

THE SYMPTOM EXPERIENCES, PALLIATIVE MANAGEMENT, AND SPIRITUAL WELLBEING IN INDONESIANS WITH ADVANCED CANCER

Jane Freyana Tedja¹, Tiraporn Junda², Bualuang Sumdaengrit³, Kanaungnit Pongthavornkamol⁴, D. E T A U Tarihoran²

¹ Mahidol University, Ramathibodi School of Nursing, Thailand, Thailand,

² Universitas Kristen Krida Wacana, Nursing, Jakarta, Indonesia

ABSTRACT

Background/aims: The prolonged multifaceted physical and psychological symptoms-distress eventually affected heavily upon many advanced cancer patients (ACPs). The aim of this correlational descriptive research was to explore the symptom experiences, palliative management, and spiritual well-being of Indonesians and examine the prevalence, frequency, severity, and distress and the effectiveness of management in relation to the personal, communal, environmental, and transcendental domains of spiritual well-being

Methods: A cross-sectional descriptive design was applied based on the Dodd's Symptom Management Theory, and the use of instruments: 1) The Demographic Background Questionnaire [DBQ], 2) The Portable Mental Status Questionnaire [PMSQ]. 3)The Memorial Symptom Assessment Scale [MSAS], 4) The Palliative Managements Questionnaire [PMQ], and 5) The Spiritual Well-being (SWb)-SHALOM Questionnaires.

Results: Participants were 120 ACPs ranging from 18 to 73 years. The mean symptom was 15 (range 2-27). The most prevalent symptoms were lack of energy, pain, worrying, hair loss, feeling sad and difficulty sleeping; most frequently reported symptoms were lack of energy, problems with sexual interest, numbness/tingling, difficulty swallowing, and difficulty sleeping; most severe symptoms were hair loss, weight loss, lack of energy, swelling of arms/legs, and difficulty swallowing; and most distressing were pain, the lack of energy, lack of appetite, vomiting, and nausea. Patients most appreciated their 'beloved immediate family and friends'; and the most effective reported management was 'relying upon the only Mighty Powerful/Most High Being/God to provide miraculous Divine Healing

Conclusions: The findings from this study provided empirical evidence to understand the symptom experiences, palliative management, and spiritual well-being in ACPs. The health care providers need to design appropriate and culturally sensitive intervention programs for ACPs, particularly on spiritual wellbeing.

Keywords: Advanced Cancer, Palliative Management, Spiritual Wellbeing, Symptom Experiences,

INTRODUCTION

The cancer burden currently has effect heavily on less developed countries⁽¹⁾⁽²⁾. Indonesian estimated habitants was 263,991,000 in 2017⁽³⁾ who are living in 17,508 islands. Indonesia nationwide cancer cases annually were around 170-190 cases per 100,000 populations or 4.3 per 1,000 population⁽⁴⁾. The statistical projection reported new cancer cases was 299,673 cases, 314,188 cases, and 366,875 cases in 2012, 2015, and 2020 respectively⁽²⁾. Also cancer death-rates in Indonesia were multiplied from previous 194,528 deaths in 2012 and estimated to 239,030 by 2020⁽²⁾.

In Indonesia, the majority of patients with cancer around 60% seek medical care when the disease is already in advance stage⁽⁵⁾. The consequences of having advanced cancer not only implicate upon patients' physical dysfunctions but followed with threats upon psychological balance and functioning⁽⁶⁾ leads to systematic imbalance impacting on patients' bio-psycho-spiritual-social function.

From literature review in Asia; Thailand top symptom experience in advanced cancer patients (ACPs) were; lack of appetite⁽⁷⁾; insomnia⁽⁸⁾; pain, lack of energy, and skin change; and difficulty swallowing⁽⁷⁾⁽⁹⁾⁽¹⁰⁾. While top five symptoms prevalence of systemic review in patients with incurable cancer in European countries were fatigue, pain, lack of energy, weakness, and loss of appetite⁽¹¹⁾. In addition, from a review literature from 22 studies from 1996-2009 reported that pain, dyspnea, and nausea were symptoms prevalence and severity across all studies⁽⁹⁾.

Meanwhile, few studies found in Indonesia which symptom prevalence was assessed by quality of life or assess unmet need in patients with advanced cancer⁽¹⁰⁾⁽¹¹⁾⁽¹²⁾. The top prevalence of symptoms were pain (72.22%), fatigue (68.33%), appetite loss (60%), sleep problems (57.78%), and dyspnea 38.89%). This study was support the study by Effendy and colleagues that top five symptom prevalence in Indonesians with advanced cancer were pain (71.1%), fatigue (66.7%), sleeping problem (53.3%), sweating (47.2%), and cough (42.2%); however, only one dimension of symptom experience was studied⁽¹³⁾.

Hence, the prolonged multifaceted physical, psychological symptoms distress eventually affected heavily upon many ACPs⁽¹⁴⁾. As mentioned by the Symptom Management Theory⁽¹⁵⁾, when the symptom occurred, the ACPs evaluated its severity and distress. As a human, they had

potential to manage symptoms by using variety of palliative management strategies based on their cultural belief to help release their symptoms.

In Get-Kong and colleagues(16) studied of Thai ACPs palliative management beside pharmacological managements (opioid analgesics, 82.9%) they also used non-pharmacological management strategies which seem to be very helpful. The most effectiveness were; getting information/ advice about self-care (100%); talking to someone who gave support (100%); reading Dhamma's book(10)(16)/ bible of own religion and making merit (96%); changing food/ eating behaviors (89%); taking vitamins or dietary supplements (79%); and meditation (61%). After the ACPs used the palliative management strategies, they received some healing, relief suffering and attentively caring by patients themselves and their caregivers in wholeness bio-psycho-social-spiritually(14)(17). Therefore it might have good spiritual wellbeing. Spiritual wellbeing described by Fisher(18) identified that it reflects the extent to which people live in harmony within relationships with oneself (personal), others (communal), nature (environment), and God (transcendental others). Which represented ACPs wholeness or harmony living with their sufferings.

In Indonesia, there was limited research studied in ACPs who suffered from symptom experiences, including palliative management, and spiritual wellbeing. Although there were some research reported in; 'comparison of problems and unmet needs of patients with advanced cancer in Netherland and Indonesia'(19); 'dealing with symptoms and issues hospitalized patients with cancer in Indonesia: The role of families, nurses, and physicians'(20); 'comparing health-care providers' perspectives on complementary and alternative medicine in childhood cancer between Netherlands and Indonesia'; and a pilot study of 'enhancing the quality of life for palliative cancer patients in Indonesia through family caregivers(20). However there was no report on symptom burdens, palliative management, and spirituality in patients with advanced cancer. To explore the symptom experience, palliative management, and spiritual wellbeing in the ACPs might find the symptoms that are prone to cause patients' suffering, identified effectiveness management as well as the spiritual wellbeing to comfort them during their cancer life trajectory period.

STUDY OBJECTIVE

The study aimed to 1) describe the symptoms experienced by patients with advanced cancer in terms of prevalence, frequency, severities and distress; 2) describe the palliative management (PM) for ACPs in terms of number and its effectiveness; and 3) investigate the ACPs' spiritual wellbeing state upon: 4 domains of personal, communal, environmental, and transcendental.

METHODS

Study design, settings, and participants:

A cross-sectional descriptive design was applied based on the Theory of Symptom Management⁽²¹⁾ to describe the symptom experience; symptom management strategies; and symptom status outcomes. Regarding the “symptom experience” dimension, it mainly focuses on the perception of symptoms (number of symptom prevalence), the evaluation of symptoms (frequency and severity of symptoms), and the response to symptoms (symptom distress). For the “symptom management strategies”, this study highlights on the number and its effectiveness of palliative management strategies. Lastly, the third dimension of the “symptom status outcomes” also focused on “spiritual wellbeing” of the ACPs.

The setting was one government hospital in West Java region. 120 APCs who met the criteria; age over 18-year old with medically confirmed as in stage 3 to 4 cancer of any types: excluding brain and hematologic cancer; patients age more than 60 years old got cognitive functioning screened under instrument (PMSQ)⁽²²⁾ with scores minimum of 8/10; and literate and willing to participate.

Data collection tools:

Data were collected from September to November 2016 by using four instruments including; 1) The Demographic Background Questionnaire [DBQ], 2) The Memorial Symptom Assessment Scale [MSAS]⁽²³⁾, 3) The Palliative Managements [PM] (developed by the primary investigators), and 4) The SWb-SHALOM Questionnaires⁽¹⁸⁾. The Portable Mental Status Questionnaire [PMSQ]⁽²²⁾ was a screen test used in patients with age more than 60 years to identify their cognitive.

Detailed of the instruments in this research study as followed;

The Demographic Background Questionnaire [DBQ] this questionnaire was developed by the investigators to gather information about general characteristics of participants. The questionnaire included personal background and health-illness related history.

The Memorial Symptom Assessment Scale [MSAS]⁽²³⁾; The principal researchers got permission from the original author of MSAS. It was a validated and globally used instrument to assess multifaceted symptoms experienced within the past 7 days to evaluate prevalence, frequency, severity, and distress-related (bio-psycho-social-spiritual) symptoms. The scoring related with assessment scale to measure the prevalence, frequency, severity, distress of symptom experienced by advanced cancer patients as followed.

The prevalence of symptom – that was any changes that patients felt or sense related with cancer disturbances. It can indicated by numbers 0 = ‘No’ and 1 = ‘Yes’. The total numbers of symptoms occurrences were counted. The higher score indicated the greater number of prevalence occurs of particular symptom(s).

The frequency and severity of symptom – evaluated by scoring of the 4-point “likert-scales”: ‘rarely’ = 1, ‘occasionally’ = 2, ‘frequently’ = 3, ‘almost constantly’ = 4. While for ‘severity’ was determined by the extent indicated from quantitative “score-rank/ level” of discomfort it caused. Grading started with ‘slight’ = 1, ‘moderate’ = 2, ‘severe’ = 3, up to rank ‘very severe’ = 4.

The symptom distress was a scale between ‘not at all’ = 0, ‘a little bit’ = 1, ‘somewhat’ = 2, ‘quite a bit’ = 3, and ‘very much’ = 4. The symptom distress score was recorded using adjusted continuous score needed upon other two dimensions (i.e., frequency and severity/ intensity). Thus recorded as division of scale between 0 - 4 as followed: 0.8; 1.6; 2.4; 3.2 and 4.0 respectively. The final score on each symptom occurrence, frequency, intensity, and distress were summed up and be made in average. The study participants took around 10-15 minutes to complete the MSAS.

In this study, the investigators translated the original in English MSAS into MSAS-Indonesian version which was back translated and content validity index was .94. The pilot test was done with 15 Indonesian participants and the internal consistency reliability was .90 for symptom prevalence, .79 for symptom frequency, .83 for symptom severity and .87 for symptom

distress. After finished with 120 participants, the internal consistency reliability was .82 for symptom prevalence, .82 for symptom frequency, .87 for symptom severity and .91 for symptom distress.

1. The Palliative Managements Questionnaire [PMQ] was developed by the investigators by reviewing literature and adapted some content from previous Thai nursing researchers' works with the similar study. The assessment reflected frequency number of uses (n) of each category Traditional Complementary Alternative Medicine (T/CAM). It covered eight sub-categories: (1) The use of T/CAM, or Mind-Body support behaviors, (2) Using self-body exercise, (3) Traditional supplement herbs/ Change in dietary patterns, (4) Books/ Reading diversities, (5) Spiritual-related approaches, (6) The Music or Artwork (7) Multimedia, (8) Support Groups. For additional section C. Spiritual healing-related resources or Transcendental/ Miraculous Encounter. The grading indicated either use it or answer 'Yes'= 1 or 'No' = 0 if not applied. The total score was counted based on how many types of T/CAM used and the average frequency from each remedy used. The more number identified more users selected the approach and felt benefit from it.

The PMQ Indonesian version was reviewed for its' face validity by respective 2 bilingual Indonesian experts in cancer setting and an English-Indonesian doctorate degree languages proficiency holder, then the PMQ - Indonesian version was back translated and content validity index was .90. This new instruments (PMQ) had been validated in the pilot test with 15 participants and Cronbach's alpha coefficient was .68 and .83 for 120 participants.

2. The SWb-SHALOM Questionnaires⁽¹⁸⁾. This questionnaire comprises 4 domains of spiritual wellbeing: personal, communal, environmental, and transcendental. The Indonesian version was allowed to use by the developer. The ACPs were asked to self-rated the 20 items of SWb-SHALOM using a five-point Likert scale from very high (= 5) to very low (= 1). It comprised questions to find out: (a). How important the patient thinks each area is for an ideal state of spiritual wellbeing, and (b). How patient feels each item reflects to their existing personal experience most of the time⁽¹⁸⁾. The score were summed up. The higher the score meaning the ideal of spiritual health dimension believed or expected to be. The SWb-SHALOM Questionnaires Indonesian version has been test in the pilot study (15 participants), and cronbach's alpha values for the Ideal SWb was .96, and .95 for Lived Experiences SWb. For

120 participants, cronbach's alpha values for the Ideal SWb was .96, and .91 for Lived Experiences SWb.

Statistical analysis: Statistical Package for Social Science (SPSS) for Windows version 19 was used to analyze the research data. Data elaborated by using descriptive statistic.

Ethical considerations: This study was approved by the Institutional Review Board (IRB) at Ramathibodi hospital, Mahidol University, Thailand; number ID 06-59-37 (MURA2016/395) and got approved from the hospital from West Java, Indonesia.

RESULTS

Participants were 120 ACPs whose age were ranged from 18 to 73 years, with a mean = 47.08 (SD = 11.54). Majority of them were women (75.4%), Islam (92.6%), married (85.0%), duration of marriage more than 20 years (47.5%), education level in senior high school (25.8%), standard school (25.0%), Family income below 3 Million Rupiah (50.0%) and between 3 - 5.9 Million Rupiah (49.2%), just sufficient financial status (74.2%), and source of treatment payment by government medical care 50.0%. Majority of them used complementary therapy (77.5%) and half of them used spirit/mind/body control (50.8%). Participants were medically confirmed of cancer in stage III (48.3%) and stage IV (51.7%). Nearly half of patients had breast cancer (43.3%) follow with head and neck (20.8%), colon-sigmoid (11.7%), and gynecology (9.2%). Their previous treatments were surgery (13.3%), radiation (10.8%), and chemotherapy (50.8%). The duration of their sickness with cancer after diagnosis was ranged from 15 days to 105 months with mean of 9.45 months. Some of them (30.8%) were in metastasis stage which lung (9.2%) was the prominent metastasis site. Most of them (82.5%) did not have other comorbid diseases (Table 1). The ACPs' self-report about the experienced symptoms in regard with the prevalence, frequency, severity, and distress response as followed;

1. *Symptom Prevalence:* The mean symptom was 15 (SD = 5.8) with range from 2 to 27 symptoms. The first top five symptom prevalence was: lack of energy (n =85; 70.8%¹), pain (n = 81; 67.5 %²); worrying (n = 81; 67.5 %²); hair loss (n = 79; 65.8%³); feeling sad (n = 78; 65.0%⁴) equally to difficulty sleeping (n = 78; 65.0%⁴) and I don't look like myself (n = 77; 64.2%⁵).

2. *Symptom Frequency*: The mean of 24 symptoms and ranged from 1.88 to 2.91 with minimum-maximum scores of 1- 4. Top-five symptom frequency were lack of energy (mean = 2.92¹, SD = 1.04), problems with sexual interest (mean = 2.89², SD = 1.13), numbness/tingling (mean = 2.80³, SD = 1.06), difficulty swallowing (mean = 2.66⁴, SD = 1.23), and difficulty sleeping (mean = 2.60⁵, SD = .94).
3. *Symptom Severity*: The mean score of symptom severity ranged from 1.50 to 2.71. Top-five of symptom severity were: hair loss (mean = 2.73¹, SD = 1.15), weight loss (mean = 2.34², SD = 1.13), lack of energy (mean = 2.32³; SD = 0.99), swelling of arms/legs (mean = 2.27⁴, SD = 1.10), and difficulty swallowing (mean = 2.24⁵, SD = 1.30).
4. *Symptom Distress*: Top-five of symptom distress were pain (Mean = 2.861, SD = 1.06); lack of energy (Mean = 2.77², SD = 1.21); lack of appetite (Mean = 2.62³, SD = 1.09); vomiting (mean = 2.52⁴, SD = 1.12); and nausea (mean = 2.42⁵, SD = 1.05).

The Palliative Management (PM) for ACPs referring to help or resources received, the use of integrative modalities through mind-body-mental, and spiritual-related healing activities as detailed; *Help/ Resources used*: The top five of help/supports used were; 1) Beloved immediate family and friends (98.3%); 2) Rely upon the only Mighty Power to provide miraculous Divine healing (97.5%) equally to doctors and other health professionals explain needed information (97.5%); 3) Nurses explain needed information (95.8%); 4) Intercessory prayers group for healing/strengthen faith (73.3%); and 5) herbalist (49.2%).

Top-five effectiveness of helps or resources perceived by the participants as the first rank was “seeking for God’s help”. For almost majority of cases (97.5%) rely upon the only Mighty Power/Most Higher Being/God to provide miraculous Divine Healing (mean = 2.88; SD = 0.33). The second rank was helps effectiveness from beloved core family and friends (98.3%; mean = 2.85, SD = 0.41). The third rank was intercessory prayer group for healing and faith (73.3%; mean = 2.64, SD = 0.55). The fourth rank was psychic hypnotism (mean = 2.50, SD = 0.71). The fifth-rank effective helps or resources perceived by the ACPs respondents, from “other” as additional expressions (mean = 2.48, SD = 0.81).

Uses of Natural Product by ACPs: Top five natural products or resources used were: 1) Herbal and botanicals (i.e., Aroma therapy, Chamomile oil, Lavender oil, and local familiar oil) (63.3%); 2) Intake multi/megavitamin/ mineral, tonics, and fish oil (55 %); 3) Others (41.7%); 4)

Intake specific diet food/ dietary supplements and modified eating patterns (33.3%); and 5) Local Folk herbs remedies “Jamu” (27.5%).

For the top five effectiveness of natural products were; 1) Intake specific diet food/ dietary supplements and modified eating patterns (mean = 2.05, SD = 0.82); 2) Intake multi/megavitamin/ mineral, tonics, and fish oil (mean = 1.98, SD = 0.73); 3) Detoxification (mean = 1.86, SD = 1.07); 4) Ayurveda, or Middle-East herbs (mean = 1.75, SD = 0.96); and 5) Homeopathic or immune system stimulator (mean = 1.64, SD = 1.01). In contrast, consuming herbal and botanicals¹ such as drink the boiled ‘daun sirsak’ (soursop leaves), ‘kulit manggis’ (mangosteen skin), or ‘Jamu’⁵ (local Folk herbs remedies) was a popular usage (63.3¹%, 27.5%⁵ respectively) but less effective had been viewed (mean = 1.58, SD = 0.96; mean = 1.15, SD = 0.80).

Mind-Body-Mental (MBM) activities experienced: Top five of using of modalities related with Mind-Body-Mental (MBM) activities of ACPs were 1) therapeutic touch (34.2%); 2) art therapies (i.e., music, art creativities, nature exposure) (30.8 %); 3) meditation (25.8 %); 4) hot-cold appliances (24.2 %); and 5) body massage therapy (18.3%).

The top five effectiveness of Mind-Body-Mental activities were; 1) meditation (mean = 2.58, SD = 0.50); 2) therapeutic touch (mean = 2.44, SD = 0.74); 3) others (mean = 2.38, SD = 0.96); 4) art therapies (i.e., music, art creativities, nature exposure) (mean = 2.32, SD = 0.48); and 5) guided imagery (mean = 2.27, SD = 0.59).

The Spiritual-related healing resources/ activities experienced: Top three of using of Spiritual-related healing resources/ activities experienced by ACPs were; Spiritual self-development and media support (89.17% mean = 2.73, SD = 0.45); active involvement in spiritual-related healing / transcendental encounter (35.0%, mean = 2.45, SD = 0.86); and others spiritual-related healing activities (15.0%, mean = 2.28, SD = 1.02).

The ACPs’ spiritual wellbeing state over the four domains of Personal, Communal, Environmental, and Transcendental refers to SWb-SHALOM and analyze whether in harmony or disharmony (balanced or dissonance)

Spiritual wellbeing state: Ideal and Lived Experience pertaining ACPs’ SWb-SHALOM domain-factors. All Ideal spiritual wellbeing scores for Personal, Communal, Environmental, and Transcendental domains have same range min-max between 9-25, but differences in each mean

and SD. Ideal Personal (mean = 20.89, SD = 3.62), Ideal Communal (mean = 21.28, SD = 3.54), Ideal Environmental (mean = 21.47, SD = 3.34), Ideal Transcendental (mean = 22.56, SD = 3.90). And the Total Ideal SWb min-max scores between 41- 100 (mean = 86.19, SD = 12.95).

In Lived Experience SWb, the Min-Max scores within the responds given by the respondents were varied unlike in the Ideal SWb. The Lived Experience in personal domain indicated Min-Max responds ranged between 13- 25 (mean = 20.68, SD = 2.99), Min-Max for Communal 14- 25 (mean = 21.38, SD = 2.80), Environmental Min-Max 13- 25 (mean = 20.73, SD = 3.90), Transcendental in Lived Experiences, Min-Max was between 15- 25 (mean = 23.18, SD = 2.44). And lastly, the Total Lived Experiences ranged between 60- 100 (mean = 85.98, SD = 9.53).

DISCUSSIONS

Participants' background information (low education, and poor economic) and illness history had contributed to participants in this study for their late seeking help (at advanced stages) which was commonly occurs in developing and under-developed countries⁽²⁴⁾⁽²⁵⁾. Beside Indonesia's incidence rate of advanced cancer was very high as 65% that patients visited medical doctors when cancer was in advanced stages⁽²⁶⁾. Even though, for those with better education and financial state, the late seeking help might still have happened owing to ignorance, or symptoms was neglected⁽²⁷⁾ or out of reason limited time to spend for health check-up⁽²⁶⁾.

In Indonesian culture, wherein family bonding and attention still strong thus family has a responsibility for the patients care and symptom management. With insufficient palliative care system in Indonesia, family caregivers were key factors to assist improving wellbeing in advanced cancer patients with multiple distress symptoms⁽²⁸⁾.

The various symptom experiences found in this studied, revealed that: consistently appeared in the top-five list of symptom prevalence, frequency, severity, and distress were: lack of energy. Pain only appeared in top-five symptom prevalence, and symptom distress. Difficulty sleeping presented in prevalence, and frequency. Difficulty swallowing presented in frequency, and severity. Hair loss appeared in symptom prevalence and symptom severity. Thus, other symptoms that once appeared in the first top-five list of symptom experiences, however, were not consistently appeared again in another domain top-five lists. Those top-five symptoms in the list

that inconsistent and less significant appeared in other symptoms dimensions were from: *Prevalence*: worrying, feeling sad, “I don’t look like myself”. From *Frequency*: problem with sexual interest, and numbness/ tingling at hands or feet. From *Severity*: weight lost, and from *Distress*: lack of appetite, vomiting, and nausea not appeared in other symptom experience dimensions. These symptom evident supported by classical findings that suggested symptoms experience was multi complex, multi-faceted⁽⁷⁾⁽²¹⁾⁽²⁹⁾⁽³⁰⁾⁽³¹⁾ and added from this study as it showed, they had symptom dimension emergence in varieties too.

Referring to demographic data, in regard with 77.5% ACPs reported used complementary and alternative medicine (CAM) therapy, was in line with the WHO palliative care management mandates and traditional medicine strategy approach which the usage can improve people’s whole health and well-being, which the implication appearing across the globe since more than two decades ago and WHO also put Traditional Medicine into the world Strategy since 2014–2023⁽³²⁾. CAM used had earlier been reported from developed and developing countries⁽¹⁶⁾⁽²²⁾⁽²⁹⁾⁽³³⁾⁽³⁴⁾⁽³⁵⁾. And with the reports from Asian regions; In 2012, Tai-Guo and colleagues⁽³⁵⁾ reported the survey of traditional-Chinese herbs medicine usage (T/CAM) from 587 cancer patients from Southwestern China; 53% use T/CAM and indicated that cancer patients were likely to use complimentary method. Report of a survey of T/CAM usage among South East Asian countries⁽³⁶⁾ indicated that 2% of Indonesians used T/CAM and among 10 countries the rate of using T/CAM was highest in cancer population (56%-84.5%)⁽³⁶⁾.

While, viewed from the top-five help/ resource most acknowledged by almost all ACPs (97.5%; mean = 2.88¹, SD = 0.32) was from ‘The Only Mighty Power/God’, that also believed God can provide Miraculous Divine healing. Of whom, the respondent ACPs (n = 117; 97.5%) expressed this resource was the most effective. For Muslims mostly follow traditional practices and belief in ‘Allah’ as Mighty Power who can help them cure from dangerous diseases⁽³⁷⁾. The results were understandably for Indonesian context, as monotheist-belief Nation. By this also explained the reason of some ACPs regardless their religion background, had joined the intercessory prayer group (73.3%; mean = 2.64³, SD = 0.55) or gathered with in the so called “prayer or sermon pleading for God’s Mercy to heal”. The terminology used in, and religious/spiritual activities referred to intercessory prayer group for Muslims and Christ-believer devotees might be different but with the same purpose to help ACPs for closer relationship with Allah/ God, strengthen faith in coping with the illness, or even expecting miraculous healing from.

For Muslims many rely on 'Allah' heal their illness with his will and bless; so they often recited Hadith word like "The One who directed the disease directed the therapy" (Muwatta 50: 5.5.12)⁽³⁷⁾. For this patients referred to intercessory prayer group for healing and faith; as patients believed from this spirituality-related resource or activities they cultivate 'hopes'⁽³⁸⁾, expectation on 'miracle healing', 'strived for stronger faith', 'gain inner peace' to cope with, and felt very much effective⁽³⁹⁾.

Nevertheless, though, still majority resources from nurses (95.8%) and doctors (97.5%) in the sample studied in contrast was perceived less effective. It might gave clue that infrequently some people in crisis tried to seek many more sources and help or the help they received may could not reach their expectation toward hope and belief. Also it could be explained that healthcare providers paid more attention toward disease and treatment than cultural and belief of patients⁽⁴⁰⁾.

Interestingly, also despite of multifaceted cancer symptoms, Indonesians with advanced cancer (I-ACPs) in this still place high appreciation upon ideal in joy in life, awe at a breath-taking view, and in harmony with the environment of which to place these aspects on top-five importance in life. And in actual course, cancer challenges enhanced their forgiveness toward others, more respect for others, and more love of other people. Thus, the additional lived experiences with advanced cancer eventually cultivate the sense of spiritually wellbeing in its own meaning to individual person despite the emerged symptoms. Of which, thought to certain extent the ACPs' response congruent with other studies - though done upon believers in miraculous healing context within Muslims tradition community⁽³⁷⁾.

In terms the essence was expectation for Divine/ Allah- related healing⁽³⁷⁾. Through this spiritual-related healing expectation which helped patients sustain their faith and yield through prayers, meditation, or contemplation⁽²¹⁾⁽⁴¹⁾⁽⁴²⁾⁽⁴³⁾. Likely as they had gained the benefits from kind of spiritual complementary therapy⁽⁴⁴⁾. In that, the religious healing expectation acknowledges the presence of a supernatural power who can restore the natural order⁽³⁹⁾ which still room for even if not physical healing but inner healing had lot of meaning to patients. Those who believed in the possibly given Miracle Healing through the presence of Divine's intervention (regardless religious background) appeared compatible with foreign study on phenomenal super-natural total healing that in the different countries had occurred randomly in the midst of big crowd gathering with healing expectation⁽³⁹⁾⁽⁴⁵⁾⁽⁴⁶⁾⁽⁴⁷⁾.

In that, similar to what Ando and colleagues⁽⁴⁸⁾ asserts three types of transformation could possibly yield from life threatening illness: those with peaceful mind, while certain people with mixed positive attitude and uneasy feeling, or kind of people with just mostly in uneasy feeling. While reflected how they grasp the meanings from presenting illness, either positive meaning, natural acceptance, negative acceptance, still searching for meaning or regret and sorrow⁽⁴⁸⁾. However, in the presenting study, the sample ACPs appeared the reflection in balanced SWb. This wellbeing spiritually might help prevent patients from the negative thoughts and sense of hopelessness or prolonged sorrow.

CONCLUSION

The findings from this study provided empirical evidences to understand the symptom experiences, palliative management and spiritual wellbeing in ACPs. The results demonstrated the different of those symptom dimensions between symptom perception (prevalence); evaluation (frequency, severity); and response (distress). The results generated knowledge for nurses as important care providers. It is strongly suggested that the knowledge generated from this investigation can be used by nurses and health care providers to design appropriate and cultural sensitive intervention programs for the ACPs. In addition professional nurses should promote spiritual wellbeing in this group because almost of them used spiritual wellbeing for healing their symptom distresses. The most important point is that care given to this group of ACPs should corroboratively be implemented by patients themselves, caregivers, and health care providers.

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CONFLICTS OF INTEREST

The author declare no conflict of interest

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