



## Spirituality in adolescents with cancer

Sembiring Lina Mahayati, Allenidekania\* and Hayati Happy

Faculty of Nursing, Universitas Indonesia, Depok, Jawa Barat, Indonesia

### KEYWORDS

Adolescent;  
Cancer;  
Experience;  
Spiritual

### Abstract

**Objective:** As adolescents with cancer are at risk of experiencing spiritual distress, they tend to have unique spiritual needs. Spirituality plays a significant role for adolescents with cancer as it contributes to increased comfort and calmness, and better coping mechanisms when confronted with the illness, which indirectly improves the adolescent's quality of life. This study aimed to explore spiritual experiences in adolescents with cancer.

**Method:** A qualitative study using a phenomenology approach was conducted. Nine adolescents with chemotherapy-treated cancer were purposefully selected to be involved in this study. The data were analyzed using thematic analysis.

**Results:** This study identified six spiritual themes in adolescents with cancer: *a)* accepting their illness; *b)* believing their illness in God's will; *c)* improving spiritual practices; *d)* expressing empathy to parents; *e)* maintaining relationships with significant others, and *f)* achieving self-actualization.

**Conclusions:** This study demonstrated that spirituality gave hope to adolescents by helping them to overcome existential problems related to cancer. We believe it is necessary for nurses to address the spiritual needs of adolescent with cancer as this will help these young people accept their condition with more grace and humility.

© 2018 Elsevier España, S.L.U. Todos los derechos reservados.

## Introduction

Cancer is a disease with a high mortality rate, and it is still an unresolved health problem in many countries. In Indonesia, cancer deaths are ranked seventh among all disease-induced deaths, with a prevalence of 1.4 deaths per 1000 population<sup>1</sup>. The International Agency for Research on Cancer (IARC) revealed that there are 14 million new cases of cancer in children and adult occurring in the world today, and the World Health Organization has estimated that cancer survivors will continue to increase up to 11 million by 2030<sup>2,3</sup>.

Cancer can strike anyone regardless of age group, including children<sup>4</sup>. Adolescence is a period of rapid growth and

development, where an individual's life potential also begins to manifest. A cancer diagnosis during this important period will affect an adolescent's next stage of life<sup>5</sup>. Adolescents who experience cancer have unique spiritual needs related to their critical health condition, and this puts them at higher risk of experiencing spiritual distress<sup>6</sup>.

As adolescents with cancer tend to have unique spiritual needs, nurses should try to understand these needs. Nurses play a pivotal role in providing spiritual care to patients, by being good listeners and encouraging patients to express their beliefs<sup>7</sup>. The International Council of Nurses Code of Ethics for Nurses said that all nurses need to look after the spiritual needs of their patients.

\*Corresponding author.

Email: [alleni2011@yahoo.com](mailto:alleni2011@yahoo.com) (Allenidekania).

Currently, the majority of nurses are mainly focused on how to meet the adolescent cancer patients' physiological needs. Despite being aware that these patients have unique spiritual needs, nurses are still more focused on the physical needs rather than these spiritual needs<sup>8</sup>. The spiritual needs of adolescents with cancer need to be explored further. This will enable nurses, as caregivers, to include addressing the spiritual needs of these patients in their repertoire, which may indirectly improve each patient's quality of life.

## Method

A descriptive phenomenological approach was used to explore the phenomenon of those patients who were affected by cancer in the study. This approach describes the essence of the experience of adolescents with cancer<sup>9</sup>. The participants were nine adolescents aged between 10-19 years, all of whom had cancer and underwent chemotherapy. A purposive sampling approach was used to recruit participants from the Indonesian Pediatric Oncology Foundation. The study was presented to the eligible participants who met the requirements of the study. The eligibility criteria included: *a*) participants were aged between 10-19 years and underwent chemotherapy; *b*) participants were Indonesian-speaking, and *c*) participants were cooperative and willing to become respondents by signing an informed consent form.

The data collection was conducted during March and April, 2016. The data collection method used semi-structured interviews with open-ended questions. Interviews were performed at the place and time agreed upon by participants, and they lasted 25-45 min. The data collection tools involved the author herself, interview guidelines, field notes, and a voice recorder. Interviews with each participant were concluded after all necessary information had been obtained, according to objectives of the study. This study was conducted after clearance was given by the Research Ethical Committee of Nursing Faculty of the Universitas Indonesia and after a study site had been issued. Ethical considerations used the principles of self-determination, privacy and dignity, anonymity and confidentiality, protection from discomfort and harm, and justice<sup>10,11</sup>.

## Results

Nine adolescents participated on this study were aged between 14-18 years. They were diagnosed with non-Hodgkin lymphoma (2 participants), nasopharynx cancer (5 participants), acute lymphoblastic leukemia (2 participants), and ovarian cancer (1 participant).

A total of 6 themes were identified to describe the spirituality of adolescents with cancer undergoing chemotherapy. The themes were:

1. Accepting their illness. This theme describes participants' feelings toward their cancer diagnosis and the treatment programs they had to endure. Two reactions were shown by participants: *a*) accepting the condition imposed on them or accepting them sincerely, and *b*) regretting their condition or questioning the condition.

Below is an expression of the participants who showed sincere feelings:

"Yes the most important thing to do is for me to recover" (P1).

"[...] however it is my destiny; I just have to go on" (P2).

Below are 2 statements from participants who bargain to accept their condition:

"[...] there are more wicked people out there than me; I think I was not that naughty so why should I suffer?" (P2).

"Sometimes I (F) say to myself, 'Why am I completely different with my sister'" (Crying) (P9).

2. Believing their illness is God's will. This theme indicates that the participants believed God had chosen this illness for them and expected them to trust Him, understanding that their condition was part of God's plan for their lives. The statements below revealed that these patients had yielded their lives to God's plan:

"All diseases surely have their cures... God also gave us this disease definitely with its cure... it is impossible it does not exist" (P1).

"Yes, I feel more grateful now and realize that only Allah's grace can heal me" (P5).

3. Improving spiritual practice. Improving spiritual practice is an act committed by participants in an effort to accept that what happened to them is a warning from God. The action arises because people begin to realize that a greater power exists beyond the reach of the human being, which would also provide them with comfort. Here are three statements that support this:

"Before, I barely prayed to God, but now Alhamdulillah (thank God) I go to pray more often" (P2).

"It changes me and makes me closer to God, thankfully..." (P5).

"After the diagnosis, I sensed that it was a warning from God, and it makes me recite Al Quran more often" (P9).

4. Expressing empathy to parents. Adolescence is a period when social and psychological changes switch focus to one's independence and identity. Adolescents with cancer, however, often feel powerless and more dependent on their parents and families. Participants also feel that their presence today is frustrating for their parents and families. The following statements are related to participants' empathy toward parents:

"[...] it could frustrate my parents..." (P1).

"Father is sending me money here continuously, so I can eat..." (P5).

Other participants revealed that their existence was a burden to their parents and families. These presumptions are identified from the following statements:

"[...] (my presence) here is burdening my family and my aunt, who live in Bekasi. During chemotherapy, she is

always accompanying me from start till dawn; I feel so sorry for her” (P5).

“I feel sad for my parents who always care for me. They try so hard to stay beside me (F) all this time” (P9).

5. Maintaining relationships with significant others. Closeness with others is explained by participants as a relationship with another whom the participant considers to be influential in their life, in this case parents, family, and friends. Here are some quotes that support this theme:

“Family is important, Sus (nurse-red), if they were not there yesterday, I do not know how my day would be yesterday Sus” (P1).

“I just wanted my family to gather even for a while, but the hospital keeps them busy. Being together like this feels nice, I think” (P2).

Friends—or peers in this case—are those the participants considered important enough to provide them with support and motivation to build positive attitudes. Statements that support this theme are:

“Ya, right when I am home alone I do not know what to do. If only there were friends to chat, joke, and laugh with me” (P2).

“Happy, my friends love to cheer me up” (P5).

“There are my friends here, having my friend beside me makes me strong, to play together and chill” (P6).

In addition, participants also expressed feelings of appreciation for their friends. Here is this patient’s statement:

“Yes, they respect and appreciate me even more” (P2).

6. Self-motivation. Cancer treatment requires a long period of time, so this makes participants feel exhausted and bored. There were some efforts made by participants to overcome this boredom. The following statements are expressed by participants:

“[...] especially when there is a song played, I try to cover it, cover is like we sing a song...” (P5).

“[...] to keep my sadness away, I read books or play games” (P9).

Achievement is a form of adolescent self-actualization. Self-actualization helps to develop and build self-potency and produce something positive. Having cancer was not an obstacle for patients; they still were outstanding individuals. This is indicated by the following statements:

“Yes, Sus, I definitely win. I am really happy, Sus” (P1).

“I felt sick after it (chemotherapy) yet also feel fortunate, because I was known by many people, I feels very proud” (P5).

Adolescents’ social lives can be viewed from emotional and intellectual perspectives. In establishing social relationships, adolescents choose their peers based on socio-

economic factors and identical interests, talents, and abilities. Participants in this study became friends with those who had a similar condition, which improved their spirit. This is expressed in the following statement:

“There are friends here, seeing my friend makes me strong to play together and chill” (P6).

Other participants said that they were happy to follow activities together with fellow children with cancer. The statements are as follows:

“I would like to participate in a charity event; there are many interesting activities there. Here, I am bored” (P6).

“Let us watch together what are children with cancer in the Foundation doing” (P7).

## Discussion

Cancer is a severe health conditions and poses great risk of spiritual distress. O’Conner-Von<sup>12</sup> stated that adolescence is a period of transition from dependent child to independent adult and if adolescence able to adapt with their illness, they will be independent and will use healthy coping strategies.

Reynolds et al<sup>13</sup> stated that positive spiritual coping strategies correlate with fewer problems in adolescents with chronic illness. Someone with a negative spiritual coping strategy could be detrimental, such as when believing that what happened was a punishment from God<sup>14</sup>.

In this study, adolescents had both negative and positive spiritual coping strategies. Negative spiritual coping strategies were shown when participants were first diagnosed with cancer. After a therapy program, these patients began to sincerely accept their condition. Positive spiritual coping strategies were mostly demonstrated by participants who had been diagnosed with cancer for more than a year and were entering the maintenance treatment phase. As matter of fact, some of them were undergoing chemotherapy again due to relapse.

Taylor et al<sup>15</sup> claimed that adolescents who were diagnosed with cancer and had the possibility of facing sudden death often have more focused attention on their spirituality regardless whether the disease is in remission, relapsing, or even cannot be cured. This result was also congruent with Engvall et al study<sup>16</sup>, which claimed that the psychosocial function of adolescents with cancer improves over time. It even becomes exemplary as their health improves, and they are often less anxious and depressed compared to the non-cancer group of adolescents the same age.

Believing that the illness they suffered was God’s will indicates that adolescents believe that everything that happens in life is part of God’s plan. Adolescents with illnesses rely more on spiritual beliefs to overcome their problems<sup>17</sup>.

Someone who is facing difficulties usually reverts to the Almighty as “something” greater than themselves<sup>18</sup>. In this study, some participants said that the disease they suffered occurred because God granted it to them, while other participants said that when God makes you ill, then He will provide the relief as well.

Some participants in this study claimed that the disease they are currently experiencing comes from God, so God will give the cure as well. Participants understood that something going on in their life was a destiny from God. Religious belief about the possibility of recovery by a miracle and God's will is also included among religious sources that give them high life expectancy<sup>19</sup>.

Fowler's spiritual development theory described that at this stage of life, an adolescent is capable of understanding abstract things and believing and accepting that God has supreme power. One of the participants gave a statement on this theme: "God gave us this disease, definitely along with its cure." The finding of adolescents' beliefs that the illness they suffered is the will of God is an indication that adolescents accept their condition. This result corresponds with Ragsdale et al study<sup>20</sup>, which stated that God has His own reason to choose them to experience the illnesses, and they believe that they are chosen by God.

Adolescents use different coping strategies and beliefs as one of the main techniques to provide comfort. Spiritual practice is a religious practice that is often identified by the patient as a prayer to cope with the disease<sup>21</sup>. In this study, all participants said that they improved their overall spiritual activity even more after experiencing the disease, as the disease increased their trust in God and their expectations of healing. Spiritual activities were performed in accordance with their religious beliefs.

Spurr et al<sup>8</sup> stated that adolescents whose spirituality represented a good relationship with God are associated with the belief in accordance with their beliefs. Another study conducted by Revuelta-Iniesta et al<sup>22</sup> revealed that respondents admitted that they used spiritual treatment. Praying is most popular for children, followed by the children praying for themselves. Prayer or religion is also often used to manage the symptoms suffered by children with sickle cell anemia<sup>23</sup>.

A phenomenology study conducted by Al Omari et al<sup>24</sup> on the coping strategies of adolescents with cancer stated that adolescents improved their prayers to overcome their suffering. Rahnama et al<sup>19</sup> said that a relationship with Allah through praying, cultivating an inner relationship with Allah, and talking to Allah are recognized as spiritual practices.

Prayer or other rituals related to spirituality or religion have the ability to produce a calming effect, love, or a sense of belonging for one's self, and this kind of practice is considered to provide health benefits<sup>25</sup>. The adolescents in this study showed closeness to God through prayer, participation in religious activities, and through reading the holy book. They said prayers made their lives better.

Empathy is a response by someone to understand others. The theme of empathy in this study demonstrated that adolescents felt their situation was a burden to their parents. Santrock<sup>26</sup> stated that autonomy is important in adolescence as autonomy makes them want to reduce childhood dependence on their parents, develop emotional autonomy, and reduce the ideal image of parents and dependence of emotional support from their parents.

Participants in this study felt sad because their parents had to wait for them during therapy, and because their parents had to afford a great amount of finance to pay for the treatment. This coincides with the study conducted

by Clayton-Jones et al<sup>27</sup>, which stated that adolescents who participate in a collaborative relationship with God believe they must do their part and should not trouble others.

Cancer experienced by adolescents changes their relationships with peers and family. Parents generally perceive themselves as protectors, and this has been proven by children responding to their parents as protectors. On the one hand, adolescents were happy to show a cheerful attitude because they were protected by parents and family members. On the other hand, the children actually wanted to avoid making their parents feel sad or disappointed about what had happened to them<sup>28</sup>.

Cancer causes some changes in adolescent relationships with parents, family, and peers. A study conducted by Pehler and Craft-Rosenberg<sup>29</sup> explained that the experience of living spiritually is interpreted by teenagers as a desire to change their lives by improving their spiritual relationships, which is shown by relationship with oneself, others, and beyond self.

Hendricks-Ferguson said that adolescents with cancer have diverse spiritual resources. The authors also suggested that when physical limitations due to treatment and side effects begin to subside, adolescents are more dependent on peer support and less on spiritual support. This is also in line with the study<sup>30</sup> by Al Omari et al<sup>24</sup> that friendship is another contributing factor in helping adolescents to cope with their disease.

Adolescents in this study motivated themselves by doing their own hobbies. Cancer treatment requires a long period of time, which made them feel exhausted and bored. Participants in this study attempted to overcome their boredom by doing beneficial activities, such as playing games, singing, sports, and following the activities held by the Cancer Foundation.

Souza et al<sup>30</sup> explained that adolescents living with cancer often experience fear, anxiety, restlessness, unreliability, despair, and helplessness. Adolescents try to find comfort, as well as cope with the stress of the illness they experience, through spirituality, belief, and faith. They keep thinking positively, which can give them strength, calmness, and confidence, as well as increase self-care to improve their health, spiritual coping strategies and emotions—giving meaning to life by being around friends and family. Activities performed by the participants to get rid of their boredom are positive activities.

## Acknowledgement

The authors would like to thank God Almighty, the adolescents with cancer who participated in this study, the founding chairman of YOAI, and Kopertis Region VII, who assisted the authors with data collection.

## References

1. Kemenkes RI. Riset kesehatan dasar nasional. Jakarta: Badan Penelitian dan Pengembangan Kesehatan; 2013.
2. World Health Organization. World Cancer Day [accessed 2016 Feb 15]. Available at: [http://www.who.int/cancer/wcd\\_2016/en/](http://www.who.int/cancer/wcd_2016/en/).

3. International Agency for Research on Cancer. Latest world cancer statistics: Estimated Cancer Incidence [accessed 2016 Dec 18]. Available at: <http://www.iarc.fr/>.
4. Weiss AR, Hayes-Lattin B, Kutny MA, Stock W, Stegeng K, Freyer DR. Inclusion of adolescents and young adults in cancer clinical trials. *Semin Oncol Nurs*. 2015;31:197-205.
5. Phillips CR, Davis LL. Psychosocial interventions for adolescents and young adults with cancer. *Semin Oncol Nurs*. 2015;31:242-50.
6. McSherry W. The principal components model: a model for advancing spirituality and spiritual care within nursing and health care practice. *J Clin Nurs*. 2006;15:905-17.
7. Mazanec P, Tyler MK. Cultural considerations in end-of-life care: how ethnicity, age, and spirituality affect decisions when death is imminent. *Am J Nurs*. 2003;103:50-8; quiz 59.
8. Spurr S, Berry L, Walker K. The meanings older adolescents attach to spirituality. *J Spec Pediatr Nurs*. 2013;18:221-32.
9. Streubert HJ, Carpenter DR. *Qualitative research in nursing: Distruption and development*. 6th ed. Philadelphia: Lippincott Williams & Wilkins; 2011.
10. Holloway I, Wheeler S. *Qualitative research in nursing and healthcare*. 3rd ed. Oxford: Wiley-Blackwell; 2015.
11. Polit PF, Beck CT. *Nursing research: Generating and assessing evidence for nursing practice*. 9th ed. Philadelphia: Lippincott Williams & Wilkins; 2012.
12. O'Conner-Von S. Coping with cancer: a Web-based educational program for early and middle adolescent. *J Pediatr Oncol Nurs*. 2009;26:230-41.
13. Reynolds N, Mrug S, Guion K. Spiritual coping and psychosocial adjustment of adolescents with chronic illness: the role of cognitive attributions, age, and disease group. *J Adolesc Health*. 2013;52:559-65.
14. Tedrus GM, Fonseca LC, De Pietro Magri F, Mendes PH. Spiritual/religious coping in patients with epilepsy: Relationship with sociodemographic and clinical aspects and quality of life. *Epilepsy Behav*. 2013;28:386-90.
15. Taylor EJ, Petersen C, Oyedele O, Haase J. Spirituality and spiritual care of adolescents and young adults with cancer. *Semin Oncol Nurs*. 2015;31:227-41.
16. Engvall G, Cernvall M, Larsson G, Von Essen L, Mattsson E. Cancer during adolescence: negative and positive consequences reported three and four years after diagnosis. *PLoS ONE*. 2011;6:e29001.
17. Hendricks-Ferguson VL. Hope and spiritual well-being in adolescents with cancer. *West J Nurs Res*. 2008;30:385-401
18. Al Omari O, Wynaden D. The psychosocial experience of adolescents with hematological malignancies in Jordan: an interpretive phenomenological analysis study. *Scientific World Journal*. 2014;27:40-36.
19. Rahnama M, Khoshknab MF, Maddah SS, Ahmadi F. Iranian cancer patients' perception of spirituality: a qualitative content analysis study. *BMC Nurs*. 2012;11:19.
20. Ragsdale JR, Hegner MA, Mueller M, Davies S. Identifying religious and/or spiritual perspectives of adolescents and young adults receiving blood and marrow transplants: a prospective qualitative study. *Biol Blood Marrow Transplant*. 2014;20:1242-7.
21. Potter A, Perry AG. *Fundamentals of nursing*. 7th ed. Singapore: Elsevier; 2010.
22. Revuelta-Iniesta R, Wilson ML, White K, Stewart L, McKenzie JM, Wilson DC. Complementary and alternative medicine usage in Scottish children and adolescents during cancer treatment. *Complement Ther Clin Pract*. 2014;20:197-202.
23. Cotton S, Grosseohme D, McGrady ME. Religious coping and the use of prayer in children with sickle cell disease with asthma. *Pediatr Blood Cancer*. 2012;58:244-9.
24. Al Omari O, Wynaden D, Al-Omari H, Khatatbeh M. Coping strategies of Jordanian adolescents with cancer: an interpretive phenomenological analysis study. *J Pediatr Oncol Nurs*. 2017;34:35-43.
25. Mooney B, Timmins F. Spirituality as a universal concept: student experience of learning about spirituality through the medium of art. *Nurse Educ Pract*. 2007;7:275-84.
26. Santrock JW. *Adolescence*. 11th ed. Boston: McGraw-Hill College; 2007.
27. Clayton-Jones D, Haglung K, Belknap RA, Schaefer J, Thompson AA. Spirituality and religiosity in adolescents living with sickle cell disease. *West J Nurs Res*. 2016;38:686-703.
28. Kamper R, Van Cleve L, Savedra M. Children with advanced cancer: responses to a spiritual quality of live interview. *J Spec Pediatr Nurs*. 2010;15:301-6.
29. Pehler SR, Craft-Rosenberg M. Longing: the lived experience of spirituality in adolescents with Duchenne muscular dystrophy. *J Pediatr Nurs*. 2009;24:481-94.
30. Souza VM, Frizzo HC, Paiva MH, Bousso RS, Santos AS. Spirituality, religion and personal beliefs of adolescents with cancer. *Rev Bras Enferm*. 2015;68:509-51.