

Original Research Article

Spirituality relationship to the quality of life of children with cancer in Dr. Sardjito general hospital

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ABSTRACT

Background: In Indonesia, the prevalence of cancer up to 1.4 per 1000 population. Acute lymphocyte leukemia is one of type of cancers. Spirituality is an element that increasing and is recognized by many patients with the disease at an advanced stage. Assessment of spirituality in children acute lymphocyte leukemia had ever done by the researcher before shows that spirituality contributes a positive influence to the coping and the achievement of adaptation. Aim of this research was to know how the relationship between spirituality with quality of life in children with cancer.

Methods: This study used a mixed design (mixed method), with sequential explanatory strategy. Quantitative approach to the cross-sectional design and in- depth interviews in qualitative data collection. Research has received permission from the The Medical and Health Research Ethics Committee (MHREC).

Results: There is a relationship between spirituality and the quality of life of children with cancer with a total value of $p=0.001$. Spirituality related to the children quality of life emotional, school, and physical domains with each value of $p=0.001$, $p=0.026$, $p=0.028$. Spirituality is not related to the social domains with $p=0.054$. Qualitative analysis shows that there are six categories from in-depth interviews, that is namely; prayer as a healing pain, the joy and gratitude; the interaction of the source of happiness; loneliness sadness source; socialitation with the enviroment; seek help in overcoming difficulties.

Conclusions: There was correlation between spirituality and quality of life of children with cancer.

Keywords: Spirituality, Quality of life, Children with cancer

INTRODUCTION

Cancer is a disease causing the highest number of death. In Indonesia, it shows that cancer prevalence reaches 1.4 per 1000 population. In developing countries, cancer is the main cause of the death of the children in the age over six month years old. The cancer cases happened to the

children reach 2 – 6% and cancer is degenerative disease causing 10% death in children.¹

Based on the data above, it shows that palliative care to the child with cancer is needed to improve life quality of the patient during the medication and to survive. This can be done in any individual aspects either physis, emotional, psychological, or spiritual with comprehensive treatment.²

There were 1.124 cases of childhood cancer that occurs at Yogyakarta. Leukemia is the most common cancer diagnosis followed by retinoblastoma and neuroblastoma.² During the period 2000 to 2009 at General Hospital Yogyakarta known acute lymphoblastic leukemia cases occurring reached 40.6%, of cases of Acute leukemia myeloblastik much as 13.9, retinoblastoma (6.7%), neuroblastoma (5.5%), Wilm's tumor (4.5%), and non Hodgkin lymphoma (4.4%).³

Based on interviews with the nurses at general hospital, assessment of spirituality rarely done by nurses or other health professionals. According showed the importance of the role of spirituality in children with ALL.⁴ Conditions of family spirituality is an influential factor is large enough on how parents perceive the situation and accept their pain.

Assessment of spirituality in children cancer showed that spirituality stress negatively impact children.⁵ That is, the higher the level of spirituality of children, the lower the stress experienced. On the other hand, spirituality a positive impact on the achievement of coping and adaptation. The higher level of spirituality of children, the higher the achievement of coping and adaptation.

Measurement of quality of life in children with cancer at General Hospital Sardjito ever undertaken showed that in children aged 2-5 years had significantly more problems in procedures, treatment, and communications that impact on anxiety. Particular care is required during interventional procedures performed useful for the development of normal children.⁶

The study of the relationship between spirituality and quality of life of children with cancer in Yogyakarta has never been conducted. Therefore the writer is interested to study and conduct a deeper research regarding the relationship between spirituality and quality of life of children with cancer.

METHODS

This study is a mixture (mix method), with sequential explanatory strategy. Quantitative approach to the cross-sectional design, and qualitative approach with in-depth interviews. Population of the study is all children with cancer which are still under medication in General Hospital Yogyakarta. Sampling a total of 41 respondents using consecutive sampling in quantitative data collection and purposive sampling in qualitative data collection as much as 7 children and parents based on predefined inclusion criteria. Exclusion criteria of this research sample was a child who experienced a decreased awareness of the known secondary data that was information from nurses who did child care cancer. The study was conducted from August to September 2014.

Spirituality Scale to assess spirituality that consists of 10 items and is filled by children with an explanation of the

officer making the data if necessary.⁵ Instruments PedsQL (Pediatric Quality of Life Inventory) to measure quality of life. PedsQL is one assessment instrument Health Related Quality of Life.⁷ Generic PedsQL consists of 23 items and categorized into 4 subscales: physical functioning (8 items), emotional (5 items), social (5 items) and school (5 items).

There are 5 pieces of open-ended questions to guide the interview about spirituality and quality of life. Five of the questions based on literature searches and based on spirituality and PedsQL scale instruments. There were 7 children and parents interviewed for qualitative data collection.

The quantitative data obtained were analyzed using independent sampel t-test and pearson t- test with significance level of $p < 0.05$. The qualitative data obtained were analyzed by making coding and category of each answer.

RESULTS

Most of the respondents are male, namely are 28 children, female respondents are 13 children. The most dominant age group is age of 8–12 years old as many of 16 children, and then age group of 13–18 years old for 15 children, and the fewest is the age group of 6–7 years old with 10 children. The type of cancer experienced by respondents is ALL (acute lymphocyte leukemia) of 28 children, and other cancer types which include AML, Burkitt lymphoma, neuroblastoma, non-Hodgkin lymphoma (NHL), rhabdomyosarcoma, astrocytoma, myelodysplasia syndrome, Ca nasopharyngeal, Swing sarcomas were 13 children.

The average mean of spirituality of children with cancer is by 43.88 with deviation standard is by 55.154. Status most dominant spirituality is spirituality are as many as 24 children, then high spirituality as much as 8 children, and the least is low spirituality as much as 9 children.

Description of the relationship of spirituality and quality of life of children with cancer. There are 6 categories derived from in-depth interviews have been done on seven children, namely; 1) prayer as a healing pain, 2) the joy and gratitude; 3) the interaction of the source of happiness; 4) loneliness sadness source; 5) socialization with the environment; 6) seek help in overcoming difficulties.

The opinion about the feelings experienced informants currently generally expressed joy and gratitude for the situation experienced this time, in a period of treatment and treatment of cancer both in Ward Estela treatment and were in Room One Day Care. One informant F expressing his opinion that.

"Perasaannya senang dan bersyukur terhadap apa yang terjadi karena ini merupakan suatu karunia dari Allah SWT".

Table 1. Table relationship characteristics and quality of life of persons with childhood cancer in Yogyakarta period from July to September 2014 (n=41).

Characteristics	Quality of Life									
	Total		Physical		Social		Emotion		School	
	P value	Mean (SD)	P value	Mean (SD)	P value	Mean (SD)	P value	Mean (SD)	P value	Mean (SD)
Age	0.068		0.734		0.015		0.974		0.001	
Gender	0.431		0.908		0.457		0.280		0.511	
Male (n=28)		68 (17)		58 (30)		81 (20)		70 (20)		64 (21)
Female (n=13)		73 (12)		59 (25)		86 (11)		78 (18)		68 (13)
Types of Cancer	0.556		0.519		0.541		0.677		0.922	
ALL (n=28)		68 (17)		56 (28)		81 (20)		72 (22)		66 (18)
Others (n=13)		71 (14)		68 (28)		85 (13)		75 (13)		65 (20)

Based on Table 1 shows the characteristics of the age-related quality of life of children with $p=0.068$, particularly in the social domain and schools with $p=0.015$. Gender and type of cancer in children is a characteristic that is not related to the quality of life of children with cancer.

Table 2: Table relationships spirituality with the Quality of Life in patients childhood cancer at the General Hospital DR. Sardjito period from July to September 2014 (n=41).

Spirituality		
Quality of life	P value	r value
Physical domain	0.028	0.343
Social domain	0.054	0.303
Emotion domain	0.001	0.523
School domain	0.026	0.347
Total	0.001	0.499

Based on Table 2 shows that spirituality in children associated with quality of life of children who indicated with $p=0.001$, but middle relationship with the value of $r=0.499$.

The opinion on the role of the power of prayer informant during his illness, generally assume that prayer plays an important role in healing, encouraging them in sickness and health. Informant B expressed his opinion about the importance of prayer.

".....doa memberikan ketenangan hati gitu"

The results of interviews with Mother of informants B reveals that the present condition of his being illness, the family is more focused on spiritual activities and spiritual wellbeing B. Parents expect to pray, child B can be more patient, sincere in the receiving state. The mother B reveals that:

"Kalau berdoanya ibaratnya gak ada berhentinya, sehabis sholat, sholat lima waktu, solat duha, solat tahajud itu rajin, dia selalu melanjutkan dengan berdoa, sebelum sakit juga rajin berdoa" (Ibu B)

".....ya dia percaya akan kekuatan doa". (Ibu B)

The opinion informant against things or difficulties encountered when in the learning process in schools, on

average, the informant was able to overcome the difficulty by asking a more credible source. The problem can be resolved. Informants expressed his opinion on the means used to overcome the difficulties, namely,

" Nyari-nyari di buku materi atau searching di google, kalau paling nggak bias Tanya sama teman-teman, kalau yang paling-paling nggak bias yang kerjain bareng, pagi-pagi kalau sudah di sekolah." (Informan E)

The opinion informants about the activities undertaken to obtain pleasure to do is to socialize with their surroundings. The opinion expressed by informants C revealed that,

" Kalau saya seringnya jalan-jalan..... saya dari kecil sudah kebiasaan jalan kaki... jalan-jalan paling kerumahteman " (Informan C)

The opinion on how disclosure of the informant happy feeling when done in various ways. Interact with the surrounding environment is a popular activity performed by most informants. The opinion expressed by informants A state that,

".....senang banget bias sekolah....bisa bermain sama teman...bisa main layang-layang sampai malam" (Informan A)

Certain moments in pain conditions can create feelings of the child to be sad. Results informant interviews indicate that boredom makes most informants feel sad. Here's one of the informant E footage expression of the things that made him feel sad;

"...Nggak ada temannya, terus nggak bisa main se bebas temen yang lain-lain." (Informan E)

The mother E in the interviews also revealed that children feel sad when E wishes are not fulfilled. In expression Mom says that,

"Kadang kalo kemaren pernah waktu mau berangkat kesini, E gamau, saya disuruhnya sama bapaknya nemeni E, saya bingung kalo nuruti E terus kan adiknya ga mau sekolah, harus sama mamanya, lalu E kan ngambek" (Ibu E).

DISCUSSION

The result of the research shows that spirituality has a relationship with the life quality of the children with cancer. The result of the field note shows that the average of respondents has a belief that sickness can be cured and trusted to the power of the worship (God). Prayer can provide suggestions to the physical condition of those who are sick so that it can be better.

Results from field notes in conducting interviews, parents reported that the child was diagnosed with cancer since until now never feel sad. Prayer and religious rituals always run regularly, but he never felt sad and inferior to the state of illness. He was very excited to undergo daily activities when no chemotherapy. Parents also explained that the child is not aware of her illness so that the practice of worship run literally only.

Level of spirituality in children is at the third level, the level of discriminatory.⁸ The awareness of the children is starting to categorize object and happening based on experiences and understand the existence of intuition and other things beyond the five senses. In this level, spiritual awareness is considered to be exist. Spirituality in a child is an ability to get personal value through the relationship with others.⁹

Spirituality significantly helps clients and service providers to adapt to the changes caused by chronic diseases. Clients who have an understanding of spiritual well-being, feel a connection with the highest strength and others, and to find meaning and purpose in life, will be able to adapt better to the disease. These adaptations can help them in improving their quality of life (1). Spirituality gives a positive influence on coping and adaptation achievement.⁵

Spiritual dimension in quality of life have been known increasingly as a component in the overall patient care in adults. The Committee on Palliative End of Life Care for Children and Their Families noted that there is still little research related to spirituality in children illness. This is important if we are able to understand that the components of a child's life so that we can provide a better support as their life goals.³

Specifically, the results of the data analysis showed that spirituality related quality of life, especially in the domain of school and emotions with a p-value of each is 0.039 and 0.013. Spirituality does not relate specifically to the quality of life of physical and social domains.

The field notes from the results of in-depth interviews showed that the average school achievement in cancer patients conducted interviews have good performance. On average parents reported that before the illness children never stay in school and be able to follow the learning process well. Likewise, after undergoing chemotherapy, some children there are still undergoing the process of school. When should start back to school, children can still attend lessons at school even though he could not attend a certain time.

Another report from the parents stating that this time the child has been difficult to concentrate and receive lessons. This makes the child feel inferior and often sad. High motivation and desire to go to school and completing school assignments, but the limitations of the physical presence so that children feel less than the maximum in the completion of schoolwork.

Is currently Cancer Unit at General Hospital Yogyakarta collaboration with the Cancer Foundation of Our Home. The Foundation is also working closely with the Education Department. Cancer child who can not attend lessons at school, Foundation House We provide the facility to bring the Department of Education to Shelter so that children can run or the Final Examination Semester Exam. Some children who do interviews a child who lives in Our Home Foundation, they said he was much helped so that the learning process can be followed by a good school. One of the parents in court records tell, that his son was helped when it got into trouble learning.

Spirituality relationship with the child's emotional depth interviews concluded that prayer as a healing sore. Children feel relieved when praying and prayer is believed to provide suggestions to yourself so that children feel more comfortable. Results from field notes indicate that on average parents try to provide emotional support to the child can be maintained. Children can always feel happy, trying to make ends meet desired by the child so that the child can feel comfortable even while undergoing chemotherapy.

The field notes indicate that the child feels happy when she has friends. Pleasure is expressed in various ways such as by writing, drawing, smiling, told the parents. Grief in children occur when a child feels lonely because they have to undergo treatment, relapse when sick and can not go to school anymore. When you feel sad average child revealed by silence. Nurses, doctors and other friends who accompanied during hospitalization becomes entertainer for children when they are in a period of treatment.

Parents reported that sometimes children feel sad when he saw the old man and his family really think about his health. He felt much time, energy, thoughts, and the money that comes out of the parents for treatment. The parents say that their children become ill since a more mature figure and not much to complain despite being sick. Children still aspire to go to school even though it

was one year does not go to school because they have to undergo treatment.

Parents consider himself as a protector when his illness. In this situation the child sometimes indicate that he was already cured, either, and show cheerfulness in front of parents, when in fact he was feeling sad.¹⁰

Spirituality child is not related to quality of life, especially the physical and social domains. The field notes indicate that the average child realizes that he felt sick and suffered physical weakness. In these conditions in order to minimize the occurrence of relapses and complications, the child does not do a lot of activities outside the home.

The decline of the vitality of cancer in children is caused by several factors, one of which is a child running processes chemotherapy. Chemical influence of chemotherapy on the body causes a decrease in energy. Another factor that led to a decrease in vitality child is a cancer that affects the management of pain, for example, the provision of drugs injection. Child cancer treatment performed at hospitals, will be isolated from family members and friends, the limitations of communication leads to depression as a result of a decrease in energy.⁴

CONCLUSION

The result of this research is , there is a relationship between spirituality and quality of life in children with cancer in Dr. Sardjito Yogyakarta. The results of in-depth interviews indicate that the average respondent has a belief that pain can be cured and they believe in the power of prayer (or God). Prayer can give suggestions to the physical condition of those who are in sickness so that it can get better. The parent provides spiritual support as a mental support to her child, so they can be patient and sincere in chemotherapy treatment. Spiritual support is also an impact on the activities of children every day.

Recommendations

Child socialization is an important aspect in the process of growing and developing children. Parents should be able to be wise while still providing opportunities for children to socialize even if the child is in a state of illness or a decline in health. Nurses can provide education and approach to parents how to socialize when the child is sick.

Education is an important element in child development. Our Home Foundation is now working with cancer unit RS RS. Sarjito has provided many facilities for cancer patients including educational facilities, but still there are some children and parents who do not know the program. The nurse may facilitate the provision of information relating to counseling service providers, and education

for children provided by Rumah Kita through the psychologists they possess.

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