PARENTS' PERCEPTION TOWARDS QUALITY OF LIFE CHILDREN WITH LEUKEMIA IN ARIFIN ACHMAD AND ERIA BUNDA HOSPITAL : A MIXED METHODS STUDY

Hendriyani[1], Henny Suzana Mediani[2], Dyna Apriany[3]
Staff of Nursing School of Health Sciences of PayungNegeriPekanbaru
Email : nershendriyani@yahoo.com

Abstract

Leukimia is a cancer which has the most prevalence to the kids. During the treatment is important to concern with their life quality. Children with leukemia experience avariety of physical and psychological problems which affect quality of life of the children. Purpose of this study was to explore perceptions and description toward the quality of life of children with leukemia. Considering the impact and the cure of physicale, psychological and social quality of life of them. This research used mixed method research with the sequential explanatory design by the total sample 34 parents ' leukimia sufferers with is intensive care in children ward of Arifin Ahmad and EriaBunda hospital. The result of quantitative research,showed that the parents' perception score was 74 in average with deviance standard 10,725 meanwhile life quality score was 71,44 in average with deviance standard 13,948. Correlation test between parents' perception with the quality of children life p 0'028. Qualitative data aimed to strengthen, deepen and widen qualitative data, The results found that parents' negative perception was stated by considering the children are weak/ risky. In addition the life quality of the children in term of physical and emotional domain experiences the change such as so weary, feeling painful, physical activity decay and the children easily tend to be angry, afraid and feeling sad. Based on the result of the research , it is recommended that by the paradigm of children's nurse family center care involves the parents in children treatment by giving information and educate the parents based on evidence based practice, so it can form the positive perception of the parents with leukemia child.

Keywords : perception, quality of life, leukemia, children

BACKGROUND

There was 11 milionpeople was diagnosed cancer in 2005. There was 7 milion death caused by cancer, 70 % among in developing country (Indonesian Onkologi Association), 84 milion people died among 2005-2015 caused by cancer (WHO).According to sirs statistic in 2006 leukimua cases were on top 5,32 % kinds of childhood cancer is leukemia 20-25% happened to children under 15 years old (Hashiani, 2012),The based on the result of previous study of medical record data from the hospitals, leukemia is on top 5 from 10 of the biggest deseases in december 2014.

The main medical treatment of leukimia is chemotheraph the chemotherapy medical treatment which is done over and over will bring the effect to physic and psyche of the children medical treatment of leukimia is able to cause the weakness of the function of the body, disfunction of endoctrine, the decreasing of neuropsikology, sleep and study disruption (Bansal, 2013). According to Chiou (2010) the result of the quality of children with leukimia is worse recorded which reflected from the lower of physic and psychosocial score.The impact to the children, 15,6 % experiencing intelligent disruption (IQ under 70) and 27,8 % teenagers experience cognitive disorder which is measured from neuropsychology test.

Effects of diseases and therapeutic will affect the ability adaptation children about the

condition of disease of physical function , emotional , social and school and the ability of the family in overcome the various the pressure that will affect the quality of a life. Perception patients who changed about himself is one of the originator the impact of medicine which most affect the quality of a child life (Momanni , 2014).

The purpose of this study was to explore perceptions and description toward the quality of life of children with leukemia. Considering the impact and the cure of physicale, psychological and social quality of life of them

METHOD

This research used mixed method research with the sequential explanatory design by the total sample 34 parents ' leukimia sufferers with is intensive care in children ward of Arifin Ahmad and EriaBunda hospital. Quantitative used cross sectional design cross sectional in this research is used for knowing how far the correlation between parents perception towards quality life of the children with leukimia. Qualitative used narrative approach by collecting narrative story by telling privacy experience about their life experience and how they see their own self

RESULT

1. **Bivariate analysis The different test mean of length of illness with quality of life and parent's perception**

Table 1.1The different test mean of length of illness with quality of life and parent's perception in RSUD ArifinAchmad and RS. EriaBundaPekanbaru on April to May 2015.

Long Hospital	Mean KualitasHidup	P value	Mean Persepsi Orang tua	P value
6bulan	62,31	0,0001	70,31	0,05
>6bulan	79,56		77,28	

Table 1.1 it can be seen that there are significant differences (p value 0.0001) the value a score the quality of life of children with leukemia who had leukemia less than or equivalent to six months (62,31) is lower compared to the quality of life of children with leukemia who had leukemia more than six months (79,56) .The perception tua there are significant differences (p value 0.05 between parents who had leukemia more than six months with the average score (77,28) was higher compared to the perception age on his son had leukemia less than or equivalent to six months (70,31) .

2. **Relationshipof Parent's Perception Toward Child's Physical Domain**

*Table 1.2Pearson Product Moment*correlation of parent's perception toward child's physical domain

Korelasi	N	R	p value
Pearson	34	0,373	0,03

Based on the test results with the Pearson product moment correlation was found that the p value is 0.03 less than alpha value of 0.05 (5%), its means there is a significant relationship between parents' perceptions toward the physical functioning of children with leukemia.

3. **Relationshipof Parent's Perception Toward Child's Emotional Domain.**

*Tabel 1.3Pearson Product Moment*correlation of parent's perception toward child's emotional domain

Korelasi	N	R	p value
Pearson	34	0,403	0,018

It means there is a significant relationship between parent's perception with emotional function of children with leukemia. Based on the statistic was found that R coefficient value is 0.403 and the value of the coefficient of determination $r^2 \times 100\% = 16.24\%$, which means that the perception of the parent contributed approximately 16.24% to the

children's emotional functioning, while the remaining 83.76% is determined by other variables.

4. Relationshipof Parent's Perception Toward Child's Social Domain

Tabel 4.4*Pearson Product Moment***correlation of parent's perception toward child's social domain**

Korelasi	N	R	p value
Pearson	34	0,165	0,352

Based on the statistic was found that, there is no significant relationship between parent's perception and social domain of children with leukemia.

5. Relationshipof Parent's Perception Toward Child's School Domain

Tabel 4.5*Pearson Product Moment***correlation of parent's perception toward child's quality of life**

Korelasi	N	r	p value
Pearson	34	0,154	0,385

Based on the statistic was found that, there is no significant relationship between parent's perception and school domain of children with leukemia.
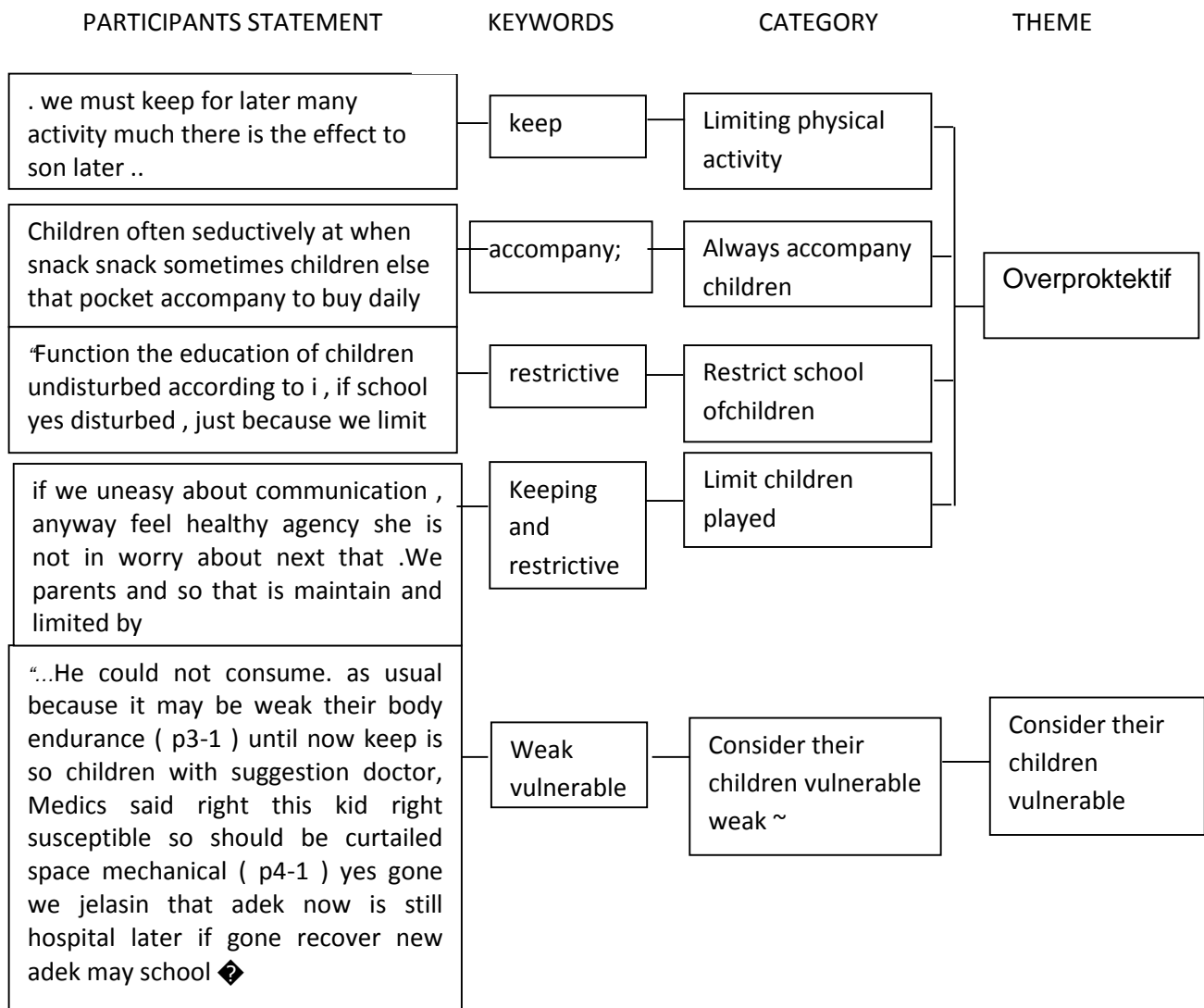
6. Relationshipof Parent's Perception Toward Child's Quality of Life

Tabel 4.6*Pearson Product Moment***correlation of parent's perception toward child's quality of life**

Korelasi	N	r	p value
Pearson	34	0,377	0,028

It means there is a significant relationship between parent's perception with quality of life of children with leukemia. Based on the statistic was found that R coefficient value is 0,377 and the value of the coefficient of determination r^2 x 100% = 14,2%, which means that the perception of the parent contributed approximately 14,2% to the child's quality of life, while the remaining 85,8% is determined by other variables

PARTICIPANTS STATEMENT	KEYWORDS	CATEGORY	THEME
. we must keep for later many activity much there is the effect to son later ..	keep	Limiting physical activity	Overproktektif
Children often seductively at when snack snack sometimes children else that pocket accompany to buy daily	accompany;	Always accompany children	
"Function the education of children undisturbed according to i , if school yes disturbed , just because we limit	restrictive	Restrict school ofchildren	
if we uneasy about communication , anyway feel healthy agency she is not in worry about next that .We parents and so that is maintain and limited by	Keeping and restrictive	Limit children played	
"...He could not consume. as usual because it may be weak their body endurance (p3-1) until now keep is so children with suggestion doctor, Medics said right this kid right susceptible so should be curtailed space mechanical (p4-1) yes gone we jelasin that adek now is still hospital later if gone recover new adek may school ◆	Weak vulnerable	Consider their children vulnerable weak ~	Consider their children vulnerable

DISCUSSION

The research finding was found that the parent's perception of children with leukemia when viewed from the quantitative data obtained an average score of 74, with a standard deviation of 10.72, its means that the perception of parents with children leukemia is good enough. Based on the result of interviews with the participants in this study revealed that parent always consider their child were weak andvulnerable. This is a negative perception that cannot reveal by using quantitative approach.Hullmann, (2010) within his study found that from 89 parents, 15-25% among them show an overprotective attitude to their child. *Self perception theory* which develomt by Daryl J. Bem, reveal that parents always have a perception that their child is weak and vulnurable.This is support by the information from observation of the environment. Its build up a perception and prove that their child is always weak and vulnurable.

CONCLUSION

This research finding that the quality of life of the child with leukemia is average 71,44 with deviance standard is 13,95.Its show that the quality of life of the child with leukemia was good enough, better than if compare it with length of illness of leukemia.There is a significant differences between child with there are significant differences between children suffering from leukemia is less than or equal to 6 months with children suffering from leukemia more than 6 months with a p value = 0.0001.The result of this research was showed there is a significant relationship between parent's perception and physical domain of leukemia children with p value 0,03 (< 0,05).Qualitative data strengthen and deepen this quantitative data with the statement that children with leukemia participants easily feel tired, difficult to do some exercise or activity and feel pain.Chaudhry and Siddiqui (2012) mentions that the perception of parents towards their children's health is more emotion focused which is why parents become anxious and depressed at the beginning of a child diagnosed with leukemia.

REFERENCES

Hashiani, A. (2012). *Survival Rate of Childhood Leukemia in Shiraz, Southern Iran.*Journal of Iran Pediatric, Vol 23 (No1), 53-58

Bansal, M. (2013).*Perception of Indian Parents on Health-Related Quality of Life of Children During Maintenance Therapy of Acute Lymphoblastic Leukemia : A Comparison With Siblings and Healthy Children.*Journal Pediatric HematologiOncologi. (36) 30-36

Chiou, S.S. (2010). *Health-related quality of life and cognitive outcomes among child and adolescent survivors of leukemia.*Journal of Supportive Care in Cancer.(Vol 18), 1581-1587

Momani, T. (2014).*Children's Perspective on Health-Related Quality of Life During Active Treatment for Acute Lymphoblastic Leukemia.* Lippincott Williams & Wilkins

Hullmann, S.E., Wolfe-Christensen, C., Meyer, W.H., McNall-Knapp, R.Y., Mullins, L.L. (2010). The relationship between parental overprotection and health-related quality of life in pediatric cancer: the mediating role of perceived child vulnerability. Springer Quality Of Life Research, 19, 1373–1380.