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SPIRITUAL DISTRESS AND SUPPORT NEEDS AMONG MUSLIM YOUNG ADULTS LIVING WITH CANCER: A QUALITATIVE STUDY

Ainul Mardiah[*], Deborah Lycett[**] and Andy Turner[***]

Abstract: In Indonesia, most research concentrates on helping adult cancer patients manage their biopsychosocial issues. It seldom examines the spiritual concerns and needs of Muslim young adults living with cancer from a comprehensive perspective. The objectives of this research are to 1) investigate the spiritual concerns of Muslim young adults with cancer from the viewpoints of healthcare providers and the young adults, and 2) identify the most effective ways to support their spiritual needs. The method employed was an online semi-structured interview with 30 participants (15 young people living with cancer and 15 healthcare providers). Data analysis employed reflexive thematic analysis. Three themes relating to spiritual concerns emerged from the analysis: death anxiety, feelings of hopelessness and helplessness regarding recovery, and the feedback loop of spiritual struggles and religious coping. Participants suggested developing a short-term online Islamic psycho-spiritual intervention.

Keywords: *Islamic spirituality*, *spiritual distress*, *young adult living with cancer*, *Muslim*

INTRODUCTION

When facing challenges such as cancer, patients tend to use religion and/or spirituality as a source of coping. A qualitative study shows that adult cancer patients in Sweden and Korea share similarities and differences in using religious/spiritual coping strategies.[1] Swedish cancer patients tend to feel more spiritual when connecting with nature and use prayer to relax, while Korean individuals living with cancer often pray to God or transcendent beings for healing.

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[1] Fereshteh Ahmadi et al., "Meaning-Making Coping Among Cancer Patients in Sweden and South Korea: A Comparative Perspective," *Journal of Religion and Health* 56, no. 5 (2017): 1806, https://doi.org/10.1007/s10943-017-0383-3.

Furthermore, different types of coping are used among religious populations such as Catholic and Muslim communities. The results of a cross-sectional study conducted on 416 Roman Catholic pilgrims with mental or physical health challenges showed that spiritual and religious practices, like pilgrimages to Lourdes, positively contributed to their health condition.[2] Meanwhile, Muslims employ other religious coping strategies. For example, Muslims living with cancer in Malaysia and Turkey consult spiritual leaders and use *nazr*, a solemn pledge to fulfil a specific action as a form of spiritual cleansing, while Iranian individuals living with cancer use *ziyarat*, an act of visiting the tombs or shrines of sacred figures to seek spiritual solace.[3]

Indonesia has a long history of believing in God through spiritual practices,[4] which affect the daily lives of Indonesian people. An ethnographic study of 48 Indonesians from three religious backgrounds (i.e., Islam, Catholicism, and Christianity) found that palliative care patients use religious rituals when dealing with their illness, such as reading sacred texts, engaging in prayer, and listening to religious music.[5] Similarly, a cross-sectional study conducted in West Sumatera revealed that religious activities are the primary spiritual needs for adult patients living with cancer, such as *sholat*—compulsory five times daily prayer. Meanwhile, inner peace and existential needs are the second and third-highest needs, respectively.[6] The majority of studies in Indonesian cancer patients is focused on assessing the physical and psychosocial needs of cancer patients.[7] However, limited studies have explored spiritual concerns and needs in Indonesia's Muslim young adults (YA) living with cancer.

YA, aged between 18 and 25, are in a transition period where they are expected to have more independent roles in life (e.g., financial and romantic relationships).[8] In terms of spiritual development, a YA is expected to be more independent in choosing their values and beliefs, free from group conformity, which is known as the individuative-reflective stage.[9] Contrary to Fowler's framework, a qualitative grounded study involving 14 YA (15-25) living with cancer

2 Jennifer Klimiuk and Kieran J. Moriarty, "The Lourdes Pilgrimage and the Impact on Pilgrim Quality of Life," *Journal of Religion and Health* 60, no. 6 (2021):3780, https://doi.org/10.1007/s10943-021-01398-0.

3 Fereshteh Ahmadi and Mohammad. Rabbani, "Religious Coping Methods among Cancer Patients in Three Islamic Countries: A Comparative Perspective," *International Journal of Social Science Studies* 7, no. 5 (2019): 79–80.

4 Retno Hanggarani Ninin, "Religious Self: The Multi-Construal Model of Indonesian Self," in *Research in the Social Scientific Study of Religion*, ed. Ralph W. Hood and Sariya Cheruvallil-Contractor, Research in the Social Scientific Study of Religion (Brill, 2020), 103, https://doi.org/10.1163/9789004416987_007.

5 Erna Rochmawati, Rick Wiechula, and Kate Cameron, "Centrality of Spirituality/Religion in the Culture of Palliative Care Service in Indonesia: An Ethnographic Study," *Nursing & Health Sciences* 20, no. 2 (2018): 234–35, https://doi.org/10.1111/nhs.12407.

6 Lenni Sastra et al., "Spiritual Needs and Influencing Factors of Indonesian Muslims with Cancer During Hospitalization," *Journal of Transcultural Nursing* 32, no. 3 (2020): 4-5, https://doi.org/10.1177/1043659620908926.

7 Fitri Annisa, Allenidekania, and Siti Chodidjah, "Do Adolescent Cancer Survivors Need Health Care and Psychosocial Services? An Indonesian Experience," *Enfermeria Clinica* 28, no. 1 (2018): 42.

8 Jeffrey J. Arnett, "A Longer Road to Adulthood," in *Emerging Adulthood: The Winding Roads from the Late Teens through the Twenties*, 2nd ed. (Oxford University Press, 2015), 7.

9 James W. Fowler, "Stage 4. Individuative-Reflective Faith," in *Stages of Faith: The Psychology of Human Development and the Quest for Meaning* (Harper Collins, 1981), 182–83.

in Turkey demonstrated that their spirituality relies on family and religious beliefs values.[10] This inconsistency highlights the importance of exploring the spiritual needs of YAs living with cancer. It is argued that spiritual needs in YAs are not only related to their cognitive maturity but also to their stage of spiritual development,[11] and depend on religious and cultural influences. The definition of spirituality is subjective and diverse, depending on one's viewpoint. Someone with a theistic background might define spirituality as something related to God or a deity. In contrast, a person from a non-religious background might define spirituality as a meaning-making process that is outside the framework of a religion.[12] The difference in defining spirituality might impact identifying and measuring spiritual stress,[13] and providing the spiritual support needed by patients.[14] Only a limited number of studies explore the spiritual care of YA Muslims living with cancer, particularly in the Indonesian Muslim population.[15] Thus, it is essential to explore spiritual distress and support for YA living with cancer from different viewpoints (e.g., healthcare providers and patients) to provide holistic and patient-centred care. Therefore, the objectives of this study are to: 1) explore YA cancer patients' spiritual and religious needs from the perspectives of healthcare providers (HCPs) and the patients, and 2) examine how spiritual and religious needs can be best supported through spiritual interventions. The two research questions for this study are: 1) What are the spiritual and religious needs of Indonesian Muslim YA living with cancer, according to patients' and HCPs' viewpoints? and 2) How can spiritual and religious needs be most effectively supported by an online spiritual-based intervention?

METHODS

Procedure and Recruitment

Due to the COVID-19 pandemic and to answer the research questions, this study combines three non-probability sampling techniques: purposive, convenience, and snowball. Participants were recruited through online cancer support communities and a hospital. After getting the Coventry University ethics approval (number P111862), the recruitment process was done by

10 Orhan Gürsu, Meltem Gürcan, and Sevcan Turan, "Rebuilding and Guiding the Self with Spirituality: A Grounded Theory of Experiences of Adolescents and Young Adults with Cancer," *Oncology Nursing Forum* 50, no. 4 (2023): 491–92, https://doi.org/10.1188/23.ONF.487-497.

11 A. Desrosiers, "Development of Religion and Spirituality across the Life Span," in *The Psychology of Religion and Spirituality for Clinicians: Using Research in your Practice*, ed. J. D. Aten, K. A. O'Grady, and E. L. Worthington (Taylor & Francis, 2011), 23–5.

12 Akram Sadat Sadat Hoseini et al., "A Concept Analysis of Spiritual Health," *Journal of Religion and Health* 58, no. 4 (2019): 1030, https://doi.org/10.1007/s10943-017-0522-x.

13 Karen E. Steinhauser et al., "State of the Science of Spirituality and Palliative Care Research Part I: Definitions, Measurement, and Outcomes," *Journal of Pain and Symptom Management* 54, no. 3 (2017): 433, https://doi.org/10.1016/j.jpainsymman.2017.07.028.

14 Debbie Selby et al., "Patient versus Health Care Provider Perspectives on Spirituality and Spiritual Care: The Potential to Miss the Moment," *Annals of Palliative Medicine* 6, no. 2 (2017): 143, https://doi.org/10.21037/apm.2016.12.03.

15 Ainul Mardiah, "Development and Feasibility Study of an Online Islamic Integrated Spiritual Self-Management Programme for Muslim Adolescents and Young Adults Living with Cancer" (PhD diss., Coventry University, 2024).

research assistants. The research assistants distributed the advertisement and arranged interview times. To verify the medical condition, the principal investigator (PI) relied on information from the hospital or participants. For the recruitment of HCPs, the PI distributed the advertisement through professional WhatsApp groups.

Online semi-structured interviews were conducted from March to June 2021. The interview schedule was approved by the supervisory team and a subject expert. Moreover, two HCPs did a readability test to the prompt questions. The interview prompts for YA living with cancer included introductory questions, core questions on spiritual matters, additional questions, and concluding questions. The opening, additional and concluding questions were drafted and discussed with the supervisory team, while questions related to spiritual needs and concerns were taken and adjusted from spiritual assessments.[16] The interview plan for this study was modified for Muslim patients, such as including words related to Islamic spirituality practices. Similarly, the HCP interview consisted of opening questions, core questions related to spiritual care, spiritual needs of cancer patients, and a concluding question. For questions related to spiritual care provided by HCPs, some were taken and modified from other questionnaires.[17] The reason for taking interview prompts from previous studies and contextualising them for Indonesian Muslim cancer patients was to ensure this research has scholarly grounding that has been adapted to the Indonesian Muslim culture.

When a prospective participant verbally agreed to be contacted, information related to this study was sent (i.e., participant information sheet and advertisement). After that, the participant completed the informed consent through Qualtrics—an online survey tool—and received the prompt questions. The participant was contacted via Teams at the agreed time. The interviews lasted from 40 to 90 minutes. Qualitative semi-structured interviews were conducted with 30 participants (15 Muslim YAs living with cancer and 15 HCPs—see tables 1 and 2). The inclusion criteria for patients were Muslim, aged 18-25 years, inpatient and/or off-treatment cancer patients with stage 2 or above, capable of giving informed consent to participate in the interview and speaking Bahasa Indonesia. The inclusion criteria for HCPs were Muslim health

16 Aaron Saguil and Karen Phelps, "The Spiritual Assessment," *American Family Physician* 86, no. 6 (2012): 548–49; Judith R. Ragsdale et al., "Identifying Religious and/or Spiritual Perspectives of Adolescents and Young Adults Receiving Blood and Marrow Transplants: A Prospective Qualitative Study," *Biology of Blood and Marrow Transplantation: Journal of the American Society for Blood and Marrow Transplantation* 20, no. 8 (2014): 1243, https://doi.org/10.1016/j.bbmt.2014.04.013; Karen Skalla and J. Patrick McCoy, "Spiritual Assessment of Patients with Cancer: The Moral Authority, Vocational, Aesthetic, Social, and Transcendent Model," *Oncology Nursing Forum* 33, no. 4 (2006): 748, https://doi.org/10.1188/06.ONF.745-751; Heather M. Tan, Annette Braunack-Mayer, and Justin Beilby, "The Impact of the Hospice Environment on Patient Spiritual Expression," *Oncology Nursing Forum* 32, no. 5 (2005): 1050, https://doi.org/10.1188/05.onf.1049-1055; W. L. Hathaway and J. Childers, "Assessment of Spiritual and Religious Issues in Clinical Child Psychology," in *Spiritual Intervention in Child and Adolescents Psychotherapy*, ed. W. L. Hathaway and Franklin (American Psychological Association, 2013), 41–46.

17 Iris Mamier and Elizabeth Johnston Taylor, "Psychometric Evaluation of the Nurse Spiritual Care Therapeutics Scale," *Western Journal of Nursing Research* 37, no. 5 (2015): 688, https://doi.org/10.1177/0193945914530191; René van Leeuwen et al., "The Validity and Reliability of an Instrument to Assess Nursing Competencies in Spiritual Care," *Journal of Clinical Nursing* 18, no. 20 (2009): 2867–69, https://doi.org/10.1111/j.1365-2702.2008.02594.x.

professionals with experience working with YAs living with cancer and speaking Bahasa Indonesia.

Table 1. Characteristics of interviewed YAs living cancer

Initial	Gender	Age	Highest education	Marital status	Cancer type & stadium	First diagnosed	Treatment status
P1	Male	21	Undergraduate student	Single	Lymphoma Hodgkin's/2	2019	Relapse and on treatment
P2	Female	25	Bachelor's degree in psychology	Single	Kidney/2	2015	Off-treatment (5 years cancer-free) and yearly check-up
P3	Male	25	Undergraduate	Single	Lymphoma Hodgkin's/3	2019	Off-treatment and regular check-up
P4	Female	20	High school	Single	Carcinoma Thyroid Papillary/2	2019	Off-treatment and regular check-up
P5	Female	20	Undergraduate (Active)	Single	Lymphoma Hodgkin's/2	2020	On-treatment and regular check-up
P6	Female	23	Unfinished high school	Single	Osteosarcoma/not available	2014	Off-treatment and regular check-up
P7	Female	25	Bachelor's degree in social science	Single	Lymphoma Hodgkin's/4	2013	Off-treatment (1 year cancer free) and regular check-up
P8	Male	25	Diploma in tourism	Single	Lymphoma Hodgkin's/2	2020	Off-treatment, regular check-up
P9	Male	21	Undergraduate (active)	Single	Lymphoma Hodgkin's/3	2020	On-treatment and regular check up
P10	Female	24	High school	Married	Breast/3C	2020	On-treatment and regular check up
P11	Female	20	High school	Single	Kidney/4	2018	On-treatment and regular check up
P12	Male	18	High school	Single	Bowel cancer/3-4	2021	On-treatment and regular check up
P13	Female	20	High school	Married	Lymphoma Hodgkin's/4	2020	On-treatment and regular check up
P14	Female	21	Undergraduate (active)	Single	Teratoma Maligna/ 2-3	2021	On-treatment and regular check up
P15	Male	18	Undergraduate (active)	Single	Lymphadenopathic/ 2	2020	On-treatment and regular check up

Table 2. Characteristics of the interviewed HCPs

Initial	Gender	Age	Profession	Work experience	Have spiritual care training?
HCP 1	Male	40	Consultant oncology surgeon	5 – 10 years	No
HCP 2	Female	31	General practitioner in emergency room	5 – 10 years	No
HCP 3	Male	35	Orthopedic resident physician	< 5 years	No
HCP 4	Male	38	Psychiatrist	> 10 years	Yes
HCP 5	Female	32	General practitioner in palliative care	5 – 10 years	Yes
HCP 6	Female	40	Palliative care nurse	< 5 years	Yes
HCP 7	Female	28	Muslim chaplain	5 – 10 years	Yes
HCP 8	Male	31	Palliative care nurse	5 – 10 years	No
HCP 9	Male	26	Palliative care nurse	5 – 10 years	No
HCP 10	Female	32	Palliative care nurse	5 – 10 years	No
HCP 11	Female	38	Psychiatrist	< 5 years	No
HCP 12	Female	27	Palliative care nurse	< 5 years	No
HCP 13	Female	39	Palliative care nurse	> 10 years	Yes
HCP 14	Female	26	Palliative care nurse	5- 10 years	Yes
HCP 15	Female	47	Psychologist	< 5 years	Yes

Data Analysis

The six steps of reflexive thematic analysis were used for data analysis: data familiarisation, generating codes, constructing, revising, defining themes, and report writing.[18] The first step is getting familiar with the data by transcribing all the interviews in the Indonesian language and translating them into English. After that, the PI re-read all the transcriptions. Second, the codes were generated by simultaneously using two orientations: orientation to theory (inductive and deductive) and focused on meaning (latent and semantic). Reason to use different types of coding is that PI cannot erase their knowledge from what they have been read, and the PI cannot remove their insider identity as a Muslim. This aligns with Saldana's argument that coding is an act of interpretation; data can be subjected to several codes, and the coding process could be influenced by the researcher's background, research paradigm, and personal interpretation.[19] At the beginning of coding, the PI used semantic coding, which involves ascribing explicit meaning to the code. Then, the PI employed deductive coding, where the coding was based on prior studies of spiritual challenges and the Islamic concept of spirituality, and PI also used inductive or open coding. Furthermore, the PI re-read and focused more on repetitive

[18] Virginia Braun et al., "Thematic Analysis," in *Handbook of Research Methods in Health Social Sciences*, ed. Pranee Liamputtong (Springer Singapore, 2019), 852–55. https://doi.org/10.1007/978-981-10-5251-4_103.

[19] J. Saldana, "An Introduction to Codes and Coding," in *The Coding Manual for Qualitative Researchers*, 2nd ed. (Sage, 2013), 4.

statements across the dataset and use latent coding, as the researcher was driven to understand the spiritual concerns of YA living with cancer. The coding process was not sequential but involves an iterative process.

The third step involves constructing themes, which the PI began developing by combining similar codes into initial themes based on meaning patterns across the datasets. Data from HCPs and patients were kept separate to identify individual patterns and trends. This process served as a form of triangulation. Afterwards, PI compared the initial findings from the HCPs and patients. Overall, the themes that emerged were consistent; however, there was variation in the amount of information provided by each group. The fourth step involved revising the themes after discussions with the supervisory team and subject experts. PI aimed to amend some themes to prevent conceptual overlap. The fifth step was defining themes by developing brief explanations of the scope of each. The final step was preparing the report. MAXQDA software, with student licence number 230931001, was used during data analysis. In reflexive thematic analysis, the concept of data saturation is regarded as incompatible with its value assumptions.[20] Therefore, saturation related to data, thematic or meaning was not reported.

Data Translation

The process of translating the interviews from Indonesian to English used the researcher-translator approach without expertise in the field of linguistics or translation. The translation process happened in two stages, which were prior to data collection (i.e., translating the interview questions from English to Indonesian) and during data analysis (i.e. after themes were generated, extracts from the interviews were translated from Indonesian into English). As part of the data analysis process, an iterative translation process was used.[21] The first step was to translate the Bahasa Indonesian interview transcripts into English. Furthermore, difficult words, colloquialisms, and utterances were rechecked. Finally, the final theme emerged from the analysis and was interpreted from Bahasa Indonesia to English. The method of translating verbatim from Indonesian to English used the transposition and explication methods.[22] Transposition means the process of translating a word from its original language into a more appropriate language for the reader (e.g., "*ngambek sama Allah*" to "sulking towards God"). Another used method was explicitation, which refers to the process of enhancing clarity of implicit participant statements when they are translated into another language (e.g., "*Saya tahu Dia memberikan tes ini ke saya* – I know He gives me this test…" to "I know God gives me

[20] Virginia Braun and Victoria Clarke, "To Saturate or Not to Saturate? Questioning Data Saturation as a Useful Concept for Thematic Analysis and Sample-Size Rationales," *Qualitative Research in Sport, Exercise and Health* 13, no. 2 (2021): 201, https://doi.org/10.1080/2159676X.2019.1704846.

[21] Krishna Regmi, Jennie Naidoo, and Paul Pilkington, "Understanding the Processes of Translation and Transliteration in Qualitative Research," *International Journal of Qualitative Methods* 9, no. 1 (2010): 22, https://doi.org/10.1177/160940691000900103.

[22] Lorena Poblete, "Pretending they Speak French: The Disappearance of the Sociologist as Translator," *Social Science Information* 48, no. 4 (2009): 637–40, https://doi.org/10.1177/0539018409344784.

this test…"). We used member checking for data triangulation by synthesising the data.[23] The five steps in conducting member checking are preparing data for sharing, asking for re-consent about the member checking, sent the data, gathering responses, added data, and integrating findings.

INTERVIEW RESULT

After identifying themes across the dataset, three spiritual needs themes emerged from the perspectives of HCPs and YAs living with cancer: death anxiety, a tendency to develop negativity towards the possibility of recovery, and the feedback loop of spiritual struggles and religious coping. A summary of the themes is presented in table 3, with details provided in the following text.

Table 3. Summary of themes of spiritual/religious needs

Themes and sub-themes	YA	HCP
Themes 1: Death anxiety		
Sub-theme 1.1. Related to receiving consequences of sins in the Hereafter	✓	✓
Sub-theme 1.2. Related to lack of good deed to parents	✓	✓
Theme 2: Tendency to develop negativity toward the possibility of recovery		
Hopeless and helpless related to cancer and its treatment	✓	✓
Theme 3: The feedback loop of spiritual struggles and religious coping		
Sub-theme 3.1. Intrusive rumination about God's decree	✓	✓
Sub-theme 3.2. Reflective thinking in finding meaning	✓	✓

Theme 1: Death Anxiety

A significant number of participants expressed anxiety about the possibility of a shortened lifespan due to cancer. The majority of participants worry about life after death, which involves two main concerns: the potential consequences in the afterlife for one's misdeeds and insufficiency of filial obligations towards one's parents.

Subtheme 1.1: Death anxiety related to receiving consequences of sins in the Hereafter

Most participants expressed death anxieties. The source of anxiety in YAs is linked to past mistakes and sins; for example, not performing the five daily prayers. They worry that they might end up in Hell to compensate for their wrongdoings. This worldview is shaped by Islamic teachings.

> "I am afraid If I die, I often did not do five-times pray, so I am not ready to die. I am afraid because of all sins I might go to hell." (YA9)

[23] Linda Birt et al., "Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation?," *Qualitative Health Research* 26, no. 13 (2016): 1804–6, https://doi.org/10.1177/1049732316654870.

In line with the YAs' concerns, a few HCPs revealed that some YAs share their worries about death anxiety because they are not ready to die young. However, there is a slight difference regarding the source of death anxiety between adolescents and YAs. YAs are more concerned about not having enough good deeds when they meet God. In contrast, adolescents worry about being alone in the grave and leaving their parents behind.

> "They are not ready to leave this world as they still have lots of sins. They are not ready because they do not have good deeds to come back to God." (HCP15)

Subtheme 1.2. Death anxiety related to lack of good deeds to parents

The second source of death anxiety is the inability to fulfil filial responsibilities towards their parents. YAs often feel guilty because they cannot repay their parents' love, support, and kindness when they should have done so during adulthood. Health problems seem to contribute to a sense of being unable to please their parents. They want to bring happiness to their parents by taking care of them as they age.

> "I want to repay their kindness by caring for them when they get older." (YA11)

A few YAs stated they are afraid of death because they did not have enough time to attain God's command to perform filial responsibilities. Some participants mentioned they are modifying their behaviour in a positive manner to bring happiness to their parents and receive Divine blessings.

> "Because God's blessing lies in the blessing of parents. I see the result now; I do not need to do chemo for more than a year." (YA3)

Similar to the YAs' statements, a few HCPs mentioned that Muslim YA are concerned about not fulfilling their obligations to their parents and feeling guilty about it. However, the HCPs suggest that the YA's filial obligation concerns stem not only from Islamic teachings but also from developmental task issues. Due to cancer and its treatment effects, YAs might not be able to achieve autonomy and may have to depend on their parents most of the time.

> "They feel that they do not do anything yet to fulfil their filial responsibilities. They are supposed to be in a productive age, but they become a burden." (HCP11)

Despite the need to implement filial obligation, HCPs reported that YAS struggle to fulfil filial responsibilities because of family support dynamics. For example, parental distress caused by their children living with cancer could trigger negative emotions and pressure in the parent-YA relationship.

> "Even his mother also got scolded when she tried to remind her son to follow the rules from healthcare providers." (HCP13)

Theme 2: Tendency to develop negativity towards the possibility of recovery

Many YAs have little hope of positive outcomes from their treatment. YAs living with cancer often feel trapped and unable to escape their situation. Cancer has made them feel powerless to carry on with "normal" activities, such as continuing education and enjoying good

health. The sense of helplessness is heightened when the YAs compare their achievements with those of their healthy friends.

> "I assume that people diagnosed with cancer eventually will die because cancer survivors might not live longer than five years. I feel sad. I can't be as healthy as before, I see my friends already do an internship…When I open my Instagram, I saw my friends hanging out, while I am at home by myself." (YA1)

HCPs also report similar findings concerning the psychological state of YAs living with cancer. YAs with cancer often exhibit signs of hopelessness, helplessness, and worthlessness. This is evident through behaviours such as losing enthusiasm, becoming quieter, showing reluctance to undergo treatment, and expressing a desire to die. Despite support from HCPs, YAs tend to view their future more negatively compared to their healthy peers, mainly because they are significantly behind in reaching life milestones. Biopsychosocial changes, such as mood swings during adolescence, tend to worsen this condition.

> "If God grants their wishes, they feel like it is just a waste because they felt left behind by friends. So, they tend to lack of motivation and quiet, refuse to try to heal, and want to die." (HCP7)

Theme 3: The feedback loop of Divine struggles and religious coping

The third theme depicts the spiritual struggle between employing positive and negative religious coping strategies. Sometimes participants actively seek to find meaning in their experiences with cancer, while at other times they blame God for their illness. Some participants initially engaged in intrusive rumination at the onset of their illness, whereas later they had a greater tendency towards reflective thinking. Nonetheless, the pursuit of significance was not a linear process but resembled a loop pattern.

Subtheme 3.1. Intrusive rumination about God's decree

Participants tend to ruminate about God's fairness, followed by comparing themselves with others. Patients believe they try to be good Muslims, but they have a miserable life, while others who do not practice Islam seem to have a better life.

> "Many people are more disobedient towards God than me, but why do I get this cancer?" (YA1)

Some HCPs gave similar description about YAs struggling to understand the meaning behind being diagnosed with cancer. YAs pondered more in their efforts to comprehend their condition, as they are unable to identify spiritual or health factors that could explain their experience with cancer.

> "Why did God give me this illness? I feel I am a good person; I always try to keep up my religious activities. I have a healthy lifestyle." (HCP11)

Subtheme 3.2. Reflective thinking in finding meaning about the cancer experience

After a while, most participants, whether on- or off-treatment, engaged in reflective thinking to find meaning in cancer. Some YAs viewed cancer as God's way of reminding them to return to living according to God's guidance, such as being more grateful and performing the five daily prayers. Other patients saw cancer as a test or trial from God intended to cleanse them of sins, increase their patience, make them stronger, and encourage greater obedience. Some participants used religious activities to help them become more contemplative about their situation.

> "After I pray to God, I know that God gives me this test because I can get through this trial that other people might not. Maybe I wasn't grateful enough. I often missed five-time prayers. So, it seems God reminds me to live based on His way." (YA4)

Similarly, HCPs revealed that YAs have a different way of understanding and giving meaning to the cancer experience. Most YAs try to make sense of their situation as a test from God, a way to seek forgiveness for sins or mistakes, or a lesson learned. However, a small group of YAs living with cancer perceived it as a punishment from God.

> "Some patients think that the cancer is torment and punishment from God, some others think that cancer is a lesson learned." (HCP4)

It is interesting to note that YAs living with cancer experienced intrusive thoughts during the relapse phase, which might suggest they still require support to understand their situation.

> "Some relapse cancer patients told me why cancer come back, so they have to re-start the treatment, why God have no mercy on me, what are my sins?" (HCP14)

Lastly, some HCPs mentioned other types of YA spiritual struggles, namely *sholat*—daily five times prayer. When HCPs reminded YA about the *sholat*, some YA listened and practiced it, but others ignored the message. Some HCPs perceive *sholat* as an integral part of spirituality.

> "Young adults' spirituality is low because some of them do not do it [*sholat*]" (HCP14)

Key Themes for Recommendations related to Developing a Spiritual Intervention Module

YAs living with cancer and HCPs provided suggestions related to the development of spiritual intervention modules, including the deliverable platform, session frequency, session duration, facilitator, and content of the spiritual support (see Table 4).

Table 4. Summary of suggestions for the spiritual intervention module development

Spiritual based intervention	YA	HCP
Delivery platform	Prefer offline spiritual support but because of COVID-19, an online platform seems more feasible	Spiritual support should be delivered offline, but due to COVID-19 an online platform should be used
Frequency	Short term	Short term
Duration	Not more than an hour	Not more than an hour
Facilitator	Combination HCP and survivors	Combination HCP and survivors
Content	Motivation, counselling, and sharing sessions with other cancer patients	Religious activities and advice on finding meaning

Recommendation 1: Use an online platform due to COVID-19

Most participants preferred offline sessions because virtual ones are seen as insufficient for genuine interpersonal contact. Additionally, the technological infrastructure in Indonesia is not available in all provinces. However, because of COVID-19, many patients argued that an online platform would be practical, as it is better to have some human connection online than none.

"Because of COVID-19, it is better to have online support" (YA6)

"It is better to have an offline support group because the bonding could be formed. An online group is good as well because they could keep in touch particularly during this pandemic time" (HCP3)

Recommendation 2: Provide a short-term spiritual support program

Patients' responses varied regarding the frequency of spiritual support. Most suggested a short-term spiritual programme. This might be related to their activity schedules, such as chemotherapy timing and its effects or other commitments.

"Three to four intermittent sessions by adjusting with chemo schedule." (YA8)

"Minimum three sessions or until their needs are fulfilled." (HCP2)

Recommendation 3: Provide short duration sessions

Almost all patients suggested that each session should not last longer than an hour, as participants might become bored. They proposed having an interactive discussion with speakers after the online meeting. It was implied that patients need some direct online interaction with invited speakers.

"40 minutes for all speakers is enough. One speaker could have like 20 minutes to deliver their lectures. If it is too long, people might be bored." (YA14)

Consistent with patients, some HCPs suggested spiritual support lasting less than an hour. They highlighted the importance of making this activity optional rather than mandatory.

> "The activity should be less than an hour if it is possible only 30 minutes. The session should be flexible…if it is kind of compulsory; the patients might feel burden." (HCP11)

Recommendation 4: Have HCPs and other cancer survivors deliver the spiritual support

Regarding the person responsible for delivering the spiritual intervention, participants' responses varied. Most patients suggested the programme should be delivered by a combination of experts and survivors. The reason was that HCPs have knowledge and skills that could inform patients on how to manage and cope with their illness. The role of the Muslim chaplain was considered necessary to help patients learn about types of prayer to promote health and to ask Muslim chaplains to pray for patients' health. Additionally, survivors' presence could enhance patients' psychological confidence that they too can survive.

> "Maybe it is needed, calling the Muslim religious chaplain, pray together, pray for a patient, pray for me to get well soon." (YA1)

> "Spiritual intervention should be delivered by a Muslim chaplain, a psychologist, a doctor, a nurse. So, an integrative approach will be better because everyone has their understanding." (HCP5)

Recommendation 5: Carefully curate the content of spiritual support

The inclusion of motivation within the framework of spiritual assistance is widely endorsed by a significant proportion of patients. The type of spiritual support they require encompasses activities aimed at fostering a deeper connection with God, maintaining motivation through their treatment, and creating a sense of optimism in their ability to overcome cancer.

> "Activities that can get us closer to God, fun, motivating us things like that." (YA5)

> "Motivation for me to not be afraid of chemo and its effects." (YA9)

> "How to have a hope that I will be better…think about the future and not give up." (YA11)

> "Give us motivation saying that patients could go through this hardship." (YA6)

Some HCPS suggested the content of spiritual intervention relate to religious activities, such as supplication, Islamic mindfulness (*dhikr*), and reminders of the daily five prayers. The aim of strengthening religious activities for patients is to improve their quality of life, such as reducing pain.

> "In pain management, usually we give them pharmacology and non-pharmacology treatment such as *dhikr* – remembrance of God. Some relaxation activities include *dhikr*, listening to Qur'an recitation, or salutation to Prophet Muhammad PBUH. *Dhikr* – remembrance of God – could be pain management for patients." (HCP14)

Findings from Member Checking

The data synthesis was shared with participants living with cancer via Qualtrics, an online survey platform. Some of them consented and completed the member checking form for a

follow-up discussion. All participants agreed that the themes generated in this research resonate with their psycho-spiritual concerns. They also expressed willingness to discuss and receive psycho-spiritual support. Below are translated quotes from members who took part in the member checking:

> "In my opinion, activities like this should be implemented immediately in every hospital that treats cancer patients."

> "The programme will be implemented soon to support cancer patients' mental health, because cancer survivors now have a venue to share their experiences."

> "The findings cover what we feel as cancer patients."

DISCUSSION

This study explored the spiritual needs of YA Muslim living with cancer. The findings underlined several key themes of the psycho-spiritual needs of YAs living with cancer. In particular, it highlighted three major themes of the spiritual/religious needs of YA Muslim living with cancer in Indonesia: death anxiety, tendency to develop negativity towards the possibility of recovery, feedback loop of Divine struggles and religious coping. These findings further support the idea that Muslim society's view of mental health is shaped by religious values and cultural practices.[24]

Most participants in this study expressed concerns about their mortality after being diagnosed with cancer. This finding offers perspective on Muslim YAs' shared experiences with a broader body of literature examining death anxiety in cancer patients, regardless of religious background, such as YA living with cancer in Sweden[25] and USA.[26] The experience of death anxiety in YAs living with cancer can be attributed to the perceived threat to their existence as human beings, as theorised in terror management theory (TMT).[27] Unlike TMT, meaning managing theory (MMT) provides a broader concept about death anxiety.[28] MMT acknowledges the terror of death, but at the same time, emphasis is placed more on living a meaningful life. This process of making meaning can be achieved through understanding oneself, one's values, the purpose of life, and knowing how to create a happy life despite life's challenges. Unlike TMT and MMT, Islamic teachings discuss death and life after death beyond coping and meaning-making subjects. In Islam, death is one of the many points to reach eternal

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24 G. Hussein Rassool, "Cultural Competence in Counseling the Muslim Patient: Implications for Mental Health," *Archives of Psychiatric Nursing* 29, no. 5 (2015): 321–23, https://doi.org/10.1016/j.apnu.2015.05.009.

25 Stefan Nilsson, Ylva Hård Af Segerstad, and Maria Olsson, "Worrying About Death: An Initial Analysis of Young Adult Cancer Patients' Needs," *Journal of Adolescent and Young Adult Oncology* 10, no. 1 (2021): 107, https://doi.org/10.1089/jayao.2020.0033.

26 Fay J. Hlubocky et al., "Death Anxiety, Psychological Distress, and Quality of Life (QOL) in Adolescent and Young Adult (AYA) Cancer Patients with Hematologic Malignancies in Early Survivorship," *Journal of Clinical Oncology* 34, no. 15 supp (2016): 10073, https://doi.org/10.1200/JCO.2016.34.15_suppl.10073.

27 Jonathan Jong et al., "The Religious Correlates of Death Anxiety: A Systematic Review and Meta-Analysis," *Religion, Brain & Behavior* 8 (2018): 5–6, https://doi.org/10.1080/2153599X.2016.1238844.

28 P. T. P. Wong, "Meaning Management Theory and Death Acceptance," in *Existential and Spiritual Issues in Death Attitudes*, ed. G. T. Tomer and P. T. P. Wong (Lawrence Erlbaum Associate, 2008), 67–81.

life,[29] and belief in the afterlife is one of the pillars of Islamic faith.[30] Being aware of the Hereafter helps Muslims to be mindful of their thoughts, behaviours, and choices in line with Islamic teachings.[31] Furthermore, Said Nursi provides a straightforward logical explanation in his work, demonstrating the concept of death and resurrection in Islamic understanding through the cycle of a plant's death and life.[32] Even though a plant looks dead and decomposing, new life arises from it. Similar with a human being, when one has a difficult life, then death is seen as a form of liberation to the more eternal peaceful and comfortable life.[33] The present study identified two main sources of death anxiety among YAs living with cancer: feelings of guilt due to sins towards God and inability to fulfil filial obligations towards parents. This finding should be considered when designing an Islamic religious or spiritual intervention.

The second theme revealed that participants become less optimistic about their chances of recovery. This pessimism stems from feeling left behind when comparing their lives with those of healthy peers. This may be related to the developmental stage of young adulthood and its challenges when living with cancer, such as cognitive capacity to understand information,[34] and interrupted psychosocial development.[35] The current study identified additional characteristics of hopelessness and helplessness in YAs. These include feelings of uselessness, lack of motivation, refusal to continue treatment, and a desire for death. These findings support those found in previous literature, such as in YAs living with cancer in Zambia.[36] In the current study, information about YAs' tendency to despair and wish for death was collected from HCP interviews. It is conceivable that the YA participants refrained from disclosing their mental health condition due to stigma within the Muslim community, where psychological challenges are sometimes associated with weakening of faith.[37]

Lastly, participants experienced a feedback loop of Divine struggle and religious coping. This illustrates the dualistic state in which YAs find themselves, especially when facing conflicting circumstances. On one hand, they use religious coping mechanisms, such as prayer, to manage their difficult situation. On the other hand, they face moments of Divine conflict,

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29 Mohamed Elaskary and Eun K. Yun, "Death, Resurrection, and Shrine Visitations: An Islamic Perspective," *Religions* 8, no. 3 (2017): 2, https://doi.org/10.3390/rel8030034.

30 S. N. Saritoprak and H. Abu-Raiya, "Living the Good Life: An Islamic Perspective on Positive Psychology," in *Handbook of Positive Psychology, Religion, and Spirituality*, ed. E. B. Davis, E. L. Worthington, and S. A. Schnitker (Springer, 2023), 186.

31 Ibid.

32 Said Nursi, *The Letters*, trans. Şükran Vahide, Risale-i Nur Collection (Söz Basım Yayın, 2012), first letter, second question, https://www.erisale.com/index.jsp?locale=en#content.en.202.23.

33 Ibid.

34 Jacqueline Gilberto Grace et al., "Evaluating and Providing Quality Health Information for Adolescents and Young Adults with Cancer," *Pediatric Blood & Cancer* 66, no. 10 (2019): 16, https://doi.org/10.1002/pbc.27931.

35 Echo L. Warner et al., "Social Well-Being among Adolescents and Young Adults with Cancer: A Systematic Review," *Cancer* 122, no. 7 (2016): 1030, https://doi.org/10.1002/cncr.29866.

36 Sharleen Sibulwa, Tamara Chansa-Kabali, and Given Hapunda, "'Every Part of Me Has Changed'–Shared Lived Experiences of Adolescents Living with Cancer in Zambia," *Health Psychology Open* 6, no. 1 (2019): 7–8, https://doi.org/10.1177/2055102919833537.

37 Ahmet Tanhan and J. Scott Young, "Muslims and Mental Health Services: A Concept Map and a Theoretical Framework," *Journal of Religion and Health* 61, no. 1 (2022): 25–33, https://doi.org/10.1007/s10943-021-01324-4.

such as feeling angry towards God. The findings of this study are different from earlier research, which has identified cancer survivors as not experiencing Divine suffering or experiencing spiritual struggles.[38] Furthermore, the experience of Divine struggle may stem from adverse life circumstances (e.g., their expectations of Divine intervention have not been fulfilled) and their orienting system (e.g., limited understanding of God).[39] The spiritual needs of YA Muslims living with cancer share some similarities with previous findings from YAs with non-religious backgrounds. However, some spiritual needs are specific to Muslim participants, such as death anxiety resulting from fear of the consequences of sins in the afterlife. These themes reflect the interaction of religious, spiritual, and psychological concerns. When viewed through mainstream psychological lenses, this study's findings can be seen as psychological. However, from the perspective of Islamic psychology, the findings may be interpreted as psycho-spiritual needs or concerns.

Lastly, YAs and HCPs suggested that a short-term online spiritual support programme was practical for YAs living with cancer. Similar to previous studies, AYAs use online psychosocial support to exchange information, provide emotional support, manage adverse situations, and rebuild self-identity.[40] However, the reason for online intervention is somewhat different. In this study, YAs and HCPs generally recommend implementing offline spiritual support due to several factors, including the feasibility of forming connections through in-person meetings and the limited availability of internet access and financial resources to purchase an internet package. Due to the COVID-19 epidemic, most patients and HCPs agreed that spiritual support should be provided through online platforms. However, differences were found in the proposed spiritual support content. YA Muslims living with cancer proposed that the programme content should emphasise enhancing spiritual connection to God, fostering hope, and gaining insight into effective coping strategies from other cancer patients. The HCPs provided additional recommendations, including Islamic mindfulness activities and incorporating Islamic religious resources to assist the YAs in finding meaning. This finding aligns with previous systematic reviews indicating that alternative Islamic spiritual interventions (e.g., Sufi music) could help with reducing anxiety and improving mental health issues.[41]

STRENGTHS AND LIMITATIONS

The strength of this study lies in its qualitative approach, which enables the discovery of new concepts. It adds to the literature on spiritual concerns among YAs living with cancer

38 M. Elizabeth Lewis Hall et al., 'Theodicy or Not? Spiritual Struggles of Evangelical Cancer Survivors.', *Journal of Psychology and Theology* 47, no. 4 (2019): 267–75, https://doi.org/10.1177/009164711 8807187.

39 K. I. Pargament and Julie J. Exline, "A Conceptual Model of Spiritual Struggles," in *Working with Spiritual Struggles in Psychotherapy: From Research to Practice* (The Guilford Press, 2022), 25–34.

40 Brad Love et al., "Defining Adolescent and Young Adult (AYA) Exercise and Nutrition Needs: Concerns Communicated in an Online Cancer Support Community," *Patient Education and Counseling* 92, no. 1 (2013): 130, https://doi.org/10.1016/j.pec.2013.02.011.

41 R. N. Gurbuz-Dogan et al., "The Effectiveness of Sufi Music for Mental Health Outcomes. A Systematic Review and Meta-Analysis of 21 Randomised Trials," *Complementary Therapies in Medicine* 57 (2021): 6–14, https://doi.org/10.1016/j.ctim.2021.102664.

within the Muslim community in Indonesia. The findings also offer a framework for addressing spiritual concerns. Additionally, it was found that spiritual concerns often overlap with psychological concerns. This contributes to deeper understanding of spirituality as an integrated aspect of psychological wellbeing. This research has some limitations; mainly, it was restricted to Muslim YAs with cancer in Indonesia, and its findings may not be applicable to YAs with different cultural and religious backgrounds. These insights are presented from an outsider's perspective with limited personal experience of cancer, which could lead to overlooked questions and unexplored patient experiences. Although these findings have been validated through member checking, spiritual support for YAs living with cancer should be approached carefully, as their spiritual development may differ from that of other patient groups of different ages.

CONCLUSION AND RECOMMENDATION

YA Muslims living with cancer experience psycho-spiritual struggles with three major themes: death anxiety, feeling hopeless and helplessness, and the feedback loop between spiritual struggles and religious coping. It is recommended to provide a short online psycho-spiritual intervention provided by HCPs to help YAs living with cancer manage their struggles. Therefore, for future research, it is recommended to develop a psycho-spiritual intervention that meets the needs of YA Muslims living with cancer.

APPENDIX- INTERVIEW SCHEDULE

Objective	Question
Demographic information	Could you please tell me about yourself?
Explore participant's experience	Could you please tell me how did you know that you have cancer? How did you feel when you were diagnosed with cancer? How did you cope with it?
Explore participant's psychological condition	How are you now? How do you feel and think about having cancer now? What are your concerns now? What kind of support do you think you need most?
Explore participant's spiritual needs and spiritual distress	How do you make sense of things that happened in your life? What do you hope for? What is your source of hope, strength, comfort, and peace? What do you hold onto during challenging times? What are the deep questions you find yourself asking these days? Would you describe these deep questions as spiritual? Why or why not? What does spirituality mean to you? What does spiritual intervention mean to you?
Explore participant's spiritual needs and struggle based on Islamic teaching	What aspects of Islam spiritual practice are most helpful to you? Does your current situation affect your ability to perform spiritual practices, such as *sholat* – compulsory prayers? Do Islamic religious practices help you? In what way? If no, why not? Comparing before and after having cancer, how do you see your relationship with God?
Explore means to facilitate patient's spiritual needs	In your opinion, who could best support the spiritual questions you have? In what way do you think people (e.g., healthcare professionals) could facilitate fulfilling your spiritual needs? Based on your understanding of spirituality, what are the most helpful things a healthcare provider can do if a patient has spiritual concerns? On a scale of 1-10 (1: less important, 10: extremely important), how important is it to have a spiritual intervention? What means or activities should be considered for developing a spiritual intervention?
Explore participant's opinion of having online support	What do you think about an online spiritual intervention? Who do you think should provide the spiritual intervention? In your opinion, what are content should be in the spiritual intervention?
Closing	What other concerns do you think people should know about young adults living with cancer?

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