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Practices of Primary Caregivers about Caring Children with Leukemia at National Institute of Hematology and Blood Transfusion

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Abstract— *This research was made to assess practices of primary caregivers about caring for children with acute leukemia at the Pediatric Blood Diseases Department, National Institute of Hematology and Blood Transfusion in 2020. Methods: This was analytical-observational research with the design of cross-sectional. Results: Study on 182 primary caregivers having children with acute leukemia treated at the Pediatric Blood Diseases Department, National Institute of Hematology and Blood Transfusion. The unsatisfactory practice of primary caregivers having children with acute leukemia accounting for 53.8%. There were 32.4% primary caregivers almost performed the wrong diet when their children had diarrhea. 38.5% primary caregivers sometimes clean their hands before and after preparing food and 33% primary caregivers sometimes clean their children's teeth and gums properly. 28% primary caregivers sometimes encourage your children to participate in social activities. There were relationships between the educational level, the marital status, receiving health educational information and practices of primary caregivers, with p <0.05. Conclusions: The practices of primary caregivers having children with acute leukemia were low. There were relationships between educational level, marital status, receiving health educational information and practices of primary caregivers, with p <0.05.*

Keywords— ***Acute leukemia, children, practice, primary caregivers.***

I. INTRODUCTION

Cancers have a high mortality rate. Cancers account for approximately 14% of all deaths worldwide, estimated 12.66 million new cancer cases and 7.56 million deaths occurred in 2011 worldwide**.** It is the leading cause of death in the developed world and the second leading cause of death in the developing world [19]. According to estimates by the World Health Organization (WHO), approximately 14 million people worldwide suffer from the disease and 8.2 million people died [15]. According to statistics of the Ministry of Health in 2015, Viet Nam had an increasing trend about 150,000 new cancer patients and 75,000 deaths. The Health Statistics Yearbook in 2017, the incidence and death from blood diseases, hematopoietic organs and immune mechanisms in the whole nation were 0.6% and 0.4%, respectively [11]. According to Saeuis W, acute leukemia is a public health and life-threatening problem for children with cancer [14]. In the process of caring for cancer patients, their family members - especially primary caregivers - play an important role in providing health care for sick children [16]. Some studies showed that the better the caregiver's main skills were, the better the child's disease management was [10], [13], [18]. According to the study of Iqubal A and et al in 2010 showed that health staff should encourage parents have children with acute leukemia looking for supports about caring for children at cancer

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centers [8]. The ability of family caregivers to provide quality care and contribute to the management of chronic diseases is a vital health care resource. Health care providers should be supportive of family caregivers and help them have knowledge and skills to maximize quality care. Providers need to help family caregivers develop problem-solving, organizational and communication skills [5]. Instructions and advice for caregivers help improve the quality of life of sick children, support the treatment process. Since then, primary caregivers with good skills in caring for sick children will reduce the mortality rate of children with acute leukemia, contribute to reduce the burden on the family and society.

Aim of the study: The present study aimed at assessing practices of primary caregivers about caring for children with acute leukemia at the Pediatric Blood Diseases Department, National Institute of Hematology and Blood Transfusion in 2020

Research Questions: What are the practices that primary caregivers do for their children with acute leukemia?

Research subject: Primary caregivers of children with acute leukemia treated at the Children's Blood Diseases Department, National Institute of Hematology and Blood Transfusion in 2020.

Selection criteria: Primary caregiver with children with acute leukemia treated at the Pediatric Blood Diseases Department, National Institute of Hematology and Blood Transfusion from March 2020 to May 2020. Primary caregivers having children with acute leukemia diagnosed more than 1 week before the study

Exclusion criteria: Primary caregivers are unable to communicate. Primary caregivers disagree with the study.

II. METHODS

Research setting

A cross-sectional survey was conducted at the Pediatric Department, National Institute of Hematology and Blood Transfusion where treated for most of the children with leukemia and blood diseases. This hospital is a center for the treatment of leukemia in Viet Nam. Therefore, the Pediatric Blood Diseases Department was selected in this study. It was estimated that about 457 children with leukemia came to examine and treat every month at the hospital in 2019.

Data collection

Data were collected from March 2020 to May 2020. All children with leukemia admitted to the participating hospital during the survey period and their primary caregivers were invited to participate in this study. Primary caregivers were defined as a family member who has the closest relationship with children, takes the major responsibility of care for the patients and commits the largest proportion of time in the care for the patients without receiving any economic retribution [2], [20].

The sample size collected in 3 months was 182 primary caregivers.

Sample selection method: Convenient sample selection

A questionnaire was administered through face - to – face interviews at a private office in the hospital. The interviewers were carried out from research members in Nam Dinh University of Nursing and health staff at the Pediatric Department, National Institute of Hematology and Blood Transfusion.

Measurements:

This study was based on the study of the author Hasan S.S, 2011 [7]. The questionnaire was tested on 30 primary caregivers having children with acute leukemia (30 primary caregivers didn't participate in the later survey). It was assessed with Cronbach's Alpha value greater than 0.70 for the total scale of the practice.

It contains 28 items, including 12 items about general information and 16 items about the practice of primary caregivers. Evaluating the practices of primary caregivers have children with acute leukemia including 4 main contents: Nutrition (8 items), hygiene (2 items), exercises/ social activities (2 items), monitoring and prevention of bleeding for children (4 items) using a five-point Likert scale with answers in 5 levels correspond to the score 1, 2, 3, 4, 5: Never, rarely, sometimes, almost, often. (Unless with the item: Giving your child a wrong diet when your child had diarrhea) The items score was added to calculate the total scores, where a higher score indicates better practice. The total score of the practices divides by 16 (items). Satisfactory level of practice from 4 – 5 points (the answer is almost or often). In contradiction, an unsatisfactory level of practice less than 4 points (the answer is never or rarely or sometimes).

Statistical analysis:

Group comparisons on the practice scores were made using a student t-test (for two groups) or one-way ANOVA tests (for multiple groups). We tested the associations of the practice and with the characteristics of primary caregivers (age, gender, residence, educational level, marital status, receiving health educational information) by Pearson correlation.

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All variables enter into the regression models were coded or transformed into categorical measurements. Collected data were coded and tabulated using a personal computer. Using an SPSS 25.0 program for Windows. Statistical significant was considered at a p-value less than 0.05.

III. RESULTS:

Table 1. Socio-demographic characteristics of research subjects (n = 182)

Variables		Socio-demographic characteristics	
		Frequencies	Percentages
Residence	Urban	60	33.0
	Rural	122	67.0
Gender	Male	83	45.6
	Female	99	54.4
Age	≤ 25 years	5	2.7
	26-35 years	74	40.7
	36-45 years	80	44.0
	> 45 years	23	12.6
Educational level	Middle school or below	54	29.7
	High school	61	33.5
	Diploma/Bachelor/Postgraduate	67	36.8
Relationship with children	Father	78	42.9
	Mother	98	53.8
	Others	6	3.3
Marital status	Single	5	2.7
	Married	170	93.4
	Widow	2	1.1
	Divorced	5	2.7

Based on table 1, primary caregivers who were mothers accounted for 53.8% and the highest percentage of caregivers' age group was from 36 years to 45 years old (44%). Primary caregivers had a high educational level with Diploma/Bachelor/Postgraduate accounting for 36.8%. Regarding the residence, primary caregivers mainly lived in rural (67%).

Table 2, Consulting – health educational information of research subjects (n = 182)

Variables		Consulting – health educational information	
		Frequencies (N)	Percentages (%)
Receiving health educational information	Yes	138	75.8
	No	44	24.2

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Health educational information sources	Infomation media/ newspaper/ books	5	2.7
	Relatives/ friends	3	1.6
	Medical staffs	86	47.3
	Others/many sources	41	22.5

Based on table 2, the majority of primary caregivers who received health educational information accounted for 75.8%. The information received mainly from health staffs accounted for 47.3%.

Table 3. Practices of primary about nutrition for children (n = 182)

Items	The answer of primary caregivers (%)				
	Never	rarely	sometimes	almost	often
Preparing small meals or snacks when your child had nausea	1.1	4.9	23.1	61.0	9.9
Encouraging your child had 5 to 6 small meals or snacks	1.1	10.4	17	61.5	9.9
Providing your child with plenty of fresh fruits and vegetables each day	1.1	1.1	17.6	51.1	29.1
Choosing foods that are moist, soft and easy to chew and swallow.	1.6	3.3	26.9	54.4	13.7
Giving your child a wrong diet when your child had diarrhea	24.7	18.7	16.5	32.4	7.7
Giving your child plenty of water/fluids every day	1.1	0.5	11.5	47.3	39.6
Encouraging a high-fiber diet to prevent children from constipation	1.6	1.6	21.4	54.9	20.3
Encouraging your child to reduce the use of stimulant drinks (caffeine, nicotine,...)	0	2.2	11.5	49.5	36.8

Based on table 3, there were 61% primary caregivers prepared small meals when children were nauseous. 26.9% primary caregivers sometimes selected soft, moist foods that children easy to chew and swallow. 32.4% primary caregivers almost had a wrong diet when children had diarrhea.

Table 4. Practices of primary about hygiene and exercises for children (n = 182)

Items	The answer of primary caregivers (%)				
	Never	rarely	sometimes	almost	Often
Hand washing before and after preparing food for children	0	4.9	38.5	46.2	10.4
Encourage brushing teeth, gums and tongue after each meal and before bedtime	0	1.6	33.0	54.9	10.4
Encourage your children to have daily gentle exercises	3.8	14.8	15.9	46.2	19.2
Encourage your children to participate in social activities	8.2	11.0	28.0	37.4	15.4

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Based on table 4, primary caregivers mostly followed the hygienic and exercise regime for children. However, there were 38.5% primary caregivers sometimes washed their hands before and after preparing food for children. 33% primary caregivers sometimes encourage their children to brush teeth, gums and tongue after each meal and before bedtime. 28% primary caregivers sometimes encourage your children to participate in social activities.

Table 5. Practices about monitoring and preventing bleeding for children

Items	The answer of primary caregivers (%)				
	Never	rarely	sometimes	almost	Often
Encourage brushing teeth with a very soft toothbrush	1.6	1.6	8.2	60.4	28.0
Avoiding sharp and hard material forms	1.1	7.7	19.8	51.1	20.3
Checking your child's mouth and tongue every day	0	7.7	29.1	42.9	20.3
Monitoring temperature when your children had a fever	0	0	5.5	54.4	40.1

Based on table 5, there were 28% primary caregivers often used the soft toothbrush to brush children's teeth. Caregivers almost/often monitored children's temperature when children had a fever. However, 29.1% primary caregivers somtimes examined children's mouth and tongue.

Table 6. Practice scores of main caregivers having children with leukemia (n=182)

Variables	Practices of primary caregivers		
	X±SD	Min	Max
Nutrition	31 ± 4.27	18	39
Hygiene	7 ± 1.15	5	10
Suitable exercises	4 ± 0.9	2	6
Bleeding prevention	16 ± 2.21	10	20
Total	63 ± 7.96	39	77

Referring to table 6 above, the overall score of practices about caring for children with acute leukemia averaged at 63 ± 7.96. In particular, the average score for nutritional practices for sick children reached a maximum value of 31 ± 4.27. Also, the average score for exercises for children had a minimum value of 4 ± 0.9.

Table 7. The practice of primary caregivers having children with leukemia (n=182)

Practice	Frequencies (N)	Percentages (%)
Satisfactory	84	46.2
Unsatisfactory	98	53.8

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Based on table 7, the unsatisfactory practice of primary caregivers for children with acute leukemia accounting for a high proportion of 53.8%.

Table 8. Correlations to the total practice score of primary caregivers (n= 182)

Variables	Practices	
	R	p
Residence	0.1	0.2
Gender	0.54	0.47
Age	- 0.1	0.2
Education level	0.21	0.00*
Marital status	0.19	0.00*
Receiving health education	0.39	0.000*

** Correlation is significant at the 0.01 level (2-tailed).*

Based on table 8, there were relationships between education level/marital status and practices of primary caregiver. Also, there was a significant relationship between health educational information that primary caregivers received and their practices about caring for children with leukemia with r = 0.39 and p <0.05.

IV. DISCUSSION

4.1. The general characteristics of primary caregivers

The capacity of family caregivers take care of the person with cancer may have a significant influence on both health outcomes and cost in terms of readmission rates and the use of inpatient facilities [6]. In this study, primary caregivers who were mothers accounted for 53.8%. The results of the study are similar to the study of Atlanta G.A showed that the majority of primary caregivers having children with blood cancer were mothers accounting for 71.3% [1]. This result was supported by Jauissy M.S who found that the majority (78.1%) caregivers were females [9]. This study showed that the majority of primary caregivers age ranged from 26-35 years and 36-45 years. This age is considered the capable age for providing care for sick members of the family. Regarding the marital status of the caregivers, the majority of the caregivers were married. These results were in agreement with Al-Jauissy [9], who conducted a study on 82 caregivers at an outpatient chemotherapy clinic in Jordan found that the majority of the family caregivers were married. Regarding the characteristics of counseling-health education, the majority of primary caregivers received educational information accounted for 75.8%. The educational information that caregivers received mainly from health staff accounted for 47.3%. Others want to receive educational information on the social network or various sources such as media, books, sharing of friends/relatives accounting for 13.2%. According to the study of Ringner A and et al in 2011, it was necessary for caregivers to receive educational information. In some cases, there was a conflict between the information received and the demand for information that caregivers want [12]. According to the research of Hassan S.S and et al in 2011 [7], up-to-date communication and health education programs for primary caregivers having children with leukemia to enhance knowledge and practices about caring for children. Pediatric leukemia is treatable with chemotherapy. To enhance the quality of care and minimize the unfavorable impacts of chemotherapy, caregivers need to be empowered and to have knowledge. Therefore, the primary investigator should be interested in implementing an empowerment framework to enhance caregivers' confidence when providing care for pediatric leukemia patients at home or when hospitalized. Sustaining patients' health in this manner will increase opportunities for successful completion of the course of chemotherapy and diminish its impacts, thus improving the quality of life for patients with acute leukemia [14].

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4.2. Practices of primary caregivers about caring for children with acute leukemia

About nutritional practices for sick children: 61% primary caregivers almost prepared small meals when children were nauseous and vomitous. Antineoplastic-induced nausea and vomiting (AINV) reduce the quality of life for all patients receiving antineoplastic therapy, including children. Nausea is identified by parents of children receiving active antineoplastic therapy in Ontario as the fourth most prevalent and bothersome treatment-related symptom seen in their children [3]. Therefore, parents having children with acute leukemia treated with chemotherapy, antineoplastic therapy, need to perform proper diet such as preparing small meals instead of main meals for children. In this study, there were 61.5% primary caregivers almost encouraged children to eat 5 to 6 small meals or snacks. Meanwhile, the study of Hassan S.S was 3.75% and 8.75% respectively. In addition, this study showed that only 26.9% primary caregivers sometimes chose soft foods, easy to chew and swallow for children. This result was higher than the result of Hasan S.S was 8.75%. Moreover, 32.4% caregivers almost performed a diet unproperly for children. For example, the children eat white porridge with salts that do not ensure adequate nutrients, this will greatly affect the children's health, even the disease will be worse. Therefore, maintaining a reasonable diet, full of nutrients to have good weight and health play an important role. 38.5% primary caregivers sometimes hand hygiene before and after preparing children's food and 33% primary caregivers sometimes clean the children's teeth and gums properly before or after meals and before bedtime. There were 60.4% primary caregivers almost performed and 28% primary caregivers often used a soft toothbrush to hygiene children's teeth. This result is also higher than the result of Hasan SS and et al, 2011 [7], which showed that primary caregivers have poor practice in preparing meals and snacks for children accounting for 96.2% and 92.5% respectively. Caregivers had poor practice about oral hygiene. In addition, 93.75% caregivers discouraged children to drink a lot of water and 92.5% caregivers discouraged children to use soft toothbrushes to hygiene their children's teeth. According to the study of Hasan S.S, 12.5% caregivers encouraged children to exercise and 23.75% caregivers encouraged children to participate in social activities [7]. Those results were lower than our research: 46.2% caregivers almost encouraged children to do soft exercise and 37.4% caregivers almost encouraged children to participate in social activities. Only 28% caregivers somtimes encouraged children. The reason for this difference is that the research subjects of the author have low educational level, the illiteracy rate accounts for the highest rate at 46.2%, compared to this study, caregivers have higher educational level, the highest proportion was diploma/bachelor/postgraduate accounting for 36.8% and high school was 33.5%. This may be related to the number of females in the study of author Hasan S.S and most the females in Egypt, especially in the rural areas where socio-economic geographical factors and gender disparities continue to affect primary education as reported by Unicef [17].

Research results showed that caregivers almost monitored children's temperature when children had a fever accounting for 54.4%. However, 29.1% caregivers sometimes examine their children's mouth and tongue. This result showed that caregivers can't know or follow signs of mouth ulcers or children's teeth were bleeding. Those results showed that we need to have ineffective strategies to improve the practices of primary caregivers. Practice change has focused on several key areas such as prevention, general nursing care (nutrition, hygiene and exercises), management of fever. These results were familiar with the study of Robinson P.D and et al in 2016 [13]. The overall score of practices about caring for children with acute leukemia averaged at 63 ± 7.96. In particular, the average score for nutritional practices for sick children reached a maximum value of 31 ± 4.27. Unsatisfactory practices of primary caregivers for sick children accounting for a high proportion of 53.8%. This result was similar to the study of Manal M in 2013 [10], the percentage of primary caregivers with unsatisfactory practices and partially satisfactory were 22.4% and 69.3% respectively.

4.3. Some factors related to the practices of primary caregivers.

Some factors related to practices of primary caregivers for children having acute leukemia. Primary caregivers with educational levels were lower, those had unsatisfactory practices about caring for children accounting for the highest percentage, 20.9%. There was a relationship between the education level and the practices of primary caregivers. The difference was statistically significant with $p < 0.05$. This result was similar to the study of Manal M and et al in 2013 [10], there was a relationship between education level and caregivers' knowledge, practices with $r = 0.36$ and $p < 0.001$. The educational level had a positive correlation between the knowledge and the practices of primary caregivers. Caregivers with higher education levels will have better knowledge and practices about caring for children with acute leukemia.

About the marital status of the primary caregivers, the majority of caregivers are married, a small percentage of caregivers who are single, widowed and divorced. The study showed a relationship between marital status and practices of primary caregivers with p <0.05.

There was a significant relationship between health educational information and practices of primary caregivers. 40.7% primary caregivers had satisfactory practices when receiving health educational information. However, no statistically significant correlation was found between the primary caregivers' gender with their practices. These results were similar with the study of Manal M, 2013 [10]. This study showed that no statistically significant references were found between the two genders. This could be related to the number of female cargivers in the study. Also, no statistically significant correlation was found between the primary caregivers' age with their practices. These results were supported by the study of Hasan S.S, 2011 and Manal M, 2013 [7], [10]. However, these results were different from the results of Fouad [4], there was a highly statistically significant negative correlation between the caregiver's ages and their home practices. In practice, health declines with age and caregiver's activities as well as the ability to care for their children will be decreased by age.

V. CONCLUSION

Practices of primary caregivers for children with acute leukemia were low. Unsatisfactory practices accounting for a high proportion of 53.8%. There were relationships between the education level, the marital status and practices of primary caregivers. The study showed a significant relationship between health educational information that primary caregivers received and their practices about caring for children with p <0.05.

VI. RECOMMENDATIONS

Based on the study results, the following recommendations are suggested:

This study recommends updating health interventional program to improve practices of primary caregivers having children with acute leukemia

Health staffs need to strengthen health education for primary caregivers having children with acute leukemia by various forms and means: direct counseling, hand out documents, indirect counseling in the public media and on the social networks.

When counseling and health education for caregivers, contents need to be more attention such as nutrition, hygiene and suitable exercises for children with acute leukemia.

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