

## DEVELOPMENT OF PALLIATIVE CARE HOLISTIC MANUAL GUIDELINES BASED ON ISLAMIC PSYCHOSPIRITUALITY

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### Abstract

Palliative care is an approach that aims to improve the quality of life for patients and their families facing problems related to life-threatening illnesses. This article aims to study the expert consensus on the necessary elements that should form part of the manual guideline of care for palliative patients from an Islamic perspective. A discussion is outlined on the application of Islamic psychospiritual knowledge in building patient resilience to improve their quality of life. The methodology applied in this research was a combination of qualitative and quantitative approaches, utilising the design and development research (DDR) approach by Richey and Klein. Literature study was used to develop the Islamic Psychospiritual manual for holistic care. The research began with the first phase, known as need analysis, which involved administering a questionnaire to assess the need for this manual among patients and

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caregivers. The second phase involved manual development through expert discussion, and a set of questionnaires was subsequently administered to experts to test the usability of the manual for the third phase of DDR. The results of the study were analysed using the Fuzzy Delphi Method. The findings demonstrate that all items listed as elements of healthcare needs-namely, physical, psychological, spiritual, emotional, social, and logistical-are accepted and essential for improving patient endurance. The results of this study provide relevant information and guidelines in the manual for health service providers and parties involved in caregiving, aiming to optimise aspects of care for patients. In addition, the results of this study can provide information to non-governmental organisations in the provision of social volunteer services to help patients deal with the difficulties of health challenges. This study highlights the importance of holistic care in enhancing the quality of life for patients. The manual guidelines that have been developed can be used by all categories of caregivers to improve the quality of life. This manual was included with the guidelines highlighted by Islam regarding faith, worship, and akhlaq during times of pain and struggle to achieve well-being in life.

**Keywords:** holistic; manual guideline; Islamic psychospiritual; palliative; quality of life.

### **Khulasah**

Penjagaan paliatif ialah pendekatan untuk meningkatkan kualiti hidup pesakit dan keluarga mereka yang menghadapi masalah berkaitan penyakit yang mengancam nyawa. Makalah ini bertujuan mengkaji konsensus pakar mengenai elemen yang diperlukan dalam garis panduan manual penjagaan pesakit paliatif. Seterusnya perbincangan mengenai penerapan ilmu psikospiritual Islam dalam membina daya tahan pesakit untuk meningkatkan kualiti hidup mereka. Metodologi yang digunakan untuk menyelidiki ini adalah kualitatif dan kuantitatif,

menggunakan pendekatan reka bentuk dan Pembangunan manual (DDR) oleh Richey dan Klein. Kajian literatur telah digunakan untuk membangunkan manual penjagaan holistik. Kajian dimulakan dengan fasa pertama iaitu analisis keperluan menggunakan soal selidik yang menunjukkan terdapat keperluan terhadap pembangunan manual ini dalam kalangan pesakit dan penjaga. Kemudian fasa kedua ialah pembangunan manual melalui perbincangan pakar dan yang terakhir menggunakan set soal selidik dalam kalangan pakar digunakan untuk menguji kebolegunaan manual bagi kajian fasa ketiga DDR. Hasil kajian bagi fasa ketiga ini dianalisis menggunakan Kaedah Fuzzy Delphi. Dapatan kajian membuktikan semua item yang disenaraikan sebagai elemen keperluan penjagaan kesihatan iaitu keperluan fizikal, keperluan psikologi, keperluan spiritual, keperluan emosi, keperluan sosial dan keperluan logistik diterima dan penting untuk meningkatkan daya tahan pesakit. Hasil kajian ini menyumbang maklumat dan garis panduan manual kepada penyedia perkhidmatan kesihatan dan pihak yang terlibat dalam penjagaan bagi mengoptimumkan aspek penjagaan pesakit. Selain itu, hasil kajian ini memberi maklumat kepada badan bukan kerajaan dalam penyediaan perkhidmatan sukarelawan sosial untuk membantu pesakit menangani kesukaran cabaran kesihatan. Kajian ini memberi pendedahan dan penekanan terhadap kepentingan penjagaan holistik untuk membantu meningkatkan kualiti hidup pesakit. Garis panduan manual yang telah dibangunkan boleh digunakan oleh semua kategori penjaga bagi meningkatkan kualiti hidup. Manual ini disertakan dengan garis panduan yang telah diketengahkan oleh Islam tentang akidah, ibadah dan akhlak semasa menghadapi keperitan dan perjuangan untuk mendapatkan kesejahteraan hidup.

**Kata kunci:** holistik; garis panduan manual; psikospiritual Islam; paliatif; kualiti hidup.

## **Introduction**

Palliative Care is a medical speciality that not only provides care for the patient but also involves the patient's family and support system in their effective and compassionate care. Palliative care is a holistic approach that enhances the quality of life for patients and their families facing problems related to life-threatening diseases. This is achieved through the prevention and relief of suffering by early detection, complete assessment, and treatment of pain and related problems, including physical, psychosocial, and spiritual aspects. Patient and their family must be provided with holistic care to ensure their quality of life and well-being during their struggle with pain and life.

This study aims to identify guidelines that can be enshrined in a manual based on the principles of Islamic psychospirituality, thereby complementing healthcare efforts to build patient resilience within palliative care. This effort will address the unmet needs of patients and their families within an Islamic framework, aiming to be a 'best fit' rather than a generic approach.

## **Literature Review**

Given that people are now living longer, there is an increasing amount of research being conducted to improve palliative care. The application of palliative care is suitable for all situations, as the concept of care is specialised, thus making it easier for caregivers and the people closest to the patient. Palliative care is an approach that encompasses all aspects of life, including physical, spiritual, psychological, and social. Additionally, the economic aspect is also given due consideration, as it is crucial in ensuring individual

well-being.<sup>1</sup> Sawatzky et al.<sup>2</sup> and Natasha et al.<sup>3</sup> argue that the financial situation is a crucial element that affects the resourcing and effective functioning of palliative care. However, all types of care elements are dependent on the patient's needs and their situation.

The primary goal of palliative care is to ensure that patients receive a high quality of life, as assessed by their well-being.<sup>4</sup> However, not all applications in the treatment fully meet the desires and needs of the patients.<sup>5</sup> Emphasising the element of spirituality for patients has been found to have a beneficial effect in palliative care, as spirituality is often the foundation of life for individuals who adhere to their faith.<sup>6</sup>

Spirituality has long been discussed in Islam, as it is the foundation of a Muslim's life, as underlined by the Quran and affirmed by al-Ghazālī in his book *Iḥyā' 'Ulūm al-Dīn*, which states that humans essentially consist of two

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<sup>1</sup> Melissa D. Aldridge et al., "Education, Implementation, and Policy Barriers to Greater Integration of Palliative Care: A Literature Review," *Palliative Medicine* 30(3) (2015), 224–239, <https://doi.org/10.1177/0269216315606645>.

<sup>2</sup> Richard Sawatzky et al., "Conceptual Foundations of a Palliative Approach: A Knowledge Synthesis," *BMC Palliative Care* 15(1) (2016), 5, <https://doi.org/10.1186/s12904-016-0076-9>.

<sup>3</sup> Natasha Michael et al., "Introducing a Model Incorporating Early Integration of Specialist Palliative Care: A Qualitative Research Study of Staff's Perspectives," *Palliative Medicine* 30(3) (2016), 303–312, <https://doi.org/10.1177/0269216315598069>.

<sup>4</sup> Claudia Virdun et al., "Preferences of Patients with Palliative Care Needs and Their Families for Engagement with Service Improvement Work within the Hospital Setting: A Qualitative Study," *Palliative Medicine* (2022), 1129-1139, <https://doi.org/10.1177/02692163221100108>.

<sup>5</sup> Beverley McNamara et al., "Palliative Care for People with Schizophrenia: A Qualitative Study of an under-Served Group in Need," *BMC Palliative Care* 17(1) (2018), 1-11, <https://doi.org/10.1186/s12904-018-0309-1>.

<sup>6</sup> Laurence Lephred, "Spirituality: Everyone Has It, but What Is It?," *International Journal of Nursing Practice* 21(5) (2015), 566–574, <https://doi.org/10.1111/ijn.12285>.

elements: the physical and the spiritual.<sup>7</sup> In this sense, Spirituality could serve as an essential element that needs to be factored in for a balanced approach, along with physical care.

The Islamic psychospiritual approach through supplication (*du'ā'*), having a sense of hope (*rajā'*) brings change to the patient.<sup>8</sup> The Divine therapy approach,<sup>9</sup> which includes repentance (*tawbah*) and acceptance (*riḍā*) of one's situation as well as sustained recitation of the Quran, is seen to treat anxiety and depression, especially among patients and forms elements of therapy, which initiates the healing (*shifā'*) process. The emphasis on Islamic principles in increasing 'meaning' and 'purpose' in life has a significant impact on patients,<sup>10</sup> by providing them a sense of direction. Mental and spiritual anxiety are interrelated elements as they involve an individual's internal processes, including their brain or cognition and their heart or emotions. Depression is one of the disorders that can occur when an individual experiences death

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<sup>7</sup> Abū Hāmid Muḥammad ibn Muḥammad al-Ṭūsī al-Ghazālī, *Iḥyā' Ulūm al-Dīn* (Jeddah: Dār al-Minhāj, 2011), 1: 14.

<sup>8</sup> Faiz Khan, "An Islamic Appraisal of Minding the Gap: Psycho-Spiritual Dynamics in the Doctor-Patient Relationship," *Journal of Religious Ethics* 36(1) (2008), 77–96, <https://doi.org/10.1111/j.1467-9795.2008.00337.x>.

<sup>9</sup> Ali Ali Gobaili Saged et al., "The Effect of an Islamic-Based Intervention on Depression and Anxiety in Malaysia," *Journal of Religion and Health* 61(1) (2022), 79–92, <https://doi.org/10.1007/s10943-021-01484-3>; Che Zarrina Sa'ari, et al., "The Development of Islamic Psychospiritual Scale for Drug Addicts," *Afkar: Jurnal Akidah Dan Pemikiran Islam*, 22(2) (2020), 279–312. <https://doi.org/10.22452/afkar.vol22no2.8>

<sup>10</sup> G. Hussein Rassool, "The Crescent and Islam: Healing, Nursing and the Spiritual Dimension. Some Considerations towards an Understanding of the Islamic Perspectives on Caring," *Journal of Advanced Nursing* 32(6) (2000), 1476–1484, <https://doi.org/10.1046/j.1365-2648.2000.01614.x>.

anxiety.<sup>11</sup> In this regard, the quality of care needs to be improved by approaching it from a spiritual viewpoint for those with faith.<sup>12</sup>

Anandarajah and Hight found that 94 per cent of patients believe in the importance of spiritual well-being in managing physical health; for example, continuously getting angry or unnecessarily worrying can cause neurophysiological changes in the body. However, it has been reported in studies that 80 per cent of medical practitioners never or rarely discuss aspects of spirituality with patients.<sup>13</sup> Medical practitioners do not seem to emphasise the elements of spirituality in care, either due to the lack of knowledge and/or skills and the lack of time to focus on it.<sup>14</sup> The study reported that 64.7 per cent of medical practitioners had not received spiritual care

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<sup>11</sup> Irvin D. Yalom, *Staring at The Sun: Overcoming the Dread of Death* (London: Hachette Digital, 2008), 7, [https://books.google.com.my/books?id=kju-nt8dL6kC&pg=PP9&dq=staring+at+the+sun&hl=ms&newbks=1&n-ewbks\\_redir=0&sa=X&ved=2ahUKEwj7sPvmk6SLAxWdSWwGHXRKDJUQ6AF6BAgLEAM#v=snippet&q=death anxiety&f=false](https://books.google.com.my/books?id=kju-nt8dL6kC&pg=PP9&dq=staring+at+the+sun&hl=ms&newbks=1&n-ewbks_redir=0&sa=X&ved=2ahUKEwj7sPvmk6SLAxWdSWwGHXRKDJUQ6AF6BAgLEAM#v=snippet&q=death anxiety&f=false).

<sup>12</sup> J. Irene Harris et al., "Spiritual/Religious Distress Associated with Pain Catastrophizing and Interference in Veterans with Chronic Pain," *Pain Medicine (United States)* 19(4) (2018), 757–763, <https://doi.org/10.1093/pm/pnx225>; David Hui et al., "The Frequency and Correlates of Spiritual Distress among Patients with Advanced Cancer Admitted to an Acute Palliative Care Unit," *The American Journal of Hospice & Palliative Care* 28(4) (2011): 264–270, <https://doi.org/10.1177/1049909110385917>.

<sup>13</sup> Gowri Anandarajah & Ellen Hight, "Spirituality and Medical Practice: Using the HOPE Questions as a Practical Tool for Spiritual Assessment," *American Family Physician* 63(1) (2001), 81–88, [https://doi.org/10.1016/S1443-8461\(01\)80044-7](https://doi.org/10.1016/S1443-8461(01)80044-7).

<sup>14</sup> Susan Ronaldson et al., "Spirituality and Spiritual Caring: Nurses' Perspectives and Practice in Palliative and Acute Care Environments," *Journal of Clinical Nursing* 21(15–16) (2012), 2126–2135, <https://doi.org/10.1111/j.1365-2702.2012.04180.x>; Anandarajah & Hight, "Spirituality and Medical Practice," 81–88.

training; however, 82.4 per cent expressed interest in participating in such training.<sup>15</sup>

The importance of spiritual approaches in care is to ensure that patients and their families achieve spiritual well-being. Spiritual well-being is reported to be positively correlated with patients' well-being and negatively correlated with symptoms of depression, pain, end-of-life despair, and hopelessness.<sup>16</sup> One of the most significant factors influencing a patient's quality of life toward the end of their life is their spiritual well-being.<sup>17</sup> The spiritual condition can deteriorate if the spiritual component is not built and carefully maintained. In fact, spirituality is something that needs to be continually renewed. If the spiritual condition continues to deteriorate, the nature of anxiety (*al-halū'*)<sup>18</sup> will occur and cause spiritual distress, that is, a spiritual condition that cannot be fulfilled, thus causing other elements also to be disturbed.<sup>19</sup>

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<sup>15</sup> Azam Shirinabadi Farahani et al., "Evaluation of Health-Care Providers' Perception of Spiritual Care and the Obstacles to Its Implementation," *Asia-Pacific Journal of Oncology Nursing* 6(2) (2019), 122–129, <https://doi.org/10.4103/apjon.apjon-69-18>.

<sup>16</sup> David Hui et al., "The Frequency and Correlates of Spiritual Distress," 264.

<sup>17</sup> Jingyi Chen et al., "The Effects of Spiritual Care on Quality of Life and Spiritual Well-Being among Patients with Terminal Illness: A Systematic Review," *Palliative Medicine* (2018), 1168, <https://doi.org/10.1177/0269216318772267>.

<sup>18</sup> Che Zarrina Sa'ari, "Penyakit Gelisah (*Anxiety / Al-Halu'*) dalam Masyarakat Islam dan Penyelesaiannya Menurut Psiko-Spiritual Islam," *Jurnal Usuluddin* 14 (2001), 1–22; Sharifah Basirah Syed Mohsin et al., "*Muḥāsabah al-Nafs (Self-Reflection)* dalam Menangani Keresahan Spiritual (*Spiritual Distress*)," *Jurnal Usuluddin* 50(1) (2022), 43–72, <https://doi.org/10.22452/usuluddin.vol50no1.3>.

<sup>19</sup> Hasimah Chik, "Punca Utama Keresahan Spiritual dalam Penjagaan Paliatif Menurut Perspektif Psikologi Agama," Unpublished Master of Islamic Studies Dissertation (Kuala Lumpur: Universiti Malaya, 2018), 17.



This condition of lack of spiritual groundedness can be identified when an individual expresses suffering, frequent crying, anxiety, alienation, lack of concern for the family, asking for the meaning in life, fear, identity crisis, lack of calmness, insomnia, inability to express creativity and others.<sup>20</sup> The family members and people around the patient are also affected by the suffering and hardship experienced by the patient, or may face the situation of the death of a loved family member. The period of bereavement can be one of intense suffering and is associated with an increased risk of developing physiological and psychological problems. They may experience more physical symptoms, such as pain, as well as higher rates of disease and disability than non-bereaved individuals. Physiological and behavioural reactions to grief and loss include fatigue, loss of appetite, sleep disturbances and agitation. Individuals can also experience various psychological reactions, such as suicidal thoughts, anxiety, depression, guilt and anger.<sup>21</sup>

The situation of a patient's condition includes physical, psychological, spiritual and social aspects, which could be worse if an individual patient or an individual around the patient questions the fate of Allah SWT on him in the process of going through the test of pain and death. In this situation, the application of Islamic psychospiritual elements and therapy is crucial to ensure that the individual is in a state of calm or revelling in spiritual well-being, which may provide a better understanding of the physical, psychological, and social aspects. Islam outlines various ways and methods to solve problems based on the

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<sup>20</sup> Teresa Velosa, Sílvia Caldeira & Manuel Luís Capelas, "Depression and Spiritual Distress in Adult Palliative Patients: A Cross-Sectional Study," *Religions* 8(8) (2017), 1-18, <https://doi.org/10.3390/rel8080156>.

<sup>21</sup> Amy Waller et al., "Assisting the Bereaved: A Systematic Review of the Evidence for Grief Counselling," *Palliative Medicine* 30(2) (2016), 132-148, <https://doi.org/10.1177/0269216315588728>.

principles of Sufism or Islamic psychospiritual knowledge, based on the selected verses from the Quran, such as in surah al-Baqarah, verse 45, about seeking help through patience and prayer and the Prophetic Sunnah, for *du'ā'* in a way seeking refuge from sadness and worry.<sup>22</sup>

Contemporary progress in medicine is centred on the discussion of holistic care, also known as the biopsychosocial-spiritual model.<sup>23</sup> Rania Awaad, clinical professor of psychiatry, applies the biopsychosocial-spiritual concept within the Islamic view, including depression and anxiety from a classical Islamic viewpoint.<sup>24</sup> The discussion in this section will focus on the study of care items in four important components based on elements in palliative care, which are physical, psychological, spiritual and social. These four elements encompass all the needs in the daily affairs of individuals, including patients and caregivers, in accordance with Islamic requirements.

### **a. Physical Aspect**

For the physical, it is a very important component of the body that must be taken care of.<sup>25</sup> The spiritual: *al-rūḥ* (soul) and *al-nafs* (self-breath) are embedded within the physical existence during life in this world. The position of

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<sup>22</sup> Che Zarrina Sa'ari & Joni Tamkin Borhan, "Relationship between Sufism and Islamic Psychospirituality," in *Horizons of Spiritual Psychology*, eds. Akbar Husin et al. New Delhi: Global Vision Publishing House, 2008, 179.

<sup>23</sup> Daniel P. Sulmasy, "A Biopsychosocial-Spiritual Model for the Care of Patients at the End of Life," *Gerontologist* 42(Special Issue 3) (2002), 24–33, [https://doi.org/10.1093/geront/42.suppl\\_3.24](https://doi.org/10.1093/geront/42.suppl_3.24).

<sup>24</sup> Rania Awaad, Danah Elsayed, Sara Ali, & Aneeqa Abid, "Islamic Psychology," in *Applying Islamic Principles to Clinical Mental Health Care: Introducing Traditional Islamically Integrated Psychotherapy* (New York: Routledge, 2020), 68.

<sup>25</sup> Sonya S. Lowe et al., "Physical Activity Interests and Preferences in Palliative Cancer Patients," *Supportive Care in Cancer* 18(11) (2010), 1469–1475, <https://doi.org/10.1007/s00520-009-0770-8>.

the physical component in Islamic psychospirituality is very valuable. The Quran mentions the physical processes of the human body, including the purification of the body to achieve spiritual growth.<sup>26</sup> The human physicality cannot be separated from the spiritual, which are two different elements that grow along with the passage of time until the end of life. The health and strength of the body reflect the heart of a steadfast Muslim.<sup>27</sup> The hadith below shows that the Prophet said that your body has rights over you.

قَالَ رَسُولُ اللَّهِ صَلَّى اللَّهُ عَلَيْهِ وَسَلَّمَ: "يَا عَبْدَ اللَّهِ أَلَمْ أُحْبِرَ أَنَّكَ تَصُومُ النَّهَارَ وَتَقُومُ اللَّيْلَ". قُلْتُ بَلَى يَا رَسُولَ اللَّهِ. قَالَ "فَلَا تَفْعَلْ، صُمْ وَأَفْطِرْ، وَقُمْ وَتَمَّ، فَإِنَّ لِحَسَدِكَ عَلَيْكَ حَقًّا، وَإِنَّ لِعَيْنِكَ عَلَيْكَ حَقًّا، وَإِنَّ لِرِوَجِكَ عَلَيْكَ حَقًّا".

Translation: Allah's Messenger (ﷺ) said, "O 'Abd Allah! Have I not been formed that you fast all the day and stand in prayer all night?" I said, "Yes, O Allah's Messenger (ﷺ)!" He said, "Do not do that! Observe the fast sometimes and also leave them (the fast) at other times; stand up for the prayer at night and also sleep at night. Your body has a right over you, your eyes have a right over you and your wife has a right over you."<sup>28</sup>

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<sup>26</sup> 'Uthmān Najātī, *al-Hadīth al-Nabawī wa 'Ilm al-Nafs* (al-Qāhirah: Dār al-Shurūq, 2005), 47.

<sup>27</sup> Muhammad al-Mahdi Jenkins & Abdul Aziz Azimullah, *Positive Islamic Psychology* (Selangor: Excellent Ummah Development Association, 2016), 56.

<sup>28</sup> Al-Bukhārī, *Ṣaḥīḥ al-Bukhārī* 5199, "Bāb: Li-Zawjika 'Alayka Ḥaqq," Kitāb no. 67, Ḥadīth: 133. Sunnah.com, <https://sunnah.com/bukhari/67>, accessed 21 February 2023.

There are several items in physical care, among which is personal hygiene care, also known as *ṭahārah* (طهارة). *Ṭahārah* is a form of hygiene care that encompasses principles related to the use of water, purification, and the nature of impurity, all within the framework of Islamic jurisprudence. All matters related to cleanliness are outlined in the Quran and the hadith of the Prophet SAW, which underscores its importance in this matter.<sup>29</sup> Al-Ghazali, in the book *Ihyā' 'Ulūm al-Dīn*, devotes a chapter specifically to demonstrating the importance of the element of hygiene in Islam.<sup>30</sup> Kathleen Galek et al.<sup>31</sup> corroborate this from a nursing perspective on the importance of maintaining cleanliness.

In addition, the physical component has an important aspect: a healthy and balanced diet, which caters to the physiological and spiritual needs that drive the physical body. There is also an understanding of the use of medicine to enhance the bodily functions from the perspective of what is permissible, that is *ḥalāl*, and what is not, that is, *ḥarām* substances.<sup>32</sup> A healthy and balanced diet is also highly recommended to ensure the patient's body condition remains stable by adhering to the diet recommended by experts.<sup>33</sup> Even if the patient suffers from a disease that is

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<sup>29</sup> Mohammad Zafir al-Shahri & Abdullah Al-Khenaizan, "Palliative Care for Muslim Patients," *The Journal of Supportive Oncology* 3(6) (2005), 432 – 436.

<sup>30</sup> Al-Ghazālī, *Ihyā' 'Ulūm al-Dīn Ihya'*, 1: 461.

<sup>31</sup> Kathleen Galek et al., "Assessing a Patient's Spiritual Needs: A Comprehensive Instrument.," *Holistic Nursing Practice* 19(2) (2005), 62–69.

<sup>32</sup> Muhammad Mustaqim et al., "The Use of Forbidden Materials in Medicinal Products: An Islamic Perspective," *Middle-East Journal of Scientific Research* 13 (2013), 5–10, <https://doi.org/10.5829/idosi.mejsr.2013.16.s.10022>.

<sup>33</sup> Paul S. Mueller, David J. Plevak & Teresa A. Rummans, "Religious Involvement, Spirituality, and Medicine: Implications for Clinical

difficult to treat, with appropriate nutritional control, it can help the patient live a better quality of life and improve their overall well-being, without being affected by the effects of uncontrolled food intake.<sup>34</sup> This is enhanced by the daily lifestyle or routine of an individual's life, which is emphasised in Islam. A World Health Organization (WHO) research study underlines the importance of an individual's lifestyle, suggesting that it can serve as an immunisation within themselves, where their spiritual beliefs can positively influence their lifestyle.<sup>35</sup>

## **b. Psychological Aspect**

The psychological aspects are important to ensure the individual's cognitive and general mental condition is stable. Islamic psychology is known to treat anxiety and illness involving psychological and spiritual components in humans.<sup>36</sup> One of the aims of psychology is to help people realise their potential to the maximum. Badri highlights that within the Islamic perspective, having an open-minded attitude to understand the meaning of the transcendent (Divine) would pave the way to try and respond to relevant

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Practice," *Mayo Clin Proc* 76 (2001), 1225–35, <https://doi.org/10.4065/76.12.1225>.

<sup>34</sup> Abū 'Alī al-Ḥusayn ibn 'Abd Allāh ibn al-Ḥasan ibn 'Alī ibn Sīnā al-Balkhī al-Bukhārī, *Al-Qānūn fī al-Ṭibb (al-Juz' al-Awwal)* (Bayrūt: Dār al-Kutub al-'Ilmiyyah, 1999), Fan 3, Ta'lim 2, 227-239.

<sup>35</sup> Neera Dhar, SK Chaturvedi & D. Nandan, "Spiritual Health, the Fourth Dimension: A Public Health Perspective," *WHO South-East Asia Journal of Public Health* 2(1) (2013): 3, <https://doi.org/10.4103/2224-3151.115826>.

<sup>36</sup> Abdallah Rothman & Adrian Coyle, "Toward a Framework for Islamic Psychology and Psychotherapy: An Islamic Model of the Soul," *Journal of Religion and Health* 57(5) (2018), 1731–1744, <https://doi.org/10.1007/s10943-018-0651-x>. Also refer Bagher Ghobari & Ali Akbar Haddadi Koohsar, "Reliance on God as a Core Construct of Islamic Psychology," *Procedia - Social and Behavioral Sciences* 30 (2011), 216–20, <https://doi.org/10.1016/j.sbspro.2011.10.043>.

questions regarding the call of the Divine and provide some insight about their existence.<sup>37</sup>

Among the essential items for psychological care is teaching patients to think rationally as a basis for making informed decisions and providing relevant methods for regulating and managing stressful situations. This exemplifies the treatment process, where various methods and protocols are followed to lay a basis for informed decisions and actions from the patient's and their family's viewpoint.<sup>38</sup> In addition, psychology can be further developed by learning medicine combined with greater insights into spiritual matters.<sup>39</sup> Knowledge- and evidence-based learning are important approaches that enable individuals to transition from a negative to a positive state. In the context of treatment, knowledge about the disease and various treatment methods is crucial for both the patient and their family.<sup>40</sup>

Within the Islamic perspective, the psychological nature of humans necessitates specific discussions regarding the diversity of emotions generated by events in human life, which are an integral part of life and cannot be

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<sup>37</sup> Malik Badri, *Contemplation: An Islamic Psychospiritual Study* (London: IIIT London Office, 2018), 67.

<sup>38</sup> Rachel McCauley et al., "Mutual Support between Patients and Family Caregivers in Palliative Care: A Systematic Review and Narrative Synthesis," *Palliative Medicine* 35(5) (2021), 875-885. <https://doi.org/10.1177/0269216321999962>.

<sup>39</sup> Malik Badri, *Contemplation: An Islamic Psychospiritual Study*, 81; Hasimah Chik, Che Zarrina Sa'ari & Loh Ee Chin, "Peranan Spiritual dalam Rawatan Paliatif," *AFKAR: Jurnal Akidah & Pemikiran Islam* 19(2) (2017), 107-42.

<sup>40</sup> Amanda L. Roze des Ordonns et al., "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 (2015), 38, <https://doi.org/10.1186/s12904-015-0035-x>.

viewed separately.<sup>41</sup> This is linked to the psychological process of managing past experiences or events that cause trauma, which disturbs the individual's well-being.<sup>42</sup>

### c. Spiritual Aspect

One of the crucial aspects that needs to be taken into account is the patient's spiritual orientation, specifically whether they hold a religious or spiritual belief. This includes the religious aspect, which is one of the central aspects of individuals with faith,<sup>43</sup> especially for Muslims.<sup>44</sup> From a religious aspect, the thing that is emphasised is the level of faith,<sup>45</sup> which includes belief in God, as well as forgiveness and mercy from God. This point aligns with the research of Silbermann et al.<sup>46</sup> and Villagomez<sup>47</sup>, where religious practice is a crucial element of the religious faith.<sup>48</sup>

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<sup>41</sup> Sa'īd Hawwā', *al-Mustakhlaf fī Tazkiyah al-Anfus* (Riyād: Dār al-Salām, 1988), 231.

<sup>42</sup> Wan Hilmi Wan Abdullah & Hidayah Zaki, "Gejala Kemurungan: Kaedah Rawatan Melalui Pengubatan *al-Tibb al-Nabawiy*," *Jurnal Islam dan Masyarakat Kontemporari* 21(3) (2020), 215–234, <https://doi.org/10.37231/jimk.2020.21.3.509>.

<sup>43</sup> Heather S. L. Jim et al., "Religion, Spirituality, and Physical Health in Cancer Patients: A Meta-Analysis," *Cancer* 121(21) (2015), 3760–3768, <https://doi.org/10.1002/cncr.29353>.

<sup>44</sup> Che Zarrina Sa'ari et al., "Analisis Keperluan Pembangunan Manual Psikospiritual Islam Dalam Penjagaan Paliatif," in *E-Prosidang Seminar Antarabangsa Islam Dan Sains 2021* (Nilai: Universiti Sains Islam Malaysia, 2021), 143–54, <http://library1.nida.ac.th/termpaper6/sd/2554/19755.pdf>.

<sup>45</sup> Al-Ghazālī, *Ihyā' 'Ulūm al-Dīn*, 1: 331.

<sup>46</sup> M. Silbermann et al., "Palliative Cancer Care in Middle Eastern Countries: Accomplishments and Challenges," *Annals of Oncology* 23 SUPPL.3 (2012), 15–28, <https://doi.org/10.1093/annonc/mds084>.

<sup>47</sup> Liwliwa R. Villagomez, "Spiritual Distress in Adult Cancer Patients: Toward Conceptual Clarity," *Holistic Nursing Practice* (2005), 285–294.

<sup>48</sup> Nor Azah Abdul Aziz & Che Zarrina Saari, "Menangani Permasalahan Laman Web Pornografi: Antara Perisian Penapis, Penguatkuasaan

While the universal aspect of faith is generally discussed, what appears essential is the spirituality component relating to finding meaning in life<sup>49</sup> embellished by having hope in Allah.<sup>50</sup> This aspect is seen to depend on the level of religious beliefs of the individual patients and therefore could vary in the things that give them meaning in life. What seems evident is that those who hold fast to religion, where the meaning of life is interconnected to the hereafter, believe that there is a better life beyond the physical realm. In spiritual practice, one of the recommended Islamic supplications is for God to live the best in this world and the hereafter, as below:<sup>51</sup>

وَمِنْهُمْ مَنْ يَقُولُ رَبَّنَا آتِنَا فِي الدُّنْيَا حَسَنَةً وَفِي الْآخِرَةِ  
حَسَنَةً وَوَقِنَا عَذَابَ النَّارِ (٢٠١)

Yet there are others who say, "Our Lord! Grant us the good of this world and the Hereafter, and protect us from the torment of the Fire."

Surah al-Baqarah 2:201

#### d. Social Aspect

Social engagement is a central aspect in Islam, contributing to the happiness of human beings, which is an important component of care. The definition of social is everything related to society, underlined by interactions between

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Undang-Undang dan Amalan Spritual," *Journal of Islamic and Arabic Education* 3 (1) (2011), 29-46.

<sup>49</sup> Zahida Ilyas, Sarah Shahed & Safdar Hussain, "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 (2020), 2715-32, <https://doi.org/10.1007/s10943-019-00969-6>.

<sup>50</sup> Muhammad Rif'aat Razman & Salasiah Hanin Hamjah, "Dakwah dalam Dimensi Kerohanian Penjagaan Paliatif Menurut Pendekatan Badi' Al-Zaman Sa'id Al-Nursi," *Jurnal Al-Hikmah* 7(1) (2015), 33-47.

<sup>51</sup> Hasimah et al., "Peranan Spiritual Dalam Rawatan Paliatif," 107-142.



individuals, particularly as members of a group or a community - the 'Umma'.<sup>52</sup> Social welfare is an activity organised to improve social welfare through the provision of assistance to people in need in various aspects, such as family assistance, children, health, life, leisure, and social relations. Social well-being pays attention to individuals, groups, communities and population unions, including prevention, treatment and preservation.<sup>53</sup>

Thus, in the social component, one of the things that must be emphasised is the relationship and role of fellow human beings.<sup>54</sup> In this context, the role of everyone around the patient is crucial in helping them, as well as providing encouragement to live their daily lives. Additionally, it involves managing social activities that are suitable for the patient's abilities and capabilities,<sup>55</sup> including visiting the patient. Pilgrimage activities are strongly encouraged in Islam but must be conducted in a manner that complies with customs and takes into account the patient's condition.<sup>56</sup>

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<sup>52</sup> Entry: "Society", *APA Dictionary of Psychology*, American Psychological Association, 2024, <https://dictionary.apa.org/society>; Mior Muhammad Syahir Zahari & Ahmad Bazli Shafie, "Faham al-Sa'adah (Kebahagiaan) menurut Islam: Analisis Matan Akidah Terpilih: The Concept of al-Sa'adah (Happiness) in Islam: An Analysis on Selected Theological Texts," *Jurnal Usuluddin* 52(2) (2024), 35–62. <https://doi.org/10.22452/usuluddin.vol52no2.2>

<sup>53</sup> Abd Wahab Haris, "Kesejahteraan Sosial dan Pembangunan Komuniti: Pendekatan dan Indikator," in *Seminar Serantau Islam Dan Kesejahteraan Sejangat* (Brunei: Universiti Islam Sultan Sharif Ali Brunei Darussalam, 2010), 1–16.

<sup>54</sup> Hasimah et al., "Peranan Spiritual Dalam Rawatan Paliatif", 107-142; Ahmad Razak, Mustafa Kamal Mokhtar & Wan Sharazad Wan Sulaiman, "Terapi Spiritual Islami Suatu Model Penanggulangan Gangguan Depresi," *Jurnal Dakwah Tabligh* 14(1) (2013), 141–51.

<sup>55</sup> Jerome Sarris et al., "Lifestyle Medicine for Depression," *BMC Psychiatry* 14(107) (2014), 1-13, <https://doi.org/10.1186/1471-244X-14-107>.

<sup>56</sup> Othman Ab Rahman, "Pendekatan Rakan Sebaya Sebagai Media Berkesan dalam Pengurusan Warga Emas Muslim: Satu Kajian Kes

Another element that needs to be considered is the patient's socioeconomic status, as this affects the smooth operation of treatment and the patient's overall life conditions, ensuring financial constraints do not burden them.<sup>57</sup>

As a conclusion, physical, psychological, spiritual and social needs are very important to be given attention to the patient to enhance the quality of life of the patients and their families as well. All the needs discussed are highlighted and listed in the manual for patients and their families to refer to, optimising the quality of life and well-being. Then, we turn to the methodology of the study.

### **Methodology**

This research was approved by the Universiti Malaya Research Ethics Committee (UMREC) (UM.TNC2/UMREC\_1200). This study employed a mixed-methods approach, combining qualitative and quantitative methods. Qualitative methods were used to obtain information for the literature review on palliative care and manual development. Keywords were used as the main theme of the literature search. Among the key themes used for the literature review were palliative care, holistic, spiritual, psychological, physical, social, Islamic psychospiritual and resiliency (endurance). Later, the manual was developed based on a review of the literature and the data generated from the research. The intervention to be applied was based on the relevant Islamic frameworks. Treatment suggestions on ways to solve the issues relating to terminal ill patients experiencing various issues, whether physical, social, spiritual and psychological, were obtained from previous studies.<sup>58</sup>

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di Persatuan Warga Emas di Lembah Klang," *Journal of Fatwa Management and Research* (2018), 660–675.

<sup>57</sup> Natasha et al., "Introducing a Model," 303.

<sup>58</sup> Max Watson et al., *Oxford Handbook of Palliative Care Third Edition* (United Kingdom: Oxford University Press, 2019), 53, <https://doi.org/10.1111/j.1365-2354.2006.00696.x>; Richard B. L. Lim

Table 1 shows the construct of elements in the manual of holistic care.

Table 1: Construct of Elements in Manual of Holistic Care

No.	Items	Details	Items Code
1	Introduction	Explains the contents of the manual, the target user of the manual.	Intro
2	Patients	Explains about the condition of patients	User-1
3	Family	Explains about care and the individuals involved in care including patients, carers and the community.	User-2
4	Healthcare Providers		User-3
5	Spiritual Care Providers		User-4
6	Others (Volunteer and Society)		User-5
7	Shariah Principles in Health Care		Info-1
8	Definition of Islamic Psychospiritual	Explains about the concept of Islamic psychospiritual on healthcare	Info-2
9	Philosophy of Islamic Psychospiritual		Info-3
10	Objective of Islamic Psychospiritual		Info-4
11	Principle Islamic Psychospiritual		Info-5
12	Psychopathology based on Islamic Psychospiritual		Info-6
13	Palliative Care		Explains the concept of palliative care
14	Elements of Palliative Care in Islamic Psychospiritual	Explains the connection between palliative care and psychospiritual	Info-8

& Diana Katiman, ed., *Handbook of Palliative Medicine in Malaysia* (Selangor: Malaysian Hospice Council, 2015), 12.

15	Module 1. Unit 1: Definition of Psychology	Explains the concept of psychology health care, psychology disorder and the suitable intervention regarding the psychology care	Module-1.1
16	Module 1. Unit 2: Symptoms of Psychological Disorders		Module-1.2
17	Module 1. Unit 3: Intervention		Module-1.3
18	Module 2. Unit 1: Definition of Spiritual	Explains the concept of spiritual health care, spiritual disorder and the suitable intervention regarding the spiritual care	Module-2.1
19	Module 2. Unit 2: Symptoms of Spiritual Disorders		Module-2.2
20	Module 2. Unit 3: Intervention		Module-2.3
21	Module 3. Unit 1: Definition of Physical	Explains the concept of physical health care, physical disorder and the suitable intervention regarding the physical care	Module-3.1
22	Module 3. Unit 2: Symptoms of Physical Disorders		Module-3.2
23	Module 3. Unit 3: Intervention		Module-3.3
24	Module 4. Unit 1: Definition of Social	Explains the concept of social health care, social disorder and the suitable intervention regarding the social care	Module-4.1
25	Module 4. Unit 2: Symptoms of Social Disorders		Module-4.2
26	Module 4. Unit 3: Intervention		Module-4.3
27	Bibliography	The references	Ref

For the questionnaire of the overall manual, we used the code as Table 2 below:

Table 2: Elements Code for Usability of The Manual

No.	Elements	Elements Code
1	Items are built to be specific and focused.	U1
2	Items are suitable for users.	U2
3	Items are not biased towards certain responses.	U3

4	Items use positive sentences.	U4
5	Items use appropriate sentences.	U5
6	The terms used are understandable.	U6
7	The items are sufficient for the construction of a manual.	U7
8	Items are sufficient to achieve manual objectives.	U8
9	Items are complete to meet the needs of the subject.	U9
10	Overall the manual is applicable.	U10

For quantitative research, the questionnaire was constructed based on the manual that had been developed. This study utilised validated questionnaire instruments confirmed by experts. The questionnaire consisted of three parts, namely Part A, which contained questions on the demographics of the respondents, Part B, on the scale of the expert on the usability of the elements and the contents of the manual and Part C, which consisted of overall scale questions regarding the manual developed. The questionnaire in Parts B and C had seven Likert scales used: (1) Strongly Disagree; (2) Disagree; (3) Somewhat Disagree; (4) Uncertain; (5) Somewhat Agree; (6) Agree; and (7) Strongly Agree.

The required element items in the questionnaire were constructed based on a manual developed based on the literature review relating to improving patients' quality of life. There were four aspects of healthcare needs, including physical, psychological, spiritual and social, that were based on the concept of palliative care, aimed at improving the care of critically ill patients. Each section allowed for additional comments and suggestions from respondents. This study was conducted among 14 experts with diverse backgrounds, including palliative care, Islamic psychospiritual studies, psychology and counseling, Sufism and morality, as well as spirituality and health. The experts were also stakeholders who would utilise the manual in

their respective fields. The study was conducted from January 2023 to March 2023. All experts gave their informed consent.

Expert consensus is reached through the calculation of data from the questionnaire given to the experts to identify, evaluate and verify all the main components and the elements contained therein based on the three conditions of expert agreement, namely (1) threshold value ( $d$ ); (2) expert agreement percentage; and (3) fuzzy score value ( $A$ ). The uniqueness of the Fuzzy Delphi method is that expert agreement is reached using scientific measurement methods<sup>59</sup>. For the triangular Fuzzy Number, it consists of  $m_1$ ,  $m_2$ , and  $m_3$  values and it is represented in the form  $(m_1, m_2, m_3)$  where  $m_1$  represents the smallest value,  $m_2$  represents the most plausible value and  $m_3$  represents the maximum value. These three values in the triangular fuzzy number can be represented in Figure 1, which shows the mean triangular graph against the triangular value.

This Triangular Fuzzy Number is used to translate linguistic variables into Fuzzy values. Its use of fuzzy set theory, or fuzzy set numbers, in which every set has a value between 0 and 1, as shown in Table 3. Analysing triangular fuzzy number data is aimed at obtaining a threshold value (threshold- $d$ ), using the following formula:

$$d(m,n) = \sqrt{\frac{1}{3}[(m_1 - n_2)^2 + (m_2 - n_2)^2 + (m_3 - n_3)^2]}$$

A threshold value less than or equal to 0.2 indicates agreement among experts. This approach saves both time and cost when assessing every question on a questionnaire. The survey rounds are shortened, the item recovery rate is

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<sup>59</sup> Ramlan Mustapha & Ghazali Darusalam, *Aplikasi Kaedah Fuzzy Delphi dalam Penyelidikan Sains Sosial* (Kuala Lumpur: Penerbit Universiti Malaya, 2018), 13-14.

raised, and experts can voice their opinions without fear of ambiguity or bias. This enhances the completeness and consistency of the opinions expressed by the experts, facilitating a consensus without compromising their initial opinions or genuine responses to the questions.

Data analysis to obtain the percentage of expert agreement is based on the recommendations by Chu and Hwang<sup>60</sup> where they insist that the value of the percentage of expert agreement must be equal to or greater than 75%, if the opposite percentage is obtained, then the second round using the Delphi fuzzy technique should be done. The defuzzification process is a process to set the ranking for each variable and sub-variable. The purpose of this process is to help see the level of need for a variable and the required sub-variables. This ranking process will help produce data as needed, based on the consensus of experts who serve as respondents to the study. Three formulas can be used in the defuzzification process, as follows:

$$A_{\max} = 1/3 * (a_1 + a_m + a_2) \quad (1)$$

$$A_{\max} = 1/4 * (a_1 + 2a_m + a_2) \quad (2)$$

$$A_{\max} = 1/6 * (a_1 + 4a_m + a_2) \quad (3)$$

The interpretation of the findings of this study is divided into three parts. Part I presents the findings on the background and demographics of the experts involved. At the same time, Part II answers questions about the appropriateness in detail for each content element in the manual, and Part III answers questions about the appropriateness of the manual content in general.

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<sup>60</sup> Hui Chun Chu & Gwo Jen Hwang, "A Delphi-Based Approach to Developing Expert Systems with the Cooperation of Multiple Experts," *Expert Systems with Applications* 34(4) (2008), 2826–2840, <https://doi.org/10.1016/j.eswa.2007.05.034>.

## Findings

### Part A: Demographic Data of The Experts

The following is the demographic data of the experts involved in the study. The analysis of the findings of the expert demographic section involves several key items related to the study, namely gender, education level, experience and areas of expertise. The analysis of the demographic section's findings involves only frequency and percentage analysis. Table 4 below shows the demographics of the 14 experts involved. The backgrounds of experts are heterogeneous and diverse, with a variety of characteristics.

Table 3: Respondent Demographic Data

No.	Item	Details	Frequency	Percentage (%)
1	Gender	Male	7	50.00%
		Female	7	50.00%
		Total	14	100%
2	Education	Doctor of Philosophy	8	57.14%
		Master's degree	4	28.57%
		Others	2	14.29%
		Total	14	100%
3	Experience	5 years	2	14.29%
		6-10 years	1	7.14%
		11-15 years	3	21.43%
		16 years and above	8	57.14%
		Total	14	100%
4	Expertise	Islamic Psychospiritual and Sufism	2	14.29%
		Islamic Philosophy and Islamic Thought	2	14.29%



Psychology and Modul/manual Development	3	21.43%
Palliative Expert	3	21.43%
Spirituality and Health	2	14.29%
Shariah	2	14.29%
Total	14	100%

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Source: Survey Questionnaire, January 2023-Mac 2023

The number of experts is balanced between male and female experts, namely 7 (50%) male experts and 7 (50%) female experts. While the level of expert education was majority of higher education and the most (57.14%, n=8) is a Doctor of Philosophy degree holder, followed by a master's degree (28.57%, n=4) and two people have a specialist course certificate in the field. This is because the production of this manual is academic and scientific in nature, thus requiring the views and opinions of the experts involved.

From the point of view of experience, involvement in each field ranges from 5 years to 30 years of experience,<sup>61</sup> dominated by experts who have experience in the field of more than 16-30 years, which is a total of 8 people (57.14%). Next is the field of expertise, which is also balanced, encompassing all aspects of assessment in the manual, namely a priority on Islamic psychospirituality, Sufism, and morality, as well as health. The Shariah expert is to evaluate the elements of worship and the implementation of the manual in accordance with the user's needs and in accordance with Islamic teachings.

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<sup>61</sup> Muhamad Zulfadli Abdul Rahman et al., "Development of Spiritual Poverty Measurements of an Urban Population Based on the Concept of Purifying the Self (*Tazkiyah al-Nafs*)," *Social Indicators Research* 169(3) (2023), 943-972, <https://doi.org/10.1007/s11205-023-03188-5>.

### **Part B: Usability of Elements in the Manual**

In this section, the evaluation of the usability and appropriateness of the elements and content in the Islamic Psychospiritual-Based Holistic Palliative Care Manual is measured and evaluated based on the views and perceptions of the study participants, specifically, the experts involved. Table 5 details the data findings for the usability evaluation of elements in the manual using threshold evaluation (d), expert group agreement, fuzzy score (A) and evaluation status of expert consensus.

Table 4: The Usability Evaluation of Elements in The Manual

No.	Items / Elements Contents in the Manual	Triangular Fuzzy Numbers		Defuzzification Process				Experts Consensus	Rank
		Threshold value, $d$	Expert Consensus Percentage, %	m1	m2	m3	Fuzzy Score ( $A$ )		
1	Intro	0.118	92.9%	0.771	0.921	0.979	0.890	ACCEPTABLE	22
2	User-1	0.099	100.0%	0.743	0.907	0.986	0.879	ACCEPTABLE	24
3	User-2	0.094	92.86%	0.786	0.936	0.993	0.905	ACCEPTABLE	18
4	User-3	0.095	92.86%	0.800	0.943	0.993	0.912	ACCEPTABLE	13
5	User-4	0.070	100.00%	0.829	0.964	1.000	0.931	ACCEPTABLE	6
6	User-5	0.051	100.00%	0.857	0.979	1.000	0.945	ACCEPTABLE	1

7	Info-1	0.095	92.86%	0.800	0.943	0.993	0.912	ACCEPTABLE	13
8	Info-2	0.249	85.71%	0.686	0.843	0.921	0.817	ACCEPTABLE	27
9	Info-3	0.172	92.86%	0.757	0.900	0.957	0.871	ACCEPTABLE	25
10	Info-4	0.151	92.86%	0.786	0.921	0.964	0.890	ACCEPTABLE	22
11	Info-5	0.111	85.71%	0.814	0.943	0.986	0.914	ACCEPTABLE	12
12	Info-6	0.115	85.71%	0.800	0.936	0.986	0.907	ACCEPTABLE	16
13	Info-7	0.194	92.86%	0.743	0.886	0.950	0.860	ACCEPTABLE	26
14	Info-8	0.087	92.86%	0.829	0.957	0.993	0.926	ACCEPTABLE	7
15	Module-1.1	0.078	92.86%	0.843	0.964	0.993	0.933	ACCEPTABLE	2
16	Module-1.2	0.120	92.86%	0.786	0.929	0.979	0.898	ACCEPTABLE	21

17	Module-1.3	0.087	92.86%	0.829	0.957	0.993	0.926	ACCEPTABLE	7
18	Module-2.1	0.087	92.86%	0.829	0.957	0.993	0.926	ACCEPTABLE	7
19	Module-2.2	0.087	92.86%	0.829	0.957	0.993	0.926	ACCEPTABLE	7
20	Module-2.3	0.115	85.71%	0.800	0.936	0.986	0.907	ACCEPTABLE	16
21	Module-3.1	0.078	92.86%	0.843	0.964	0.993	0.933	ACCEPTABLE	2
22	Module-3.2	0.087	92.86%	0.829	0.957	0.993	0.926	ACCEPTABLE	7
23	Module-3.3	0.120	92.86%	0.800	0.936	0.979	0.905	ACCEPTABLE	18
24	Module-4.1	0.078	92.86%	0.843	0.964	0.993	0.933	ACCEPTABLE	2
25	Module-4.2	0.078	92.86%	0.843	0.964	0.993	0.933	ACCEPTABLE	2
26	Module-4.3	0.095	92.86%	0.800	0.943	0.993	0.912	ACCEPTABLE	13

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27	Ref	0.120	92.9%	0.800	0.936	0.979	0.905	ACCEPTABLE	18
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In Table 5 above, there is a threshold value, expert agreement percentage, fuzzy score and evaluation status showing that the elements in the manual are accepted and that they are suitable for use based on the agreement and views of the experts involved.

### Part C: Usability of the Manual

In this section, the evaluation of the overall applicability and appropriateness of the Islamic Psychospiritual-Based Holistic Palliative Care Manual is measured and evaluated based on the views and perceptions of the study participants, the experts involved. Table 6 below is the result of the threshold value ( $d$ ), which has been analysed as a result of the study in Part B.

Table 5. The Usability Evaluation of the Overall Manual

No.	Items / Elements	Triangular Fuzzy Numbers		Defuzzification Process			Experts Consensus	Rank	
		Threshold value, $d$	Expert Consensus Percentage, %	m1	m2	m3			Fuzzy Score (A)
1	U1	0.092	92.9%	0.814	0.950	0.993	0.919	ACCEPTABLE	1
2	U2	0.115	85.7%	0.800	0.936	0.986	0.907	ACCEPTABLE	8
3	U3	0.078	92.9%	0.843	0.964	0.993	0.933	ACCEPTABLE	3
4	U4	0.062	100.00%	0.843	0.971	1.000	0.938	ACCEPTABLE	2

5	U5	0.092	92.86%	0.814	0.950	0.993	0.919	ACCEPTABLE	6
6	U6	0.179	92.86%	0.700	0.864	0.950	0.838	ACCEPTABLE	10
7	U7	0.087	92.86%	0.829	0.957	0.993	0.926	ACCEPTABLE	5
8	U8	0.111	85.71%	0.814	0.943	0.986	0.914	ACCEPTABLE	7
9	U9	0.120	92.86%	0.800	0.936	0.979	0.905	ACCEPTABLE	9
10	U10	0.078	92.86%	0.843	0.964	0.993	0.933	ACCEPTABLE	3

In Table 6 above, the threshold value, expert consensus percentage, fuzzy score, and evaluation status show that the elements in the manual are acceptable, and the manual usability is approved.



## Discussion

### **i. The ultimate support and comfort for patients**

Family members, including spouses, children, siblings, relatives, and parents, are crucial individuals and support systems for patients receiving palliative care. They are the closest to the patient. When a patient is diagnosed with a serious or life-limiting illness, this diagnosis affects not only the patient individually, but it also affects the entire family mentally and emotionally.<sup>62</sup> Spouses, children and siblings were the best support system for the patients. Families can provide spiritual, emotional, and social support to patients during challenging times, helping them manage their pain, symptoms, and their own lives. Friends, neighbours, healthcare providers, and others are important individuals for patient support.<sup>63</sup> They are the users of the manual that has been developed.

Based on the results, all items were significant healthcare elements, consisting of multidisciplinary settings that encompassed physical, psychological, spiritual, and social aspects.<sup>64</sup> All the items were important in different situations and patient conditions. Physical needs were important in providing comfort, while social needs were crucial in making patients feel good about their

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<sup>62</sup> Amit Arya et al., "Pandemic Palliative Care: Beyond Ventilators and Saving Lives," *Cmaj* 192(15) (2020), E400–404, <https://doi.org/10.1503/cmaj.200465>.

<sup>63</sup> Anja Bieber et al., "Influences on the Access to and Use of Formal Community Care by People with Dementia and Their Informal Caregivers: A Scoping Review," *BMC Health Services Research* 19(1) (2019), 1–21, <https://doi.org/10.1186/s12913-018-3825-z>.

<sup>64</sup> Yousuf ElMokhallalati et al., "Identification of Patients with Potential Palliative Care Needs: A Systematic Review of Screening Tools in Primary Care," *Palliative Medicine* 34(8) (2020), 989–1005, <https://doi.org/10.1177/0269216320929552>; Benzi M. Kluger et al., "Defining Palliative Care Needs in Parkinson's Disease," *Movement Disorders Clinical Practice* 6(2) (2019): 125–131, <https://doi.org/10.1002/mdc3.12702>.

lives. Logistics were also necessary to ensure the treatment process ran smoothly. The spiritual element is the root of the patient's inner strength.<sup>65</sup> Emotional and mental needs are crucial for maintaining the quality of life and well-being of patients.<sup>66</sup>

All the elements were necessary to improve the quality of life and well-being of palliative care patients. The goal of holistic health care is the realisation that although patients and their families struggle with different challenges, which can be overcome with spiritual acceptance, calmness and embracing support for the patient's well-being. The emotions of palliative patients and caregivers also needed to be highlighted as they also underwent many challenges in carrying out their responsibilities in dealing with the patients physically, emotionally, spiritually and socially. The emotion formed an influential element throughout the treatment as patients experienced changes and complications in various phases during the treatment. One of the most important things to do when dealing with patients in critical condition is to show compassion, especially caregivers and medical professionals who are always by their side during the treatment. This is one approach to help ease the emotional struggles of patients.

## **ii. Techniques to Help Improve Patients' Quality of Life**

Therapy begins with forming a relationship and showing compassion to the patient. This technique is called compassionate presence.<sup>67</sup> This technique is a mandatory process to provide comfort to the patient, thus bringing peace and well-being to him. This technique also serves as

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<sup>65</sup> Chen et al., "The Effects of Spiritual Care," 1168.

<sup>66</sup> Watson et al., *Oxford Handbook of Palliative Care*, 63-68.

<sup>67</sup> Siri Andreassen Devik, Ingela Enmarker & Ove Hellzen, "Nurses' Experiences of Compassion When Giving Palliative Care at Home," *Nursing Ethics* 27(1) (2020), 194-205, <https://doi.org/10.1177/0969733019839218>.

a starting point for the next session, as well as establishing the patient's trust in the spiritual health service provider. Islam places a strong emphasis on maintaining relationships between individuals and fostering love among people. During the pandemic, patients faced additional challenges and had to improve their self-resilience through self-efficacy.

Within the Islamic framework, the techniques recommended for therapy sessions to increase patient endurance begin with *muḥāsabah al-nafs* (self-reflection), *ma'rifah al-nafs* (knowing oneself), *mujāhadah al-nafs* (self-effort), *riyāḍah al-nafs* (self-exercise) and *al-sa'adah* (gaining happiness) or quality of life. The beginning of *muḥāsabah al-nafs* is to comprehend oneself as a servant and that Allah always listens to the grieving and prayers of His servants and the *ma'rifah al-nafs* through the therapy of *rajā'* (hope), the patient places hope in Allah and has patience in facing the trial. Patients have the right to strive for their wishes and happiness in life. In addition, through the therapy of repentance (forgiveness), Allah forgives His servants and every test is to elevate their ranks. The patient has the right to seek and receive forgiveness from everyone so that he can attain peace by lightening their psychological burdens.<sup>68</sup>

To maintain self-resilience, *mujāhadah* (effort) and *riyāḍah* (exercising) techniques are crucial for developing persistence in practising religious practices, which ultimately enhances self-motivation.<sup>69</sup> Among the

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<sup>68</sup> Che Zarrina Sa'ari & Sharifah Basirah Syed Muhsin, "Cadangan Model Psikoterapi Remaja Islam Berasaskan Konsep *Tazkiyah al-Nafs*," *Jurnal Usuluddin* 36 (2012), 49–74; Che Zarrina Saari, et al. "Spiritual Growth Aspects among Caregivers of Children with Cancer." *Afkar: Jurnal Akidah Dan Pemikiran Islam*, 24(1) (2022), 311–342. <https://doi.org/10.22452/afkar.vol24no1.9>.

<sup>69</sup> Norhafizah Musa & Che Zarrina Sa'ari, "Pendekatan Psikoterapi Islam dalam Menguruskan Tekanan Pesakit Kronik," *Jurnal Usuluddin* 47(1) (2019), 1–34,

recommended practices is Quran therapy, which brings peace through listening to and reading the Quran. Next is *qiyām al-layl*, which means voluntary prayers at night or spending the night, or part of it, by doing worship such as prayer, reading the Quran and remembering Allah (*dhikr*).<sup>70</sup> *Qiyām al-layl* therapy can build the resilience of the soul by drawing oneself closer to Allah, thus training the self to be calm and patient.

In addition, ablution therapy helps maintain the cleanliness of the body parts, has a special effect on the nerves, and promotes a positive outlook. Meanwhile, the movement involved in praying itself has numerous benefits, as supported by scientific research.<sup>71</sup> *Ṣadaqah* therapy teaches the individual to cultivate gratitude for the gift of sustenance while also developing patience in the face of Allah's tests. Last is the therapy of *dhikr* (remembrance) and *du'ā'* (*supplication*). Various recitations of *dhikr* and *du'ā'* can be practised. Among the recommended *dhikr* that are encouraged to cultivate confidence and faith in Allah SWT when facing difficulties and pain<sup>72</sup> are *tahlīl*, *tasbīh*,

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<https://doi.org/10.22452/usuluddin.vol47no1.1>; Sharifah Basirah Syed Muhsin & Che Zarrina Sa'ari, *Kaedah Psikoterapi Islam Berasaskan Konsep Maqamat Abu Talib al-Makki* (Kuala Lumpur: Dewan Bahasa dan Pustaka, 2015), 60.

<sup>70</sup> Mohd. Suhardi Mat Jusoh, Shaik Abdullah Hassan Mydin & Jasni Sulong, "The Implementation of *Tarbiyyah* Program Based on the Hostel Student Development Module (MPMA): A Study at the Religious Secondary Schools (SMKA) in Penang," *International Journal of Academic Research in Business and Social Sciences* 8(8) (2018), 375–385, <https://doi.org/10.6007/ijarbss/v8-i8/4475>.

<sup>71</sup> Fatimah Ibrahim, *Solat Kebaikan dari Perspektif Sains* (Kuala Lumpur: Penerbit Universiti Malaya, 2008), 1-2.

<sup>72</sup> Syarifah Basirah & Che Zarrina, *Kaedah Psikoterapi Islam Berasaskan Konsep Maqamat*, 32; Mohd Syukri Zainal Abidin, Che Zarrina Sa'ari & Syed Mohammad Hilmi Syed Abdul Rahman, "Pendekatan Psikoterapi Islam Terhadap Kanak-Kanak Muslim Autistik: Pendekatan Psikoterapi Islam Terhadap Kanak-Kanak Muslim Autistik," *Akademika* 88(1) (2018), 65–73.

*tahmūd* and *takbīr*, *dhikr ism al-dhāt*,<sup>73</sup> or the remembrance of the name of Allah SWT the Glorious (*al-Asmā' al-Husnā*).<sup>74</sup>

*Tahlīl* (لَا إِلَهَ إِلَّا اللَّهُ) is the word of *shahadah* mean there is no God but Allah. Then *tasbīh* (سُبْحَانَ اللَّهِ) is the Glorious of Allah, praising Allah by saying *tahmūd* (الْحَمْدُ لِلَّهِ) and magnification of Allah by saying *takbīr* (اللَّهُ أَكْبَرُ), meaning Allah is the Most Great.<sup>75</sup> Systematic and consistent practices of *dhikr* can help the healing process, especially in mental and spiritual health.<sup>76</sup> Any *dhikr* or remembrance can be practised by the patients depending on their ability. Carers must encourage, guide and help them from time to time due to their weak condition.

## Conclusion

Palliative care aims to enhance the quality of life for patients, caregivers, and their families. However, much research is needed to conceptualise the actual and specific needs of patients and their families. In conclusion, spiritual, mental, emotional, psychosocial and logistical support needs for the patients and their caregivers with life-limiting illnesses should not be underestimated in the daily clinical practice of palliative and hospice care. Therefore, holistic care comprises elements that are crucial and mutually necessary to enhance the quality of life for patients and caregivers. This study provides a more holistic approach to working with patients and caregivers.

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<sup>73</sup> Al-Ghazālī, *Ihyā' 'Ulūm al-Dīn*, 351-354.

<sup>74</sup> Muhy al-Din Abu Zakaria Yahya bin Syaraf al-Nawawi, *al-Azkar*, ed. Ahmad 'Abd Allah Bajur (Cairo: al-Dar al-Misriyyah al-Lubnaniyah, 2007), 146. Mohd Syukri Zainal Abidin, "Psikoterapi Zikir dalam Meningkatkan Motivasi Kanak-Kanak Autistik." Unpublished PhD Thesis (Kuala Lumpur: Universiti Malaya, 2018) 273.

<sup>75</sup> Abu al-Hussain Muslim Ibn al-Hajjaj, *English Translation of Sahih Muslim*, trans. Nasiruddin al-Khattab & Abu Khaliyl, ed. Hafiz Abu Tahir Zubair 'Ali Za'i (Saudi Arabia: Darussalam International Publication, 1997), 533.

<sup>76</sup> Mohd Syukri et al., "Pendekatan Psikoterapi Islam," 67.

Appropriate guidelines are suggested for patients and caregivers, as they often require guidance and advice when faced with challenges in the palliative care setting. This type of support should come from all parties and support groups involved in playing their respective roles to create a positive impact on patients and their families. The diversity of expertise in caring for patients and dealing with their families is a factor that needs to be considered and expanded upon through further research and practice to achieve better quality of care and patient well-being. Future research is recommended to investigate emotional needs in cultural healthcare environments, which could have a significant impact on patients and their families.

Based on our review and testing of relevant elements with experts, we can conclude that the approach and manual based on the Islamic Psychospiritual perspective can be an effective model for treating patients with faith (*imān*), worship and *ihsan* (*akhlāq*) when facing the pain and its struggles. Islamic Psychospiritual can be proposed as an alternative in addressing mental-intellectual ('aql), emotional ('*atifah*), or moral behaviour (*akhlāq*), to achieve the well-being of patients in terms of psychological, spiritual, physical, and social aspects.

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