

## Research Article

# Pocket book of anxiety for parents of children with acute lymphoblastic leukemia

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**Received:** 17 February 2016

**Accepted:** 22 March 2016

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## ABSTRACT

**Background:** Parents of children with acute lymphoblastic leukemia (ALL) often experience psychological disorders, mainly of anxiety. Anxiety can have a bad impact on the health of parents and children. The study aims to see the effect of education using a pocket book against the anxiety parents of children with ALL. In addition to looking at the relationship between age, number of children, education, employment and length of treatment to anxiety.

**Methods:** This study used quantitative and qualitative approaches, quasi experiment pre-test, post-test without control group design. The research sample amounted to 28 parents of children with ALL in the Dr. Moewardi General Hospital Surakarta and interviews conducted on 3 respondents. Anxiety instrument consists of 31 statements valid and reliable that created specifically for anxiety parents of children with ALL. The effect of education measured after day 18 from the treatment time. Respondents are educated in two sessions with a time of 20-30 minutes each session.

**Results:** Based on the statistical analysis of paired sample t test in get difference the average value of anxiety before and after the education from 73.1 to 66.6 and average reduction of anxiety was 6.5 ( $p=0.020$ ;  $p<0.05$ ). Changes in the level of anxiety of respondents before and after treatment is correlate with age of the respondents ( $r=-0.425$ ,  $p<0.05$ ). Meanwhile, the number of children, education, employment and duration of treatment was not associated with anxiety.

**Conclusions:** The results showed there are significant educational use pocket book to anxiety parents of children ALL.

**Keywords:** Anxiety, ALL, Parents, Education

## INTRODUCTION

Cases of cancer in children was found to increase each year and become a leading cause of death in children.<sup>1</sup> Meanwhile, the number of children suffering from acute lymphoblastic leukemia, comprising 75% of children with cancer.<sup>2</sup> In Indonesia, the prevalence of cancer in children by 4.7% and mortality from the disease reaches 50-60%. The Ministry of Health reported the incidence of cancer based on type in children is 2.8 leukemia, 2.4

eyeball cancer, 0.97 osteosarcoma, 0.75 lymphoma, and 0.43 nasopharyngeal cancer per 100,000 children.<sup>3</sup>

Damage to the lymphoid with characteristic proliferation of immature lymphoid cells in the bone marrow called acute lymphoblastic leukemia. The prognosis of acute lymphoblastic leukemia is determined by the number of leukocytes at the time of diagnosis, the higher the number of leukocytes that is  $\geq 50.000/\mu\text{L}$  it can worsen the condition.<sup>4</sup> Chemotherapy is a specific treatment that aims to cure his leukemia. The drug works by inhibiting

the multiplication of cells or stimulate cell death (apoptosis). Process of cancer treatment requires a long time and regularly. Side effects that may arise after receiving chemotherapy include nausea, vomiting, abdominal pain, mouth sores, poor appetite, sometimes be found children become irritable, become more depending, hair loss, immune system can be decreased, lethargy, and fatigue.<sup>5</sup>

The diagnosis of acute lymphoblastic leukemia (ALL) in children will make parents more vigilant in caring for children at home, managing symptoms and treatment side effects, purchasing, providing and preparing drugs, preventing infection of the child, in addition to the parents are engaged in coordinating and scheduling of treatment, learn about the process of treatment, sources and the health care system and are looking for information on other family. The new task that parents often experience sleep disturbances, fatigue, and changes in appetite. Emotional symptoms such as depression, guilt, anger and anxiety into a psychological disorder parents.<sup>6</sup> Anxiety and depression are perceived by parents as caregivers of children with cancer reached 56% and 53%. Psychological disorders that can be perceived parents settled up to 5 years and can return to normal after a several years.<sup>7</sup>

Anxiety is an individual's responses to what they're getting. Anxiety is a feeling that is individualized and one of the emotional stress. Stress due to non-fulfillment of demand that exceeds the ability of so the impact on the physical wellbeing and psychological.<sup>8</sup> Through the social cognitive learning theory, Bandura stated that the fear and anxiety resulting from a negative self-expectations because they believe that they cannot cope with situations that may threaten them, in other words, a low perception of confidence in dealing with the problem can increase anxiety.<sup>9</sup>

One effort to reduce of anxiety parent's face is to provide support sufficient information about the disease and advice on how parents can to manage anxiety. The research showed that the positive effect of knowledge on of anxiety.<sup>10</sup> While research show different results, that is psychoeducation program to parents with children of cancer can increase the knowledge but can not significantly decrease anxiety.<sup>11</sup> Based on this phenomenon, it is important to do research on the effect of education using the pocket book against anxiety parents of children with acute lymphoblastic leukemia and see the influence of age, number of children, education, occupation and length of treatment against anxiety parents of children acute lymphoblastic leukemia.

## METHODS

We conducted a confidential and anonymous questionnaire survey among parents of children with acute lymphoblastic leukemia (ALL). The ethical and scientific validity of this study was approved by the

institutional review board of Faculty of Medicine, Gadjah Mada University.

This study is quasi experimental pretest-posttest design without control. The approach used is combination of quantitative and qualitative approach in which quantitative approach as the primary approach assisted with the data qualitative approach. The research population is all parents who have children with acute lymphoblastic disease leukemia in Melati 2 Ward DR. Moewardi General Hospital Surakarta and the amount of sample of 28 respondents. The sampling technique was performed consecutive sampling to parents of children with ALL using the inclusion criteria in this study is parents are willing to be a study respondents, can read and write and parents who do their children treatment in Dr. Moewardi General Hospitals. The exclusion criteria of this study include parents who have children with ALL disease and other comorbidities as well as the child's condition is unstable or critically. Anxiety instruments made specifically for anxiety parents of ALL children that is by adopting and modifying of some anxiety questionnaire. The results of the validity and reliability of questionnaires obtained 31 statements valid and reliable with an alpha value of 0,738 cronbach. Favourable statement amounted to 24 items and unfavourable 7 items in each statement was measured with a scale rating with a favourable assessment items (1) very rarely (once a week perceived), (2) sometimes (3-4 days), (3) often (2 days), (4) always (daily), whereas for unfavorable statements with the opposite assessment. Intervention is education with the pocket book is information delivery to parents of children with ALL in the form of pockets book that contains the definition of acute lymphoblastic leukemia, treatment and side effects, prognosis, definition of anxiety, signs and symptoms of anxiety, anxiety effects, and how to overcome anxiety. Education is given in two sessions, with a time of 20-30 minutes each session. Prior to the initial measurement of anxiety through the pretest, respondents were willing to participate in the study signed a consent form research. After the pretest respondents, further education about ALL and tips to overcome anxiety given to respondents through face to face individually in two sessions. Then measuring the anxiety after 18 days of ongoing educational process that is as post-test. Education given by the researchers in person individually by the researcher (face to face). Test the validity of pocket book using content validity expert. Anxiety was measured before being given education and 18 days after being given education. Data were analyzed using paired sample t-test with a significance level  $\alpha = 0.05$ .

After completion of the quantitative phase, researchers conducted a qualitative approach to sharpen the data obtained. Qualitative data retrieval is done by means of interviews. Interviews were conducted after quantitative data retrieval. The selection of respondents based perposive sampling that is taking the respondents in the sample quantitatively based on extreme value upper limit

and lower limit to the number of respondents decreased anxiety as many as three people.

## RESULTS

Characteristics of respondents in this study include: 1) age, 2) the number of children, 3) education, 4) employment and 5) length of treatment. Distribution of respondents by respondent characteristics shown in Table 1. In addition to quantitative approaches made in this study was also carried out a qualitative approach with three informants. Criteria for selection of informants is respondents who have worried that the sharp decline in value and respondents who have worried that the sharp increase in value, they are included as well as a quantitative subject. Overview anxiety respondents can be seen in Table 2. Based on the description of anxiety during the pre-test and post-test can be seen that the number of respondents who experienced weight anxiety is reduced 2.5 fold after getting of education. Based on the qualitative exploration the anxiety felt by parents related to the disease or diagnosis of ALL. The informant stated that the feelings will lose his son, fear, and sadness felt after hearing the diagnosis of ALL. In addition, anxiety about the treatment process is also felt, informants revealed that the side effects of chemotherapy make parents renders them increasingly powerless. On one side of chemotherapy is a treatment to cure the child and on the other side effects of treatment cause symptoms such as nausea, vomiting, mouth sores and hair fall.

Anxiety about the future and his death was also felt by the parents. The informant said that they were afraid when they heard the news that there are children with ALL died.

**Table 1: Characteristics of respondents (n=30).**

Variable	n	%
<b>Age (year)</b>		
17-25	2	6.7
26-35	10	33.3
36-45	14	46.7
46-55	4	13.3
<b>Number of children in one family</b>		
≥ 2 Child	24	80
1 Child	6	20
<b>Education</b>		
Low ≤ junior high school	17	56.7
High ≥ senior high school	13	43.3
<b>Employment</b>		
Work	11	36.7
Did not work*	19	63.3
<b>Duration of treatment</b>		
Week 1-7	9	30
Week 8-12	3	10
Week 14-17	0	0
Week 18-111	18	60

\*Housewife

**Table 2: Overview of anxiety respondents (n=28\*\*).**

Variable	The anxiety before treatment			The anxiety after treatment		
	Height (%)	Medium (%)	Mild (%)	Weight (%)	Medium (%)	Mild (%)
<b>Age (year)</b>						
17-25	0 (0)	2(100)	0(0)	0(0)	0(0)	2(100)
26-35	2 (22.2)	7(77.8)	0(0)	0(0)	6(66.7)	3(33.3)
36-45	1(7.7)	9(69.2)	3(23.1)	0(0)	11(84.6)	2(15.4)
46-55	2(50)	1(25)	1(25)	2(50)	1(25)	1(25)
<b>Number of children</b>						
≥ 2 children	4 (18.2)	14(63.6)	4 (18.2)	2(9.1)	16(72.7)	4(18.2)
1 children	1 (16.7)	5 (83.3)	0 (0)	0 (0)	2 (33.3)	4(66.7)
<b>Education</b>						
≤ junior high school	4 (25)	10(62.5)	2 (12.5)	2(12.5)	10(62,5)	4 (25)
≥ senior high school	1(8.3)	9 (75)	2 (16.7)	0 (0)	8 (66.7)	4 (33.3)
<b>Employment</b>						
Work	2 (18.2)	7 (63.6)	2 (18.2)	1(9.1)	6(54.5)	4(36.4)
Did not work*	3 (17.6)	12(70.6)	2 (11.8)	1(5.9)	12(70.6)	4(23.5)
<b>Length of treatment (treatment phase)</b>						
Week 1-7	3 (42.9)	4 (57.1)	0 (0)	1 (14.3)	4 (57.1)	2 (28.6)
Week 8-12	0 (0)	3 (100)	0 (0)	0 (0)	2 (66.7)	1 (33.3)
Week 14-17	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Week 18- 11	2 (11.1)	12(66.7)	4 (22.2)	1 (5.6)	12(66.7)	5 (27.8)

\* Housewife; \*\* two respondents drop out.

Statistical analysis using paired samples t-test in Table 3 obtained an average value of anxiety before treatment (pre-test) of 73.1 with a standard deviation of 14.9 and an average rating of anxiety after treatment (post-test) of 66.6 with a standard deviation of 15.5. The difference in the average difference of anxiety before and after treatment was 6.5 with a p value of 0.020 ( $p < 0.05$ ). These results indicate that there are significant differences in the average difference of anxiety before and after treatment. This means of education with pocket book can reduce

anxiety the parents of children with acute lymphoblastic leukemia.

The statistical analysis influence the characteristics of respondents to the average difference parental anxiety include age tested with correlation person momento product; gender, education, number of children, and the work was tested with independent sample t-test, the influence length of treatment was tested by ANOVA shown in Table 4.

**Table 3: Anxiety scores after treatment (n=28\*\*).**

Variable	N	Mean±SD	Min-max	P value	95%CI
Anxiety					
Pre test	28	73.1±14.9	44–104		67.31–78.90
Post test		66.6±15.5	30–97		60.58–72.56
Pre – post test		6.5±13.9	-24–36	0.02*	1.11– 1.95

P value significant  $p < 0.05$ ; \*p value: 0.02,  $p < 0.05$ ; \*\* Two respondents droop out

**Table 4: The influence of characteristics respondents to the anxiety.**

Variable	The average difference anxious (delta)		
	Mean±SD	r	p value
<b>Age</b>		-0.425	0.024
<b>Number of children</b>			0.060
≥ 2 children	3.9±13.2		
1 children	16±13.5		
<b>Education</b>			0.799
≤ junior high school	5.9±16.8		
≥ senior high school	7.3±9.6		
<b>Employment</b>			0.254
Work	2.7±16.9		
Did not work*	9±11.6		
<b>Length of treatment</b>			0.685
Week 1–7	9.4±22.6		
Week 8–12	10.3±8.7		
Week 14–17	0		
Week 18–111	6.5±13.9		

\*Housewife

## DISCUSSION

### *Influence of education using the pocket book to anxiety*

The verdict of cancer, process of treatment and side effects of chemotherapy on the body of the psychological impact particularly anxiety in children and parents who care for children with acute lymphoblastic leukemia. Emotional symptoms such as depression, feelings of guilt, anger and anxiety into a psychological disorder the parents. Meanwhile, on the other parents have an important role and become the main source for the child in providing support to the whole process of treatment.<sup>7</sup>

The results showed that of education with pocket book significant influence ( $p < 0.05$ ) of anxiety in the parents of children with acute lymphoblastic leukemia, in addition to the number of respondents who experienced severe anxiety is reduced 2.5 fold after the educational process. The same is also disclosed in the research that parents of children with early diagnosis of cancer in the intervention group reported anxiety and traumatic symptoms is reduced after getting concise information about cancer and psychological treatment.<sup>12</sup> The process of education and discussion that happens to have a positive influence on the parents, because the parents improve cognitive assessment to sources of stress encountered. Based on

cognitive theory states that anxiety is a mistake of interpreting a situation that is considered threatened and endangered. The support information can assist parents in interpreting the problem correctly, so as to prevent any misinterpretation. Through social cognitive theory of Bandura in 1997 states that when the support information can assist parents in maintaining emotional stability, anxiety and stress, this can improve the self-efficacy.<sup>13</sup>

High perception of confidence in dealing with the problem can reduce anxiety, so parents can exercise self-control and autonomic nervous system response to anxiety and gradually disappears anxious. Anxiety symptoms such as emotional, physiological, cognitive and behavioral well back to normal.<sup>13</sup> In general, the process of educating the parents revealed using a pocket book can add to the information and knowledge of the parents so as to reduce feelings of anxiety, anxiety and worried.

Similar results were also expressed by Rachmaniah which revealed that psychoeducation with the media booklet and discussions were also influential on anxiety and coping the parents who have children with thalassemia.<sup>14</sup> The process of education with media pocket book assessed effectively increase the knowledge the parents because pocket book contains a lot more information can be stored, read repeatedly by parents anytime and anywhere.<sup>15</sup> In addition, the material written on the pocket book using simple sentences making it easier for the layman to understand the message. Pocket book also comes with interesting pictures, making it easier for the parents to capture the message in question, remember and practice it in everyday life.

From various sources a large number of studies have shown that people remember 10% of what they read, 20% of what they hear, 30% of what they see, 50% of what they see and hear, 80% of what they hear, see and was told.<sup>16</sup> In addition to the foregoing, according medium of learning through a more concrete image that is can overcome the limitations of space and time and show the appropriate comparison of the actual object.<sup>17</sup>

However, these results different to studies conducted by who did psychoeducation program to parents with children of cancer in Malaysia.<sup>11</sup> In his research revealed that there is a decrease in anxiety in the intervention group, but the decrease was not statistically significant. The difference in the results of this study can be caused by many things, including the differences in anxiety instruments used in collecting the data.

The process of education is conducted in previous studies was conducted face-to-face individual, pamphlets and information via the website, while the educational process conducted in this study was face to face individually, in a group discussion and the provision of pocket book. Learning styles that involve group activities and online learning encourages learning motivation of

older adults. In addition, the educational process that takes place in a discussion group that parents get the information together and discuss together well with educators and other parents, this is an opportunity for parents to ask each other and tell their experiences in caring for children with acute lymphoblastic leukemia. In addition, parents who do not know each other finally can get acquainted and share stories in their care. So that the interaction that exists makes respondents became more confident with the treatment of children. This is consistent with research which revealed that the psychoeducation is done on the family in the group can increase social interaction among family members.<sup>19</sup>

Enthusiastic the parents also looks at the process of education which should formally be done 2 times face to face become more because every researcher came to the ward, the parents tried to meet the researcher to ask about things that it is still confused. This incident makes the process of education have enough time make the parents satisfied to share and asked a lot of things. Telephone number of researchers given also be used by the parents, the purpose of the contact person given is to facilitate the parents to discuss with researchers, provide criticism and suggestions on the material in the pocket book. However, when the condition of the child's fever, shortness of breath, low hemoglobin and transfusion should make parents still feel fear and anxiety.

When the child's condition is unstable or critically make the parents increased anxiety, feeling weak and helpless. This is reasonable and cannot be avoided by the parents even after getting education. When conditions are such that the parents reveal to reduce anxiety is to pray, surrender and cry as it has been taught in the pocket book. Parents also expressed trying to share the anxiety with close friends, family, and friends or with the parents of child cancer as taught in the pocket book. So has the spirit and strong conviction to be able to live and survive in the treatment process.

In addition, the ease anxiety expressed as attention, information and experiences shared by the parents of children with ALL others. Interaction that exists between the parents grew stronger after the process of education and discussion groups. High sense of family that is felt among the parents, a sense common fate.

#### ***Effect of age, number of children, education, employment and length of treatment to anxiety***

##### *Age*

The results showed that age had a relationship in the opposite direction to the change of anxiety means the young age of the parents, the greater the anxiety changes that occur when given intervention and the older the parents will be smaller changes that occur anxious when given intervention. However, age has a weak influence to change of anxiety before and after the intervention. This

is consistent with the results of exploration informants with different age levels which have differences of anxiety reduction.

Based on the interview for two the parents who have age over 40 years revealed that the pocket book given not read again (lazy to open the book) at home because of the condition of children in general is good, the parents have forgotten about the tips that have been taught, has a busy that much and does not have time to practice tips reduce anxiety, reliable information is information that is given by their children are children first or second child, due to a sick child leukemia is the last child.

Different things expressed by the parents who have early adulthood, in general a sick child is the first child, parents are more proactive in seeking information through internet sources, other families who have children acute lymphoblastic leukemia, health workers, pleased read them book information, and reveal still remember what is taught in the pocket book, so that a greater decrease in anxiety felt by the parents who have younger age. This is consistent with studies that found by that the age of a higher or lower level of education than older adults, the lower their learning motivation and younger people, a woman and environment quiet support and have high motivation to learn.<sup>18</sup>

#### *The education of parents*

The statistical results showed that the respondents' education does not affect the change in anxiety. Based on the informants exploration with equal education appears to have a different manifestations of anxiety and this supports quantitative data. The education is a process of learning outcomes in an institution with various levels of education. Someone who has a high level of education will have a high cognitive development as well, so hopefully someone can receive well informed. The education respondents mostly have low education that is ≤ junior high school, allowing respondents are less able to identify stressors and overcome anxiety experienced. In accordance that education can change the mindset, behavior and decision-making.<sup>15</sup>

However, the results of the study showed different results that the educational level of the respondents had no effect on anxiety after respondents are educated. This can be caused by the messages conveyed in the educational process easily understood by the layman that is a simple language and their images to clarify the message, does not special skills and competencies needed in practicing the material that has been taught. The results of the same study also revealed that cognitive abilities does not significantly alter the relationship between education and health behavior, which means that the effect of education on health behavior is the same among the educated or does not.<sup>20</sup> Cognitive abilities of a person is not the dominant factor affecting the education of health behavior.

#### *Employment of parents*

Based on the characteristics of the respondents indicated that most respondents does not work or a housewife. Based on the informants exploration with work of equal value appears to have different manifestations of anxiety and this supports the quantitative data. The father did duty as head of the family breadwinner for the family's needs. Although the work and has a dual role, taking into account the child's condition and share tasks with mother. As expressed by respondents that her husband would come to the hospital after work and for other respondents came from outside the city chose not to work and accompany the child for treatment. Most respondents who work revealed that the state of his disease has been known to the leadership of the working place and co-workers so that when the schedule had to go to the hospital, then there is no sanction or warning (average respondent private work), so that the work not be an obstacle and a burden for respondents whether they work or do not work (housewife). That which supports the findings that there is no difference in anxiety respondents who work and does not work.

The results of this study supported the results (21) which revealed that all people if it has one of the family members who were treated in intensive care and in an unstable state, then it will experience anxiety regardless of the work and does not work.<sup>21</sup> The same thing also revealed that there is no significant relationship between the effect of a job with anxiety levels in premenopausal women because women who have social activities outside the home will be a lot of information from a friend in the surrounding.<sup>22</sup>

#### *Number of children in the family*

Respondents who had two or more children tend to be more anxious about having to fulfill responsibilities to other children healthy. According to feeling of guilt against other healthy children also perceived as does not able to give full attention.<sup>6</sup> However, from the results of statistical analysis showed that the number of children in the family has no effect in changing anxious respondents after education. This could be due to that other children have grown larger, have been married and working, and there have been shifting roles. The role of parents as caregivers of healthy children was taken over by a brother, grandmother or grandfather. At the time of the interview there are of parents admitted that the other children does not jealous against attention given to the sick brother, but sometimes of parents who have feeling of guilt against healthy child.

#### *Length of treatment*

Based on the length of treatment, the respondents who have children with long treatment week 18 to 111 lots more. Exposure to stress that occurs in a long time will make a person to perform the process of adaptation and

coping behavior as a form of stress out of the situation, while exposure to stress that just experienced will cause severe anxiety response.<sup>23</sup> Statistical analysis showed that there is no effect of treatment time to changes in anxiety respondents after the intervention. Based on the exploration informant with an equivalent length of treatment appeared to have different manifestations of anxiety and this supports the quantitative data. This could be due to the verdict diagnosis of acute lymphoblastic leukemia disease is traumatic for the respondents. Respondents may experience post-traumatic stress disorder (post-traumatic stress disorder or PTSD).

PTSD is a condition that occurs after a stressful event or situation that is threatening or disaster that is likely to cause the widespread pressure on everyone. Approximately 25-30% of people who experience a traumatic event can develop into PTSD.<sup>24</sup> PTSD the possibility lasted for months, years, or up to several decades and may not appear until several months or years after exposure to a traumatic event, so that both the parents who have children with a short length of treatment and who have long had the same anxiety about the condition of the child's future, considering the effects of chemotherapy.<sup>25</sup> In addition, although the respondents who have children with length of treatment weeks to 18-111 have experience in chemotherapy and child care, respondents still feel worried and anxious when suddenly drop the child's condition (deteriorated) as the respondents who have children with length of treatment weeks 1-7.

## CONCLUSION

Education with pocket book may reduce the anxiety the parents of children with acute lymphoblastic leukemia. Although does not dominant, age negatively related to anxiety reduction, while the number of children, education, employment and length of treatment was not associated with decreased anxiety. Researchers recommend to use pocket book as a media in providing health education to parents of children with acute lymphoblastic leukemia in order to prepare the psychological parents in supporting the process of treatment and child care.

## ACKNOWLEDGEMENTS

The authors would like to thank for the nurses at the pediatric cancer ward Dr. Moewardi Hospital for their support in this study, the parents who agreed to participate in this study and also DR. Pudjo Hagung Widjajanto, Sp.A (K), Ph.D. at DR. Sardjito Hospital.

*Funding: Ministry of Research Technology and Higher Education of the Republic of Indonesia*

*Conflict of interest: None declared*

*Ethical approval: Medical and Health Research Ethics Committee, Faculty of Medicine, Gadjah Mada University (No.KE/FK/775/EC).*

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**Cite this article as:** Rahmawati E, Gamayanti IL, Setyarini S. Pocket book of anxiety for parents of children with acute lymphoblastic leukemia. *Int J Res Med Sci* 2016;4:1438-45.