements presented in Table 7 indicates a significant correlation, with a value below 0.05 ($p \leq 0.05$). Based on this value, all the elements were suggested to be incorporated into the manual to help improve quality of life for patients and carers.

[Place Table 7 about here]

iv. Discussion

a. Needs Analysis of the Manual for the Islamic Psychospiritual Approach

The need for a spiritual and cultural sensitive psychological or clinical therapy and the gap that exist in this regard is flagged by the need for increasing number of clinicians or therapists, where Tasmim (2023:12), for example, points out that “equipping therapist with the appropriate skillset to integrate religion, spirituality and culture, while training is an important step to address this gap”. In terms of operationalising this type of approach, Tasmim (2023:14) highlights that apart from psychoeducation training the psychotherapist and counsellor in this type of approach, works collaboratively with spiritual leaders, where possible. In this connection, he piloted a study with clients from a Muslim population and found this collaboration to be very effective (Tasmim, 2023:14).

Religious, spiritual and cultural sensitive forms of counselling is a useful form of intervention to support and relieve the segment of population at the end-of-life, especially those who live by their faith (Glyn-Blanco et al., 2023; Kissane et al., 2023). Based on this, guidelines and protocol will be useful for this purpose, which constitutes essential parts of the proposed manual. However, it is to be borne in mind that religious coping mechanisms within the Islamic framework, may be both positive or negative

based on the religious coping perspective of the client or patient (Munsoor, 2019; Isgandarova, 2019).

Based on the data analysis, the proposed development of an Islamic psychospiritual manual of palliative care gained majority approval among the participants. This approval was based on the specificity of this particular manual in terms of its spiritual framework. This type of manual featuring an Islamic psychospiritual framework has not yet been developed in the context of palliative patients; thus, it is necessary to design and develop such a manual.

Based on the results of this study, a case can be made for the development of an Islamic psychospiritual approach to address problems related to physical, emotional, spiritual, psychological and social aspects. Previous studies have indicated the influence of religious practices in reducing depression and suicidal behaviour among cancer patients (Abbas et al., 2021; Moreno-montoya et al., 2016) as well as assisting in controlling responses to trauma among individuals (Kucharska, 2020; Sabki et al., 2019; Wani & Singh, 2019). While the Islamic psychospiritual approach has been shown to be able to control spiritual, mental and emotional issues among the general population (Sabki et al., 2019; Wani & Singh, 2019) as well as among patients and their families (Almoajel, A., 2020), the Islamic psychospiritual approach has been used despite the fact that no related manual or guidelines for this purpose yet exist.

b. Important Elements in the Proposed Manual

Table 4 indicates the elements that were prioritized in the context of the necessary construction of the proposed Islamic psychospiritual manual of palliative care according to the participants in the study. The emotional elements were clearly shown to be the most important for the manual. The mean average rating demonstrated that

the Islamic psychospiritual approach is crucial **to the task** of controlling emotions. According to the World Health Organization (2000), emotions are a very influential element throughout the course of treatment because patients **must deal with** changes **during** various phases of treatment, including by coping with complications, which is corroborated by Seiler & Jenewein, 2019 and Sekhar et al., 2016.

In light of these findings, the emotions of caregivers **must** also be highlighted because of the challenges **they face in fulfilling** their responsibilities to patients physically, emotionally, spiritually and socially (Willemijn Y. van der Plas, Benjamins, & Schelto Kruijff, 2020). This **conclusion** is in line the findings of this study, which showed that the family member items **exhibited** the highest means **with respect to** the emotional support element. Many situations **have shown** that the psychospiritual manual is important to family members based on the study findings that the family is a core element in patient care (Krug et al., 2016).

The second highest element was faith in God. This **finding** is in line with what has been **emphasized** by the Islamic scholar Imam al-Ghazali in his seminal work, the *Ihya' `Ulum al-Din* (the revival of religious sciences). **Imam al-Ghazali** stated that this element of belief can drive one's life positively towards the ultimate goal of receiving the best in this world as well as the next and making one's **entire** life better, as represented by repeated Islamic supplications (Al-Ghazali, 2011). He further emphasized this element in his book *Kimiya' al-Sa`adah* (the alchemy of happiness), noting that belief in God (*Allah*) the Almighty has **positive** effects on **people's** emotions (Al-Ghazali, 2017).

The third element that was **emphasized pertained to** spiritual and religious practices related to the aspects of faith, which tend to regulate life. **The effects** of psychotherapy are more impactful when patients exhibit spiritual belief and when

health care providers are aware of the spiritual needs of the patients (Syed Muhsin & Sa'ari, 2015; Kelly et al., 2006). This spiritual aspect generally becomes manifest when patients have fundamental faith in God as well as an understanding the related tenets and identify as practitioners.

Other elements that were also noted as necessary for the manual were physical management, support for trauma management, and guidelines for patients' social activities, which are more closely related to external factors. External factors are basic points that must be included in care, such as personal hygiene, good nutrition, socialization, and outdoor activities, which affect individual patients in the process of restoring quality of life to some degree (Y. van der Plas et al., 2020).

This study indicated that a manual of palliative care is essential to the improvement of patients' quality of life as well as carers' well-being. A manual based on the Islamic psychospiritual approach is suggested to represent a form of integrated therapy that can help people improve their lives, achieve success in this earthly life and prepare for a more positive hereafter as per the tenets of the Islamic faith.

v. Study Limitations

The study was conducted by reference to the general population, especially carers who were involved in caring for patients such as family members, including spouses, parents, siblings, children and others. Other carers involved in the study were friends, neighbours, health care providers and volunteers. Furthermore, in this study, participants less than 18 years old were excluded because they were children who were not eligible to serve as adult carers (Keshavarz Haddad et al., 2019). In the current study, participants were recruited online due to the COVID-19 pandemic. The

questionnaires pertained to participants' perceptions and opinions concerning health care needs as well as the need to design and develop the manual as a guide for carers.

vi. Conclusion

Based on the data generated, this study provides a necessary rational basis for the development of a manual based on Islamic psychospiritual principles and highlights the elements that are necessary to develop the required framework. The manual is needed to help carers and patients cope with the obstacles they face throughout their daily life routines during this critical phase of their life. It would provide insights into the best ways of confronting difficulties such as trials and tribulations by providing guidance and elucidating relevant practices.

A Muslim should receive guidance and advice when faced with such challenges, especially in the context of palliative care. This type of support must be provided by all concerned parties as well as support groups, which can have positive impacts on patients and their families. The manual should be developed based on the key elements revealed by this research while bearing in mind the sociocultural practices of individuals in general and those of Muslims in particular. It can be operationalised by conducting training in the Islamic Psycho-Spiritual area with those closely involved in the end-of-life care, as well as collaborating with spiritual leaders to augment and institutionalise it. The diversity of expertise in terms of caring for patients and dealing with their families is a factor that must be taken into consideration and can be expanded based on further research and praxis to promote better quality of care and well-being.

a. Author Contributions

All authors contributed to the conception and design of the study. Material preparation, data collection and analysis were performed by Che Zarrina Sa'ari, Hasimah Chik, Sharifah Basirah Syed Muhsin, Sheriza Izwa Zainuddin, Nor Azah Abdul Aziz, Khairul Hamimah Mohammad Jodi, Che Zuhaida Saari, Abdul Salam bin Muhamad Shukri, Salmah Karman and Abdul Ghafar Bin Surip. The first draft of the manuscript was written by Che Zarrina Sa'ari and Hasimah Chik, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

b. Funding

This study was sponsored by the Ministry of Higher Education (FRGS) scheme, grant number FP095-2019A, referring to code FRGS/1/2019/SSI03/UM/02/5. Special thanks are also extended to the University of Malaya.

vii. Declaration

a. Competing Interests

The authors have no relevant financial or nonfinancial interests to disclose.

b. Ethics Approval

This research was approved by the University of Malaya Research Ethics Committee (UM.TNC2/UMREC_1200). Participants were drawn from the general population; they were informed that their participation was voluntary and that consent was implied by completing the questionnaire.

c. Consent to Participate

Informed consent was obtained from all individual participants included in the study.

d. Consent to Publish

The authors affirm that the human research participants provided informed consent for publication.

viii. References

- Abbas, Q., Kanwal, U., Khan, M. U., Shahzadi, M., & Faran, M. (2021). *Relationship of Muslim Religiosity and Death Anxiety with the Mediating Effect of Optimism and Depression Among Cancer Patients*. <https://doi.org/10.21203/rs.3.rs-465671/v1>
- Abbas, Q., Kanwal, U., Saeed, W., Khan, M. U., Shahzadi, M., & Faran, M. (2022). Relationship of Muslim Religiosity and Death Anxiety with the Mediating Effect of Optimism and Depression Among Cancer Patients in Pakistan. *Journal of Religion and Health*, 61(2), 1418–1436. <https://doi.org/10.1007/s10943-021-01415-2>
- Aghabarary, M., & Nayeri, N. D. (2016). Nurses' Perceptions of Futile Care. *Holistic Nursing Practice*, 30(1), 25–32. <https://doi.org/10.1097/HNP.0000000000000012>
- Al-Ghazali (2017). *The Alchemy of Happiness*, Trans. Claude Fields. CreateSpace Independent Publishing Platform.
- Al-Ghazali, A. al-H. M. bin M. al-T. (2011). Kitāb al-`Ilm. In Imam Al-'Aydarus (Ed.), *Ihya' `Ulum Al-Din (Vol. 1)* (p. 800). Dar al-Minhaj.

- Ali, B., Khan, F., Keshavarzi, H., & Awaad, R. (Eds.). (2020). *Applying Islamic Principles to Clinical Mental Health Care: Introducing Traditional Islamically Integrated Psychotherapy*. Taylor & Francis.
- Almoajel, A. (2020). Quality of palliative care: perspective of healthcare providers at a tertiary hospital in Riyadh, Saudi Arabia. *Journal of religion and health*, 59(5), 2442-2457. <https://doi.org/10.1007/s10943-020-00998-6>
- Amanda L Roze des Ordon, Nishan Sharma, Daren K Heyland, & John J You. (2015). Strategies for effective goals of care discussions and decision-making: perspectives from a multi-centre survey of Canadian hospital-based healthcare providers. *BMC Palliative Care*, 14, 38. <https://doi.org/10.1186/s12904-015-0035-x>
- Baba, A. (1999). *Statistik Penyelidikan dalam Pendidikan dan Sains Sosial*. Penerbit Universiti Kebangsaan Malaysia.
- Badri, M. (2018). *Contemplation: An Islamic Psychospiritual Study*. London, International Institute of Islamic Thought (IIIT).
- Badri, M. (2013), Abu Zayd al-Balkhi's Sustainance of the Soul: The Cognitive Behaviour Therapy of a Ninth Century Physician, London, International Institute of Islamic Thought (IIIT).
- Barnette, J. J. (2012). Likert Scaling. In Neil J. Salkind (Ed.), *Encyclopedia of Research Design* (pp. 715–718). SAGE Publications. <https://dx.doi.org/10.4135/9781412961288>
- Bond, T. G., & Fox, C. M. (2015). *Applying The Rasch Model Fundamental Measurement in The Human Sciences (Third Edit)*. Routledge & T. & F. Group, Eds. <https://doi.org/10.4324/9781315814698>

- Bond, T. G., Yan, Z., & Heene, M. (2020). Applying the Rasch Model. In *Applying the Rasch Model*. Routledge. <https://doi.org/10.4324/9780429030499>
- Chik, H., Sa'ari, C. Z., & Ee Chin, L. (2017). Peranan Spiritual dalam Rawatan Paliatif. *AFKAR*, 19(2), 107–142. <https://doi.org/10.22452/afkar.vol19no2.4>
- Cleland, M., Schmall, V., Sturdevant, M., Abrams, L., Congleton, L., Kirkbride, K., McFalls, J., Ross, S., & Sponsler, V. (2013). *The Caregiver Helpbook: Powerful Tools for Caregivers* (Third). Legacy Caregiver Services.
- Connolly, M., & Timmins, F. (2022). Experiences Related to Patients and Families' Expression of Spiritual Needs or Spiritual Support Within Healthcare Settings During the COVID-19 Pandemic: A Scoping Review. *Journal of religion and health*, 1-27. <https://doi.org/10.1007/s10943-022-01556-y>
- Ferguson, L., & Barham, D. (2020). Palliative Care Pandemic Pack: a Specialist Palliative Care Service response to planning the COVID-19 pandemic. *Journal of Pain and Symptom Management*. <https://doi.org/10.1016/j.jpainsymman.2020.03.026>
- Glyn-Blanco, M. B., Lucchetti, G., & Badanta, B. (2023). How do cultural factors influence the provision of end-of-life care? A narrative review. *Applied Nursing Research*, 73(March). <https://doi.org/10.1016/j.apnr.2023.151720>
- Green, C. (2018). New Nursing Faculty and Incivility: Applying Mindfulness-Based Strategies. *Holistic Nursing Practice*, 32(1), 4–7. <https://doi.org/10.1097/HNP.0000000000000246>
- Hoelterhoff, M., & Chung, M. C. (2013). Death Anxiety and Well-Being; Coping With Life-Threatening Events. *Traumatology*, 19(4), 280–291. <https://doi.org/10.1177/1534765613477499>

- Ilyas, Z., Shahed, S., & Hussain, S. (2020). An Impact of Perceived Social Support on Old Age Well-Being Mediated by Spirituality, Self-esteem and Ego Integrity. *Journal of Religion and Health*, 59, 2715–2732. <https://doi.org/10.1007/s10943-019-00969-6>
- Isgandarova, N. (2019). Muraqaba as a Mindfulness-Based Therapy in Islamic Psychotherapy. *Journal of Religion and Health*, 58(4), 1146–1160. <https://doi.org/10.1007/s10943-018-0695-y>
- JAKIM. (2017). *Panduan Bersuci & Bersolat Bagi Pesakit*. Atin Press. <http://library1.nida.ac.th/termpaper6/sd/2554/19755.pdf>
- Kelly, B., McClement, S., & Chochinov, H. M. (2006). Measurement of psychological distress in palliative care. *Palliative Medicine*, 20(8), 779–789. <https://doi.org/10.1177/0269216306072347>
- Keshavarz Haddad, G. R., Habibi, N., & Rafiee, S. (2019). Decomposition of cohort, age and time effects in Iranian households' cigarette consumption. *Journal of Economic Studies*, 46(1), 228–244. <https://doi.org/10.1108/JES-09-2017-0256>
- Kissane, D. W., Watson, M., & Breitbart, W. (Eds.). (2023). *Psycho-Oncology in Palliative and End of Life Care*. Oxford University Press. <https://doi.org/10.1093/med/9780197615935.001.0001>
- Krikorian, A., Maldonado, C., & Pastrana, T. (2020). Patient's Perspectives on the Notion of a Good Death: A Systematic Review of the Literature. *Journal of Pain and Symptom Management*, 59(1), 152–164. <https://doi.org/10.1016/j.jpainsymman.2019.07.033>
- Krug, K., Miksch, A., Peters-Klimm, F., Engeser, P., & Szecsenyi, J. (2016). Correlation between patient quality of life in palliative care and burden of

- their family caregivers: a prospective observational cohort study. *BMC Palliative Care*, 15(1), 4. <https://doi.org/10.1186/s12904-016-0082-y>
- Kucharska, J. (2020). Religiosity and the psychological outcomes of trauma : A systematic review of quantitative studies. *Journal of Clinical Psychology*, 76, 40–58. <https://doi.org/10.1002/jclp.22867>
- Lim, R. B. L., & Katiman, D. (2015). Handbook of Palliative Medicine in Malaysia. In Richard B. L. Lim & Diana Katiman (Eds.), Malaysia, *Malaysian Hospice Council*.
- Lin, H.-R., & Bauer-Wu, S. M. (2003). Psycho-spiritual well-being in patients with advanced cancer: an integrative review of the literature. *Journal of Advanced Nursing*, 44(1), 69–80. <https://doi.org/10.1046/j.1365-2648.2003.02768.x>
- Manning, L., Ferris, M., Narvaez Rosario, C., Prues, M., & Bouchard, L. (2019). Spiritual resilience: Understanding the protection and promotion of well-being in the later life. *Journal of Religion, Spirituality and Aging*, 31(2), 168–186. <https://doi.org/10.1080/15528030.2018.1532859>
- Mckillip, J. (2001). Case studies in job analysis and training evaluation. *International Journal of Training and Development*, 5, 4.
- Mohd Jamil, M. R., & Mat Noh, N. (2020). *Kepelbagaian Metodologi dalam Penyelidikan Reka Bentuk dan Pembangunan* (I. Noh, Ed.; 1st ed.). Qaisar Prestige Resources.
- Mohd, M., Kadir, A., Iskandar, M., Atiqah, N., Demong, R., Normalina, E., Khalid, M., & Abbas, M. (2016). Islamic Personality Model : A Conceptual Framework. *Procedia Economics and Finance*, 37, 137–144. [https://doi.org/10.1016/S2212-5671\(16\)30104-6](https://doi.org/10.1016/S2212-5671(16)30104-6)

Moreno-montoya, J., Palacios-espinoza, X., & Gracia-ruiz, J. (2016). Association Between Religion and Suicidal Behaviors in Cancer Patients. *Revista Colombiana de Psiquiatría*, 46(4), 209–214. <https://doi.org/10.1016/j.rcpeng.2017.08.002>

Munsoor, H. S. (2023). Personal Communication on the 25th July 2023. Clinician at the Nightingale Hospice, Wrexham, North Wales, United Kingdom.

Munsoor, M. S. (2021). *Well-Being and the Worshipper: Insights into an Islamic Spiritual Order*, Switzerland, Springer International. <https://doi.org/10.1007/978-3-030-66131-1>

Othman, K., Mohd Sukor, N., Md Hamdani, S., Nik Nazli, N. N. N., Mahyuddin, M. K., Ahmad, Y., Mutalib, M. M., Sulaiman, M., & Jusoh, N. A. S. (2020). The Needs for Psycho Spiritual Competencies for Disaster Workers in Malaysia. *Abqari Journal*, 22(2), 21-33. <https://doi.org/10.33102/abqari.vol22no2.320>

Paiva, B. S. R., Carvalho, A. L., Lucchetti, G., Barroso, E. M., & Paiva, C. E. (2015). “Oh, yeah, I’m getting closer to god”: spirituality and religiousness of family caregivers of cancer patients undergoing palliative care. *Supportive Care in Cancer*, 23(8), 2383–2389. <https://doi.org/10.1007/s00520-015-2604-1>

Pallant, J. (2016). *SPSS Survival Manual 6th Edition: A Step by Step Guide to Data Analysis Using IBM SPSS*. www.allenandunwin.com/spss

Pollock, K., & Seymour, J. (2018). Reappraising “the good death” for populations in the age of ageing. *Age and Ageing*, 47(3), 328–330. <https://doi.org/10.1093/ageing/afy008>

- Richey, R. C., & Klein, J. D. (2007). *Design and Development Research: Method, Strategies and Issues*. Erlbaum. <https://doi.org/10.4324/9780203826034>
- Ross, M. K., Doshi, A., Carrasca, L., Pian, P., Auger, J., Baker, A., Proudfoot, J. A., & Pian, M. S. (2017). Interactive Palliative and End-of-Life Care Modules for Pediatric Residents. *International Journal of Pediatrics*, 2017, 1–7. <https://doi.org/10.1155/2017/7568091>
- Sa'ari, C. Z., Zainal Abidin, M. S., Hj Ahmad, S. S., Syed Abdul Rahman, S. M. H., Che Nordin, M. K. N., Syed Muhsin, S. B., & Mohd Akib, M. M. (2020). The Development of Islamic Psychospiritual Scale for Drug Addicts. *Afkar*, 22(2), 279–312. <https://doi.org/10.22452/afkar.vol22no2.8>
- Sabki, Z. A., Sa'ari, C. Z., Muhsin, S. B. S., Kheng, G. L., Sulaiman, A. H., & Koenig, H. G. (2019). Islamic Integrated Cognitive Behavior Therapy : A Shari ' ah- Compliant Intervention for Muslims with Depression. *Malaysian Journal of Psychiatry Ejournal*, 28(1).
- Saged, A. A. G., Sa'ari, C. Z., Abdullah, M. bin, Al-Rahmi, W. M., Ismail, W. M., Zain, M. I. A., & alShehri, N. bint A. bin M. (2022). The Effect of an Islamic-Based Intervention on Depression and Anxiety in Malaysia. *Journal of Religion and Health*, 61(1), 79–92. <https://doi.org/10.1007/s10943-021-01484-3>
- Seiler, A., & Jenewein, J. (2019). Resilience in cancer patients. In *Frontiers in Psychiatry* (Vol. 10). Frontiers Media S.A. <https://doi.org/10.3389/fpsy.2019.00208>
- Sekhar, W. Y., Connor, S., McCarthy, S., & Hamzah, E. (2016). *Penjagaan Paliatif: Penilaian Keperluan (Malaysia)*. Hospis Malaysia.

https://www.hospismalaysia.org/wp-content/uploads/2017/06/HM-BM-Report_Full-004.pdf

Sulmasy, D. P. (2002). A biopsychosocial-spiritual model for the care of patients at the end of life. *The Gerontologist*, *42 Spec No(III)*, 24–33. https://doi.org/10.1093/geront/42.suppl_3.24

Syed Muhsin, S. B., & Sa'ari, C. Z. (2015). *Kaedah Psikoterapi Islam berasaskan Konsep Maqamat Abu Talib Al-Makki*. Dewan Bahasa dan Pustaka.

Tasmim, S. (2023), *Bridging the gaps, Thresholds: Counselling with spirit*, British Council of Counselling and Psychotherapy, United Kingdom.

van Riet Paap, J., Vissers, K., Iliffe, S., Radbruch, L., Hjermland, M. J., Chattat, R., Vernooij-Dassen, M., & Engels, Y. (2015). Strategies to implement evidence into practice to improve palliative care: recommendations of a nominal group approach with expert opinion leaders. *BMC Palliative Care*, *14(47)*, 1–6. <https://doi.org/10.1186/s12904-015-0044-9>

Vermette, D., & Doolittle, B. (2022). What Educators Can Learn from the Biopsychosocial-Spiritual Model of Patient Care: Time for Holistic Medical Education. *Journal of General Internal Medicine*. <https://doi.org/10.1007/s11606-022-07491-8>

Wang, Q., Chan, I. K. W., & Lou, V. W. Q. (2020). Effectiveness of a Holistic Capacity-Building Program for Volunteers in Community-Based End-of-Life Care. *Research on Social Work Practice*, *30(4)*, 408–421. <https://doi.org/10.1177/1049731519898530>

Wani, I. A., & Singh, B. (2019). Effect of Islamic psycho-spiritual therapy in managing craving, withdrawal symptoms, and mental health problems among

cannabis users. *Mental Health, Religion and Culture*, 22(7), 674–685.

<https://doi.org/10.1080/13674676.2019.1581755>

World Health Organization. (2000). *Health ethics in South-East Asia, Vol. 3: Volume 3: ethical issues in clinical practice. a qualitative interview study in six asian countries* (No. SEA-HSD-241). WHO Regional Office for South-East Asia.

World Health Organization. (2020, August). *Palliative care*. World Health Organization. <https://www.who.int/news-room/fact-sheets/detail/palliative-care>

World Health Organization. (2022). *Health and Well-Being*. World Health Organization (WHO). <https://www.who.int/data/gho/data/major-themes/health-and-well-being>

Y. van der Plas, W., Benjamens, S., & Kruijff, S. (2020). The increased need for palliative cancer care in Sub-Saharan Africa. *European Journal of Surgical Oncology*, xxx, 3–6. <https://doi.org/10.1016/j.ejso.2020.03.212>

Table 1. Demographic Characteristics of the Study Population

Characteristics	Number (n)	% Study Population
Age group (years)		
18-30	135	64.3
31-45	55	26.2
46-60	16	7.6
61 and above	4	1.9
Gender		
Male	47	22.4
Female	163	77.6
Marital Status		
Single	108	51.4
Married	97	46.2
Widowed	5	2.4
Ethnicity		
Malay	195	92.9
Chinese	9	4.3
Indian	2	1.0
Other	4	1.9
Region		
City	136	64.8
Suburbs	34	16.2
Rural	40	19.0
Education Level		

Master's/PhD	73	34.8
Bachelor's	79	37.6
Diploma/A-level	44	21.0
Secondary School	14	6.7
Monthly Income (MYR)		
0-2500.00	108	51.4
2501.00-4850.00	52	24.8
4851.00 and above	50	23.8
Relationships between Participants and Patients		
Family member	88	41.9
Health care provider	5	2.4
Friend	10	4.8
Volunteer	3	1.4
Other (multiple roles)	28	13.3
General population	76	36.2

References: Chik, H (2020) Survey data, unpublished PhD thesis, Kuala Lumpur: Universiti Malaya

Table 2. Needs Analysis for the Development of a Palliative Care Manual Based on the Islamic Psychospiritual Approach

Item	Manual for Patients	Manual for Carers
Mean (\bar{x})	4.57	4.66
Standard Deviation, (<i>SD</i>)	.743	.600

Reference: Chik, H (2020) Survey data, PhD thesis unpublished, Kuala Lumpur: Universiti Malaya

Table 3. Participants Involved in the Study

Role	Frequency (<i>f</i>)	Percentage (%)	Percent Valid (%)	Cumulative Percentage Σ (%)
Valid 0	1	.5	.5	.5
Family Member	84	40.0	40.0	40.5
Health Care Provider	5	2.4	2.4	42.9
Friend	9	4.3	4.3	47.1
NGO Worker or Volunteer	3	1.4	1.4	48.6
Other (multiple roles)	32	15.2	15.2	63.8
General population	76	36.2	36.2	100.0
Total (<i>N</i>)	210	100.0	100.0	

References: Chik, H (2020) Survey data, unpublished PhD thesis, Kuala Lumpur:
Universiti Malaya

Table 4. Patient Category

Roles	Frequency (<i>f</i>)	Percentage (%)	Percent Valid (%)	Cumulative Percentage Σ (%)
Valid Infant (0–2 years)	1	.5	.5	.5
Teenager (11–17 years)	1	.5	.5	1.0

Youth (18–40 years)	12	5.7	5.7	6.7
Adult (40–60 years)	35	16.7	16.7	23.3
Elderly Person (61 years and above)	70	33.3	33.3	56.7
Other	91	43.3	43.3	100.0
Total (N)	210	100.0	100.0	

References: Chik, H (2020) Survey data, unpublished PhD thesis, Kuala Lumpur: Universiti Malaya

Table 5. Average Mean Values of Care Element Needs

Element	Patient		Family Member		Community		Health Care Provider		Religious Volunteer		Overall Average Mean (\bar{x})
	Average Min (\bar{x})	Standard deviation	Average Min (\bar{x})	Standard deviation	Average Min (\bar{x})	Standard deviation	Average Min (\bar{x})	Standard deviation	Average Min (\bar{x})	Standard deviation (SD)	
Emotional Support	4.56	.948	4.64	.860	4.54	.902	4.58	.873	4.51	.924	4.57
Faith in God	4.59	.955	4.59	.909	4.52	.939	4.54	.923	4.54	.933	4.56
Spiritual Support and Religiosity	4.5	.994	4.57	.922	4.5	.934	4.55	.933	4.52	.939	4.53
Physical Management	4.47	.949	4.61	.869	4.39	.987	4.54	.908	4.41	.980	4.48

t

Traumatic/Past												
Experience	4.28	1.09	4.5	.955	4.38	.996	4.54	.918	4.41	.965	4.42	
Management												
Social Activity	4.43	.967	4.47	.903	4.4	.944	4.44	.943	4.36	1.013	4.42	

References: Chik, H (2020) Survey data, unpublished PhD thesis, Kuala Lumpur: Universiti Malaya

Table 6. Pearson Correlation Analysis of the Relationships Between Manual Needs and Caregivers

	Pearson Correlation (<i>r</i>)	Sig. (2-tailed) (<i>p</i>)	Significant
Patients	0.182	0.008	S
Family and Carers	0.205	0.003	S
Community (Friends)	0.238	0.001	S
Health Care Providers	0.216	0.002	S
Religious Volunteers	0.221	0.001	S

References: Chik, H (2020) Survey data, unpublished PhD thesis, Kuala Lumpur: Universiti Malaya

Table 7. Pearson Correlation of the Elements to Be Included in The Manual

	Pearson Correlation (<i>r</i>)	Sig. (2-tailed) (<i>p</i>)	Significant
Faith in God	0.326	0.000	S

Spiritual and religious support	0.319	0.000	S
Emotional support	0.172	0.013	S
Traumatic management	0.187	0.007	S
Self-management	0.163	0.018	S
Daily routine	0.174	0.012	S
Social activities	0.192	0.005	S

References: Chik, H (2020) Survey data, unpublished PhD thesis, Kuala Lumpur: Universiti Malaya

Accepted manuscript