

SPIRITUAL GROWTH ASPECTS AMONG CAREGIVERS OF CHILDREN WITH CANCER

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Abstract

Spirituality is one of the essential aspects of one's life. It offers a broader perspective towards a meaningful life while undergoing trials such as caring for children with cancers. Cancer caregivers commonly experience physical, emotional, social, and spiritual challenges. Spiritual issues such as lost hope and associating negative meanings with cancer prognosis may reduce the caregiver's quality of life. However, this caregiving burden can be a great source of post-traumatic growth. Therefore, the objective of this study is to explore spiritual change, a significant domain in post-traumatic growth among 24 caregivers of children with cancer at one of the teaching hospitals in Kuala Lumpur. Following in-depth interviews, the result of the thematic analysis demonstrated two themes; main religious and

mindfulness practices, a significant caregiver's spiritual development. The majority of caregivers reported increasing spiritual awareness levels, feeling closer to God, and focused on religious practices as caregivers coping mechanisms and patients' complementary therapy. Hence, spiritual concerns among families of children with cancer need to be addressed during cancer treatment. This study suggests the development of an appropriate quick reference on spiritual aspects for caregivers which would be useful during the cancer trajectory and improve the whole family's quality of life.

Keywords: Spiritual growth; religious practices; caregivers; children with cancer; quality of life.

Khulasah

Spiritual ialah suatu aspek penting dalam kehidupan insan. Ia menawarkan perspektif yang lebih luas ke arah kehidupan yang bermakna ketika menghadapi ujian, antaranya menjaga kanak-kanak yang menghidap kanser. Penjaga pesakit kanser lazimnya menghadapi cabaran fizikal, emosi, sosial dan spiritual. Isu spiritual seperti hilang harapan dan mengaitkan makna negatif dengan prognosis kanser boleh menjejaskan kualiti hidup penjaga pesakit. Walau bagaimanapun, bebanan penjagaan tersebut boleh menjadi punca kepada pembangunan pasca trauma yang sangat berkesan. Oleh itu, kajian ini bertujuan meneroka perubahan spiritual yang merupakan aspek signifikan dalam pembangunan pasca trauma 24 orang penjaga kanak-kanak kanser di sebuah hospital pendidikan di Kuala Lumpur. Berdasarkan temu bual mendalam, hasil analisis tematik menunjukkan bahawa pengamalan ibadat dan penghayatan nilai agama yang utama merupakan dua elemen penting bagi pembangunan spiritual penjaga. Majoriti penjaga menyatakan terdapat peningkatan tahap kesedaran spiritual, rasa lebih dekat dengan Tuhan serta penumpuan kepada amalan agama sebagai mekanisme mengatasi tekanan dan terapi

komplementari kepada pesakit. Oleh itu, isu spiritual dalam kalangan keluarga kanak-kanak kanser perlu ditangani semasa rawatan kanser. Kajian ini menunjukkan keperluan kepada pembangunan rujukan pantas yang sesuai berkaitan aspek spiritual untuk penjaga yang sangat berguna semasa trajektori kanser bagi meningkatkan kualiti hidup mereka sekeluarga.

Kata kunci: Perkembangan spiritual; amalan keagamaan; penjaga; kanak-kanak kanser; kualiti hidup.

Introduction

Post-traumatic growth is the significant transformation in an individual's life driven by a traumatic event.¹ Traumatic events or life crises may lead to positive and negative changes² depending on the individual worldview or perspective³ and how they encounter the crisis.⁴ Therefore, cognitive intelligence (*al-'aql al-salīm*) is salient in guiding a person to gain the rightful insight or wisdom (*hikmah*) behind the life trajectory and trials. There are five major domains of post-traumatic growth discovered which includes initiating a better relationship, unlocking the individual true self and strength, inspiring a new life weltanschauung, triggering and encouraging a

¹ Calhoun, Lawrence G. Tedeschi, Richard G., "Facilitating Posttraumatic Growth: A Clinician's Guide," in *LEA Series in Personality and Clinical Psychology* (London: Lawrence Erlbaum Associates, Publishers, 1999), 11; Miriam Akhtar, *What is Post-Traumatic Growth?* (UK and USA: Watkins, an imprint of Watkins Media Limited, 2017), 33-34.

² *Ibid.*, 17.

³ Didericksen, Katharine Wickel, et al., "Rethinking Parental Coping with Child Health: A Proposed Theoretical Model," *Marriage & Family Review* 55(5) (2019), 424, <https://doi.org/10.1080/01494929.2018.1501631>.

⁴ Wilt, Joshua A., et al., "Open-Ended and Closed-Ended Measures of Religious/Spiritual Struggles: A Mixed-Methods Study," *Religions* 11(10) (2020), 2, <https://doi.org/10.3390/re11100505>.

turning point towards new opportunities, and flourishing spiritual⁵ wellbeing.⁶ Therefore, with spiritual intelligence, the individual may reflect on the wisdom (*hikmah*) of the calamities as an immense source for a better quality of life and wellbeing.

Life crises such as cancer diagnosis among family members especially for a beloved child may overwhelm the caregivers or parents with grief and sadness. Furthermore, cancer is a complex disease that impacts patients beyond physical symptoms along with spiritual, emotional, psychosocial,⁷ and financial constraints,⁸ specifically for low-income families. The diagnosis, treatment-related complications,⁹ unexpected treatment

⁵ Spiritual connects to the human spirit rather than the body or physical things, an intrinsic dimension relating to sacred matters or concerned with religious values and beliefs. See https://www.oxfordlearnersdictionaries.com/definition/english/spiritual_1?q=spiritual, <https://www.merriam-webster.com/dictionary/spiritual> and <https://www.britannica.com/dictionary/spiritual>, accessed on 11th March 2022. Spirituality is a broader terminology than religion. Thus, anybody that senses a meaningful connection or relationship is said to have spirituality. The majority of people experience a sense of spirituality based on their religious beliefs and practices. Sulmasy, Daniel P, "A Biopsychosocial-Spiritual Model for the Care of Patients at the End of Life," *The Gerontologist* 42(3) (2002), 24–33; 24, 25, https://doi.org/10.1093/geront/42.suppl_3.

⁶ Calhoun, Lawrence G. Tedeschi, Richard G., *Facilitating Posttraumatic Growth: A Clinician's Guide*, 11.

⁷ Puchalski, C. M., "Spirituality in the Cancer Trajectory," *Annals of Oncology* 23 (2012), 49, <https://doi.org/10.1093/annonc/mds088>.

⁸ Sedhom R., "Caring for the Patient with Cancer: Body and Soul," *Journal of Pain and Symptom Management* 60(5) (2020), 1068. <https://doi.org/10.1016/j.jpainsymman.2020.05.008>; Currie, Roseanne, et al. "Parental Distress in Response to Childhood Medical Trauma: A Mediation Model," *Journal of Health Psychology* 25(10–11) (2020), 1682, <https://doi.org/10.1177/1359105318770728>.

⁹ As an example, the high prevalence of sensorineural hearing loss for children with medulloblastoma (MB) after chemotherapy; Rajagopal, Revathi, et al., "Challenges of Treating Childhood Medulloblastoma

results, and erroneous prognosis are commonly associated with a high prevalence of psychological and spiritual distress not only to the patient but among the rest of the family members,¹⁰ especially the main caregiver¹¹ who has to witness the patient suffering every day. Vast studies have shown that childhood illnesses have a huge impact on a caregiver's quality of life.¹²

As the main caregiver, a parent's role becomes more intense in order to manage the special health care needs of their chronically ill children¹³ while at the same time keeping a balance with their daily routine as a parent, spouse, and worker.¹⁴ For some individuals, a cancer crisis may shatter their worldview on the meaning of life, faith, and they may experience a loss of faith and leading them to question their beliefs and the power of God. Hence, there is a need to promote and guide a positive spiritual development among individuals in crisis or trauma such as cancer in order to promote better quality of life among the family of cancer patients. This study explores the spiritual

in a Country with Limited Resources: 20 Years of Experience at a Single Tertiary Center in Malaysia," *Journal of Global Oncology* 3(2) (2017), 151, <https://doi.org/10.1200/JGO.2015.002659>.

¹⁰ Currie, Roseanne, et al., "Parental Distress in Response to Childhood Medical Trauma: A Mediation Model," *Journal of Health Psychology* 25(10-11) (2020), 1681, <https://doi.org/10.1177/1359105318770728>; Szilagyi, Csaba, et al., "Interprofessional Spiritual Care Education in Pediatric Hematology-Oncology: A Pilot Study," *Pediatric Blood & Cancer* 69(3) (2022), 2, <https://doi.org/10.1002/pbc.29515>.

¹¹ Sedhom R., "Caring for the Patient with Cancer," 1068; Didericksen, Katharine Wickel, et al., "Rethinking Parental Coping with Child Health," 436.

¹² Currie, Roseanne, et al., "Parental Distress in Response to Childhood Medical Trauma," 1682.

¹³ Didericksen, Katharine Wickel, et al., "Rethinking Parental Coping with Child Health," 425.

¹⁴ Tan, Chai-Eng, et al. "Information Needs of Malaysian Parents of Children with Cancer: A Qualitative Study," *Asia-Pacific Journal of Oncology Nursing* 9(3) (2022), 149.

growth among Muslim caregivers in one of the teaching hospital in Kuala Lumpur, a tertiary referral centre for pediatric hematology-oncology in Malaysia.¹⁵

This study is important for researchers and physicians involved in the care of children with cancer to better understand the spiritual concerns of caregivers of children with cancer, especially parents who may have greater risk factors for developing serious emotional and spiritual distress. While witnessing the life-threatening events of their child, do caregivers experience post-traumatic growth? Are caregivers able to create positive meanings from a life crisis such as cancer? What spiritual transformation do the caregivers undergo and what are their coping strategies? A better understanding of spiritual domains will also help the health care staff and social worker to provide more holistic care that goes beyond physical treatment and focuses on the individual patient as a whole.

In clinical settings, health care providers may apply this knowledge by offering an alternative view on cancer crises and at the same time improve on personal soft skills to show more compassion and empathy to patients and their family members. In practice, this input will help patients and family members, especially the parents, to reframe a positive meaning of the child's illness, sense their personal strength, and experience positive growth, especially in the spiritual aspect.

Literature Review

Spirituality is broad and dynamic, its dimensions are related to faith, connection and love, community, meaning, purpose, hope, and the expression of a person's

¹⁵ Rajagopal, Revathi, et al. "Challenges of Treating Childhood Medulloblastoma in a Country with Limited Resources," 144.

interior essence, the internal aspect of a human being.¹⁶ Spirituality is defined as a person's search for, or expression of, their connection to a greater and meaningful context.¹⁷ As a result, spirituality is described as the quality or state of being attached to the human spirit,¹⁸ religious values,¹⁹ and the transcendent.²⁰ Religion is a specific terminology of spirituality corresponding to a set of organized beliefs about God that is shared by the religious members.²¹ Generally, spiritual intelligence themes of Islamic and Western philosophical perspectives can be categorized as the meaning/purpose of life, consciousness, transcendence, spiritual resources, self-determination, reflection-soul purification, and spiritual coping with obstacles.²²

According to Muslim scholars there are seven based domains of spiritual intelligence or intelligence quotient of religiosity, that is spirit (*rūh*), heart (*qalb*), soul (*nafs*),

¹⁶ Mohd Afifuddin Mohamad and Mohammad Faris Iman Leong Abdullah, *Kemurungan: Terapi dari Sudut Psikiatri dan Spiritual* (Pulau Pinang: Penerbit USM, 2020), 112.

¹⁷ Barbara Barnum, *Spirituality in Nursing*, 2nd ed. (New York: Springer Publishing Company, Inc., 2006), 127.

¹⁸ *Oxford Learners Dictionaries*, entry "spiritual", accessed on 11 March 2022, <https://www.oxfordlearnersdictionaries.com/definition/english/spirituality?q=spirituality>

¹⁹ *Merriam Webster*, entry "spiritual", accessed on 11 March 2022, <https://www.merriamwebster.com/dictionary/spirituality>; Britannica, entry "spiritual", accessed on 11 March 2022, <https://www.britannica.com/dictionary/spirituality>; *Oxford Learners Dictionaries*, entry "spirituality", accessed on 11 March 2022, <https://www.oxfordlearnersdictionaries.com/definition/english/spirituality?q=spirituality>

²⁰ Sulmasy, Daniel P, "A Biopsychosocial-Spiritual Model for the Care of Patients at the End of Life," 25.

²¹ Puchalski C.M., "Spirituality in the Cancer Trajectory," 49.

²² Hanefar, Shamsiah Banu, Che Zarrina Sa'ari, and Saedah Siraj, "A Synthesis of Spiritual Intelligence Themes from Islamic and Western Philosophical Perspectives," *Journal of Religion and Health* 55(6) (2016), 2076. <https://doi.org/10.1007/s10943-016-0226-7>.

intellectual (*'aql*), faith (*īmān*), devotions (*'ibādah*) and morality (*akhlāq*).²³ These demonstrate the human being as a complex spiritual creation connected with Allah the Almighty and created with intrinsic as well as extrinsic aspects. For a meaningful life and well-being, the vertical connection with Allah the Almighty and horizontal connection with other creations must be balanced and be in harmony.

Spiritual connection with the transcendent can be developed by following religious commands, performing religious rituals, and having optimism about fate. For a pious servant, the sense of love to Allah the Almighty (*maḥabbatillāh*) flourishes from the consistencies in performing religious practices, and mindfulness (*murāqabah*)²⁴ is the greatest source of hope (*rajā'*).²⁵ Growing literature and human history have shown that an individual gains more strength during or after facing adversity. Growth outcome or post-traumatic growth triggers an individual to optimize self-potential, and to feel a deeper sense of gratitude, tranquillity, and life purpose.²⁶ Evidently, the religious belief system is influential for the individual to recover cognitive adjustment during life trajectory and is a crucial coping mechanism.²⁷

²³ Elmi Baharuddin and Zainab Ismail, "7 Domains of Spiritual Intelligence from Islamic Perspective", *Procedia - Social and Behavioral Sciences* 211 (2015), 575, <https://doi.org/10.1016/j.sbspro.2015.11.075>.

²⁴ Sharifah Basirah Syed Muhsin and Che Zarrina Sa`ari, *Kaedah Psikoterapi Islam: Berasaskan konsep Maqamat Abu Talib al-Makki*, (Kuala Lumpur: DBP, 2015), 199.

²⁵ Asadzandi, Minoo, "An Islamic Religious Spiritual Health Training Model for Patients," *Journal of Religion and Health* 59(1) (2018), 177, <https://doi.org/10.1007/s10943-018-0709-9>.

²⁶ Miriam Akhtar, "What is Post-Traumatic Growth?", 30.

²⁷ Calhoun, Lawrence G. and Tedeschi, Richard G., "Facilitating Posttraumatic Growth: A Clinician's Guide," 12; Religious coping refer to the mechanism used during stressful or traumatic events

In the Islamic perspective, suffering in this worldly life is a blessing, chosen by God and a subtle way that God wants to draw His creations closer toward Him. This view also can be found in other world religions such as Judaism, Christianity, Hinduism, and Buddhism.²⁸ In an international study conducted among patients and caregivers' spiritual needs, caregivers described faith and spiritual aspects such as meditation, prayer, and faith community as additional support that helped them to cope.²⁹ Hence, spirituality and religiosity have been recognized and acknowledged as important source of individual motivation.³⁰ Therefore, this research focuses on Muslim caregivers' religious practices and their impact on their lives. A face-to-face in-depth interview provides more detailed information for this study.

The discussion over the impact of spirituality on mental health has been started in early human civilization.³¹ Spirituality is associated with improved physical and mental health as well as increased life

based on spiritual or religious beliefs, approaches, and practices; Sulmasy, Daniel P, "A Biopsychosocial-Spiritual Model for the Care of Patients at the End of Life," 28.

²⁸ Calhoun, Lawrence G. & Tedeschi, Richard G., "Facilitating Posttraumatic Growth: A Clinician's Guide," 108.

²⁹ Selman, Lucy Ellen, et. al., "Patients' and Caregivers' Needs, Experiences, Preferences and Research Priorities in Spiritual Care: A Focus Group Study across Nine Countries," *Palliative Medicine* 32(1) (2017), 225, <https://doi.org/10.1177/0269216317734954>.

³⁰ Nur Shahidah Paad, Sharifah Basirah Syed Muhsin, Mohd Syukri Zainal Abidin, "Implementasi Psikospiritual Islam Dalam Pembentukan Model Motivasi Pembangunan Diri Remaja: Islamic Psychospiritual Implementation in Motivational Model of Adolescents' Self-Development," *Afkar: Journal of Aqidah & Islamic Studies* 23(2) (2021), 409, <https://doi.org/10.22452/afkar.vol23no2.11>.

³¹ Fisher, John, & David Ng, "Presenting a 4-Item Spiritual Well-Being Index (4-ISWBI)," *Religions* 8(9) (2017), 179, <https://doi.org/10.3390/re18090179>.

expectancy.³² A cross-national study analysis among adolescents in Canada, England, and Scotland identified a strong and consistent association between positive mental health and higher scores for each of the four spiritual health domains (connections to "self", "others", "nature", and the "transcendent").³³ This is because spiritual health is dynamic and results from the harmonization of the four domains stated.³⁴ A qualitative study conducted by interviewing the parents of children with cancer in Malaysia also reported that the caregiver's faith in God and religious practices helped them to cope with their child's illness.³⁵ Therefore, this study aims to explore the spiritual growth in terms of coping mechanisms and positive meaning-making among caregivers of children with cancer at one of the teaching hospitals in Kuala Lumpur, a tertiary referral centre for pediatric cancer.

Research Methodology

A qualitative approach was used to explore spiritual growth via semi-structured in-depth interviews. The questionnaire was adapted from In-depth Spiritual Distress Interview Questions (LY2021W06551).³⁶ However, in this

³² Rafeah Saidon, Siti Khadijah Ab Manan, Rosilawati Sueb, Fairuz Nazri Abd Rahman, "Islamic Psycho-Spiritual Support Model for Disaster Victims", *Environment-Behaviour Proceedings Journal* 6 (2021), 71, <https://doi.org/10.21834/ebpj.v6iS15.2932>.

³³ Michaelson, Valerie, et al, "Domains of Spirituality and Their Associations with Positive Mental Health: A Study of Adolescents in Canada, England and Scotland," *Preventive Medicine* 125 (2019), 12, <https://doi.org/10.1016/j.ypmed.2019.04.018>.

³⁴ Fisher, John, & David Ng, "Presenting a 4-Item Spiritual Well-Being Index (4-ISWBI)," 2.

³⁵ Tan, Chai-Eng, et al., "Information Needs of Malaysian Parents of Children with Cancer: A Qualitative Study," 150.

³⁶ Hasimah Chik, Che Zarrina Saari & Loh Ee Chin "The Role of Spirituality in Palliative Care", *Afkar: Journal of Aqidah & Islamic Thought* 19 (2) (2017), 107-142; Hasimah Chik, "Punca Utama Keresahan Spiritual dalam Penjagaan Paliatif menurut Perspektif

article researchers only focused on the spiritual development or changes among the caregivers of children with cancer-based on the answer of two questions; "Do you have your own ritual, like going to the mosque, praying, and how much it has affected your life?" and "Does your child's illness affect your life?"

The inclusion criteria included Muslim participants who are above 18 years old and must be the caregivers of children with cancer at any treatment stage. Caregivers must also be able to understand and speak in Malay or English. The in-depth interviews were conducted face-to-face at a ward and pediatric oncology clinic at one of the teaching hospitals in Kuala Lumpur. The exclusion criteria were caregivers who were unable to read and speak Malay or English, refused to participate in this study, and the caregivers of children with benign tumours which is a non-cancerous tumour.

Data collection was conducted from 8 March until 21 April 2021. Participants for this study included caregivers of children with cancer who were either newly diagnosed with cancer, ongoing treatment, completed treatment and under clinic follow-up, or under palliative care services. Researchers use a purposive sampling technique based on the criteria of the participants and based on informative and useful data to achieve the study objective. The interviews were audio-recorded and transcribed for thematic analysis. Analysis was done manually using constant comparative methods to identify related concepts to form meaningful themes and categories. These themes and categories were then illustrated using concept maps for better visualization.

This research was approved by the medical research ethics committee (20191224-8104). Consent forms were distributed during the interview session and participants

Psikologi Agama", Islamic Studies master thesis, Universiti Malaya, Kuala Lumpur, 2018, 111.

were aware that their participation was absolutely voluntary.

Results

1.0 Demographic characteristics

A total of 24 Muslim, Malay native speakers caring for children who were receiving treatment and cancer care at a hematology-oncology unit at one of the teaching hospital in Kuala Lumpur were involved in this study. For the purpose of confidentiality, participants are labelled anonymously as R1, R2, R3, and so on until R24. Demographic characteristics and the date of interview are tabulated in Table 1.

Table 1: Demographic characteristics

Participant	Gender	Age (Year)	Child's Treatment Phase	Date of Interview
R1	Female	41	Relapse, Intensive chemotherapy	03/08/2021
R2	Male	31	Intensive chemotherapy	03/11/2021
R3	Female	36	Post-surgery, chemotherapy	on 03/12/2021
R4	Female	32	Maintenance	03/12/2021
R5	Female	32	Intensive chemotherapy	03/15/2021
R6	Female	44	Intensive chemotherapy	03/16/2021
R7	Female	25	Intensive chemotherapy	03/16/2021
R8	Female	36	Post-surgery, Chemotherapy	03/16/2021
R9	Female	38	Maintenance	03/17/2021
R10	Female	38	Intensive chemotherapy	03/22/2021

R11	Female	27	Radiotherapy	03/23/2021
R12	Female	43	Intensive chemotherapy	03/26/2021
R13	Female	47	Follow-up	03/26/2021
R14	Male	48	Palliative	03/26/2021
R15	Female	55	Follow-up	03/29/2021
R16	Female	39	Palliative	04/02/2021
R17	Male	33	Follow-up	04/05/2021
R18	Female	43	Intensive chemotherapy	04/14/2021
R19	Female	36	Follow-up	04/14/2021
R20	Female	37	Follow-up	04/14/2021
R21	Female	41	Intensive chemotherapy	04/15/2021
R22	Female	42	Follow-up	04/19/2021
R23	Male	51	Newly- diagnosed	04/21/2021
R24	Female	37	Follow-up	04/21/2021

Source: Interview with Participants

Based on the tabulated data, most participants are mothers (n=20) and only (n=4) of them are fathers (Figure 1: Gender). This sample population is equivalent to other studies which show that most caregivers are women.³⁷ The

³⁷ Quast, Lauren F., et al., "Psychosocial Functioning Among Caregivers of Childhood Cancer Survivors Following Treatment Completion," *Journal of Pediatric Psychology* 46 (10) (2021), 1240, <https://doi.org/10.1093/jpepsy/jsab061>; Ding, Teck Yong Gabriel, et al., "Factors Associated with Family Caregiver Burden among Frail Older Persons with Multimorbidity," *BMC Geriatrics* 22 (1) (2022), 1, <https://doi.org/10.1186/s12877-022-02858-2>; Sullivan, Suzanne S., et al. "Development of a Longitudinal Dataset of Persons with

total mean age of the parents is 37.56 years (SD=7.203) ranging from 25 to 55 years old (Figure 2: Age).

Figure 1: Gender

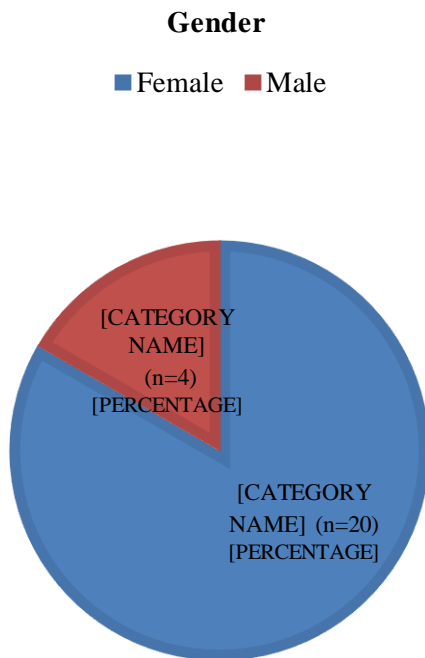
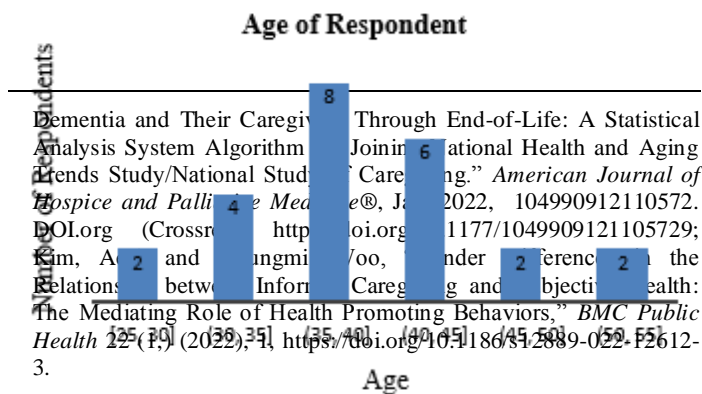
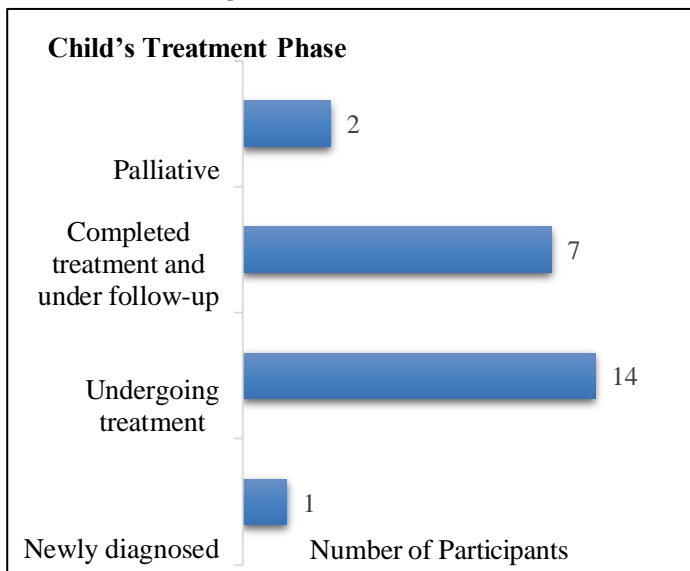


Figure 2: Age



Participants for this study involved parents of children with cancer at various stages of the cancer trajectory including newly diagnosed with cancer, n=1 (6 %), undergoing treatment (including intensive, maintenance, relapse, radiotherapy, and post-surgery), n=14 (44 %), completed treatment and under follow-up, n=7 (39 %) and under palliative care service, n=2 (11 %). The majority of participants in this study, n=14 were those caring for children undergoing treatment (Figure 3: Child's Treatment Phase).

Figure 3: Child's Treatment



2.0 Spiritual Growth

Based on the interview questions, "Do you have your own ritual, like going to the mosque, praying, and how much it has affected your life?" and "Does your child's illness affect your life?", two main themes were identified: main religious practices among caregivers and religious mindfulness practices among caregivers. Data saturation was achieved where there were no more new themes identified in the later transcript and there were noticeable similarities figured. In this study, the data on these two main themes were counted based on their responses in the interview. Therefore, the numbers calculated as shown in the figures below are more than $n=24$.

2.1 Main Religious Practices among Caregivers

There are five main religious practices among caregivers reported, namely performing supererogatory prayer (*ṣalāt*

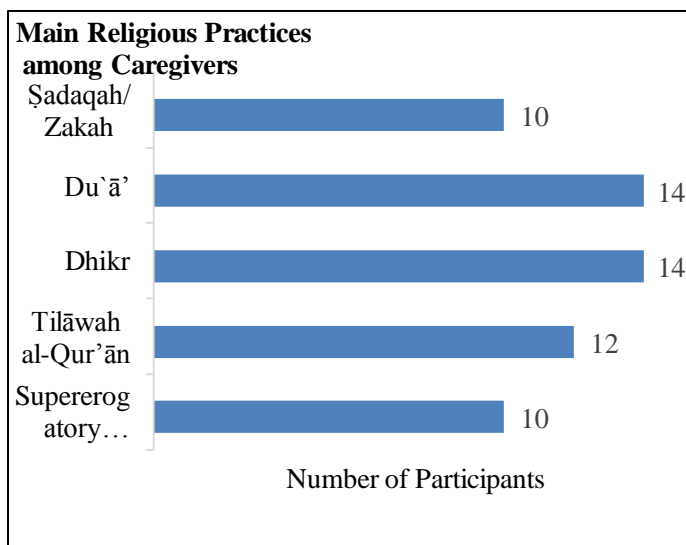
al-nawāfil), reciting the *Qur'ān* (*tilāwah al-Qur'ān*), remembrance of Allah the Almighty (*dhikr*), supplication (*du'ā'*) and giving alms (*ṣadaqah/zakāt*). The majority of caregivers, n=14 (23%), reported that they perform a lot of supplications for their child's recovery, for the effectiveness of treatment, and for the provision of strength and tranquillity. In addition, four respondents shared about the power of a mother's supplication and one respondent expressed the supremacy of supplication during the barakah month of Ramadan.

In addition, n=14 (23%) caregivers mentioned the practicing abundant *dhikrullāh* such as *Subḥānallāh*, *Alḥamdulillāh*, *Allāhu Akbar*, *Istighfār*, *al-Ma'thūrāt*, certain *dhikr* (*dhikr al-khuṣūṣ*) as well as *ṣalāwāt* for the Prophet Muhammad (PBUH). Other than *dhikrullāh*, and *ṣalāwāt*, n=12 (20%) caregivers increased their *tilāwah al-Qur'ān*. Some of the caregivers shared that they recite *āyāt al-Kursī* (n=2), *sūrah Yāsīn* (n=3), *sūrah al-Fīl* (n=3), *sūrah al-Ikhlāṣ* (n=2), *sūrah al-Falaq* (n=2), *sūrah al-Nās* (n=2) and *Āyāt al-Ruqyah* (n=1) as a complementary effort from a religious perspective to cure cancer. One caregiver mentioned that they always play *dhikr*, *sūrah*, and *āyāt al-Ruqyah* on MP3 for her child. Other than that, three caregivers mentioned reciting the Holy Quran as daily worship for the Muslim believer.

Furthermore, n=10 (17 %) caregivers explained that they increased their attention to performing supererogatory prayers such as *ḥājat* (n=6), *tahajjud* (n=5), *tawbah* (n=4), *sunnah* prayer of *fajr* (n=1) though a caregiver did not mention on a specific type of prayer. Most of them described the supererogatory prayers as a source of hope and strength where they ask for ease on their affairs and forgiveness, and a source of the feeling of total reliance on His mercy and helps and a sense of being closer to Allah the Almighty that helps to rejuvenate their faith.

Additionally, n=10 (17 %) caregivers emphasized *ṣadaqah* as a great religious assurance to cure illness. Regarding *ṣadaqah*, caregivers informed that: *ṣadaqah* after *fajr* prayer is the best (n=1), that it becomes easier to give *ṣadaqah* after a cancer diagnosis (n=3), *ṣadaqah* was accompanied with the intention of healing (n=3), *ṣadaqah* was offered for the sake of life in this world and hereafter (n=1), a sense of sufficiency when they started to give more (n=2), all affairs become easier after giving *ṣadaqah* (n=2), as an effective method of purifying the soul (*tazkiyah al-nafs*) (n=1) and draw oneself closer towards Him (n=1). One of the caregivers shared that she transferred online *zakāh* using e-zakāt every day (Refer to Figure 4: Main Religious Practices among Caregivers).

Figure 4: Main Religious Practices among Caregivers



2.2 Main Religious Mindfulness Practices Among Caregivers

There are four themes of religious mindfulness practices among the caregivers categorized: effort to cure cancer with total submission (*tawakkul*), acceptance (*riḍā*), wisdom (*ḥikmah*), and gratitude (*shukr*). Firstly, in the effort to cure cancer, the caregivers commonly describe their experience and practice along with elements of worship and *tawakkul*. Most of them, R2, R8, R10, R15, R19, and R23, mention the effort to complete their child's cancer treatments and recovery consistently with *du`ā'* and *tawakkul*. Some of them express a sense stronger after *ṣalāt* and Allah the Almighty is there to help (R10) and a sense of *tawakkul* after performing *ṣalāt* (R15).

Other than that, R8 shared her practice, "sometimes my child had fever two to three days, we gave him medication, a doctor gives him antibiotic, we recite *āyāt al-Kursī*, *sūrah al-Ikhlāṣ*, *sūrah al-Falaq*, *sūrah al-Nās*, rub the hands on the child's face, *tawakkul*, this is the last thing we did, tomorrow he's getting ok."³⁸ These examples demonstrate that Muslim society puts an effort to cure chronic illnesses such as cancer as a complementary between conventional medicine and a spiritual approach.

For further details on *tawakkul*, R2 explained, "on my behalf to cure I can *tawakkul* and trying, others I let to Him, I will keep trying."³⁹ R24 mentioned, "He is the only one that we can rely on, nothing else."⁴⁰ In addition, R13 stated, "At first, it was really shocking, we never experienced it, we totally surrender, we can't do anything, we left it to the doctors who are expert, the doctor knows what to do, so we rely upon Him as we can't do

³⁸ Interview transcript R8, 16 March 2021.

³⁹ R2, 16 March 2021.

⁴⁰ R24, 21 April 2021.

anything..."⁴¹ These show *du`ā'*, *tawakkul*, or relying totally upon Him and trying to complete the treatment as recommended by the pediatric hematology-oncology specialist resulted in serenity and contentment of the caregiver's heart.

Secondly, acceptance (*riḍā*) has also been interpreted by nine caregivers. The majority mentioned they accept this fate and trial R1, R4, R5, R12, R15, R17, R13, and R23. R5 shared, "Every time when the doctor informed about her, diagnose her, we perform *ṣalāt ḥājat*, we accept."⁴² Furthermore, other caregivers acknowledged acceptance with sufficient trust in His help (R1) and believe only Him can heal the illness (R15) while R17 positively saw themselves as the chosen one to be tested.⁴³

Thirdly, 13 caregivers expressed a sense of wisdom (*ḥikmah*) during the trajectory of the illness. R2, R4, and R23 summarized that there must be *ḥikmah* behind the trials. Other caregivers elaborated their insight more specifically based on their experience. For example, R1 and R7 described the trials as a wake-up call and a chance to spend more time with their children because previously they were too focused on their respective jobs. Moreover, three caregivers R8, R22, and R24 declared the development of spiritual strength in the ward because they had a lot of free time while accompanying their children in the ward for treatment.

These caregivers stated that staying in the ward gave them the opportunity to learn more religious knowledge via online sources and from the other caregivers,⁴⁴ that it was easier to *istiḳāmah*⁴⁵ and that the extra time meant that they were able to perform more religious practices.⁴⁶

⁴¹ R13, 26 March 2021.

⁴² R12, 26 March 2021.

⁴³ R17, 5 April 2021.

⁴⁴ R24, 21 April 2021.

⁴⁵ R8, 14 April 2021.

⁴⁶ R22, 19 April 2021.

Eight caregivers narrated that they perceived being closer to Allah the Almighty with the sense of spiritual growth as well as added supererogatory prayer,⁴⁷ trust in Allah's the Almighty help,⁴⁸ more spontaneous *dhikrullāh*,⁴⁹ being more focused (*khushū*) during prayers,⁵⁰ and attempted to be more punctual with prayers.⁵¹ Not only that, three caregivers shared their big positive spiritual changes compared to before which before they had sometimes forgotten to perform obligatory prayers while working and traveling,⁵² had skipped obligatory prayer when tired working,⁵³ and were very reluctant to give charity.⁵⁴

Fourth, *shukr*, five caregivers expressed their gratitude. R1, R2, R12, and R16 felt deeper gratitude when they saw others with a heavier trial. In addition, R1 described the sense of gratitude becoming a source of strength to face the trials. Last but not least, R23 shared that she was very grateful because she was surrounded by a positive and supportive family as well as friends. This shows that trials in life could build better and closer relationships with others. (Refer Figure 5: Religious Mindfulness Practices among Caregivers).

⁴⁷ R1, 15 April 2021.

⁴⁸ R2, 26 March 2021.

⁴⁹ R6, 2 April 2021.

⁵⁰ R19, 14 April 2021.

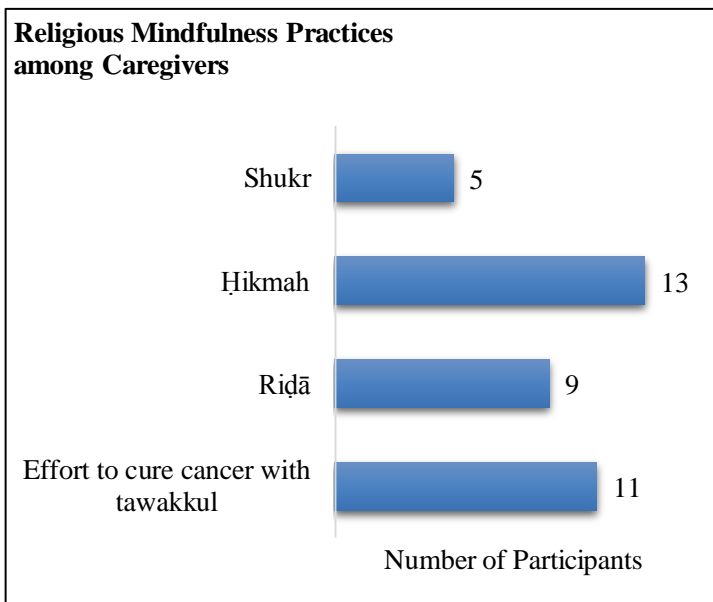
⁵¹ R5, 15 March 2021.

⁵² R11, 23 March 2021.

⁵³ R7, 16 March 2021.

⁵⁴ R4, 12 March 2021.

Figure 5: Religious Mindfulness Practices among Caregivers



Discussion

Based on the conducted interviews, two main themes were identified: main religious practices and religious mindfulness practices among caregivers. The majority of caregivers have had positive post-traumatic growth and use positive spiritual ways of coping while dealing with their child's cancer trajectory. Caregivers reported their spiritual development in reference to their improvement in devotions and closer connection with Allah the Almighty.

Caregivers mentioned intensifying supplication (*du`ā'*), remembrance of Allah the Almighty (*dhikr*), reciting the Qur'ān (*tilāwah al- Qur'ān*),⁵⁵ performing

⁵⁵ Reciting *āyah al-sakīnah* during anxiety and chaos bring about comfort and assurance; Kamarul Zaman, Rahim, Mohd Khairul Naim Che Nordin, and Khairulnazrin Nasir "Rabbānī Therapy in Treating Neurosis Problem," *Afkar: Journal of Aqidah Islamic*

supererogatory prayer (*ṣalāt al-nawāfil*), and alms (*ṣadaqah/zakāt*). All the religious practices bring about a deep sense of affection for caregivers as stated in the Noble Qurʾān and other studies, sincerity and wholehearted devotions result in serenity and calmness.⁵⁶ The most frequent religious practices mentioned by the caregivers in this study are *duʿāʾ* and *dhikr*. This is because *duʿāʾ* and *dhikr* are the easiest and most effortless forms of devotions and can be done at any moment. Besides, caregivers recite certain verses of al-Qurʾān such as *āyāt al-Kursī*, *sūrah Yāsīn*, *sūrah al-Fīl*, and *āyāt al-Ruqyah* as a religious effort as well as medical treatment to cure cancer. For example, reciting *sūrah al-Fīl* with the intention to cure was shared by three caregivers R4, R9, and R20 based on *ustādh* suggestions in religious talk. The recitation's purpose is to destroy the cancerous cell such as Abrahah's army that had been destroyed as described in the *sūrah*.

A few caregivers in this study described the supererogatory prayers as a source of their hope and strength. During *ṣalāt ḥājat*, they ask for ease in their affairs regarding their child's treatment effectiveness, recovery, good prognosis, and comfort. *Ṣalāt ḥājat* is a common Muslim ritual in which they asked Allah the Almighty for help in accordance with His commands in *sūrah al-Baqarah* verse 45. Caregivers also asked forgiveness from Allah the Almighty by performing *ṣalāt tawbah* and improving their religious practices that have been taken for granted before. Besides that, the caregivers

Thought 23 (2) (2021), 59,
<https://doi.org/10.22452/afkar.vol23no2.2>.

⁵⁶ "Surely in the remembrance of Allah do hearts find comfort," al-Ra'd: 28; Mustaffa, Nurul Hidayawatie, Noor Shakirah Mat Akhir, and Salasiah Hanin Hamjah, "The Impact of Spiritual Practice in Overcoming Loneliness at Elderly Care Centre," *Afkar: Journal of Aqidah & Islamic Thought* 23 (2) (2021), 32, <https://doi.org/10.22452/afkar.vol23no2.1>.

highlighted *ṣadaqah* as a miracle to cure illness and provide financial sustenance. Some caregivers explained that they became more generous and felt a sense of sufficiency after giving more charity and accompanied *ṣadaqah* with the intention of healing.

Furthermore, mindfulness and spiritual insight as well as total submission (*tawakkul*), acceptance (*riḍā*), wisdom (*ḥikmah*), and gratitude (*shukr*) become a great source of strength for caregivers. Caregivers sensed a closer connection to Allah the Almighty with regards to the increase in devotion and *tawakkul* while coping with the stressful situation and hoping for their child's healing. Most of them mentioned the effort to complete their child's cancer treatments and recovery consistently with *du`ā'* and *tawakkul*. According to al-Ghazali, a layman's *tawakkul* should be accompanied by enough human effort and a convincing prayer that results from absolute faith (*tawḥīd*).⁵⁷

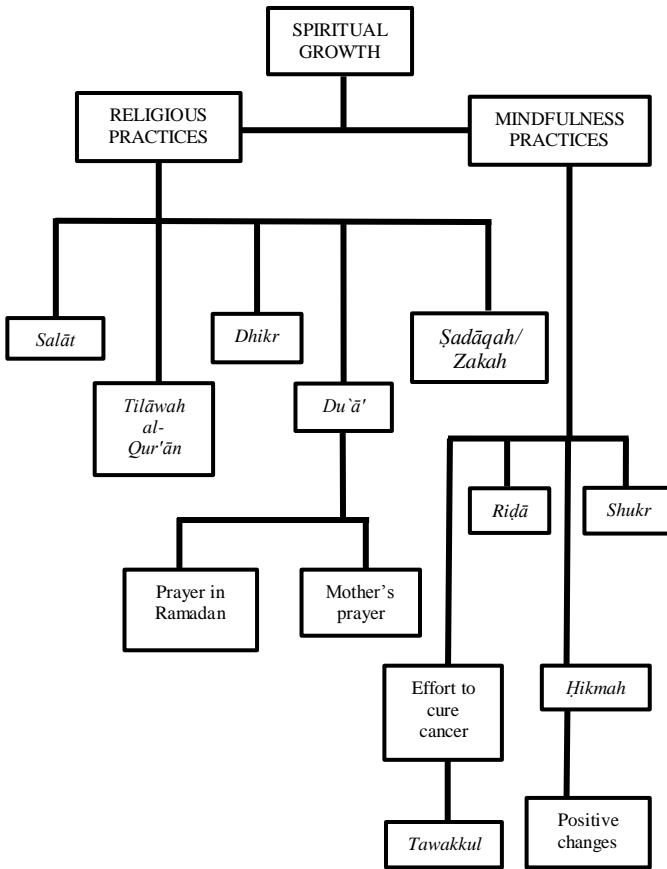
The absolute trust in Allah the Almighty and spiritual strength gained from the religious practices help caregivers buffer their spiritual and emotional distress as well as enhance caregivers' acceptance (*riḍā*) of their child's cancer prognosis. In most situations, *riḍā* is the key to moving on and a window to glance at the silver lining. Based on the above discussion, there is great *ḥikmah* behind childhood cancer which can be seen in caregivers who experienced positive spiritual growth. Other than that, they were able to create a positive meaning as well as develop a closer connection with Allah the Almighty and their children compared to before the cancer diagnosis. The child's cancer diagnosis eventually became a turning point for caregivers to become better servants (*ibād al-Raḥmān*).

⁵⁷ Abū Ḥāmid al-Ghazālī, *Iḥyā' 'Ulūm al-Dīn*, ed. al-Shaykh As`ad al-Saghari (Syria: Dār al-Fayḥā', 2010), 507-508.

The frequent and long hospital stays during a child's intensive treatment provided a great opportunity for caregivers to perform a lot of religious practices which developed spiritual strength and resilience. Caregivers had a lot of time to study religious knowledge via online sites and through discussions with others in the ward. Besides, the caregivers also reported a better quality of religious practices in the ward because they did not have as many commitments as usual. Finally, the caregivers expressed their deepest gratitude (*shukr*) because of their spiritual growth, ability to see *hikmah* behind these trials, and realizing they have the best support system from Allah the Almighty, family, and health care team, other caregivers, and friends.

In fact, all the religious practices or devotions manifest the remembrance of Allah the Almighty and reliance totally on His mercy and help, creating a closer relationship with Allah the Almighty and reviving the caregivers' faith. Furthermore, this study shows religious practices does not only act as the caregiver's coping mechanism for facing the spiritual and emotional distress but an important and meaningful effort to cure cancer. Spiritual growth through religious and mindfulness practices is demonstrated in the data extracted. (Figure 6 Spiritual Growth).

Figure 6: Spiritual Growth



Conclusion

The caregivers' well-being is important for a successful patient's treatment. The effort to cure cancer from a spiritual aspect improves a caregiver's spirituality, helps them to become more optimistic, and results in a better state of mental health and wellbeing for all family members. Thus, this study has shown that identifying a caregiver's spiritual and psychological well-being can help them to improve the caregivers' and families' quality of life. The study suggests the concerned parties such as the ministry of health, non-government organizations, and others to provide spiritual care services to caregivers of children with cancer. The development of an appropriate quick reference on spiritual aspects for caregivers is very important.

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