Knowledge of Primary Care Provider Regarding Basic Home Care Skills of the Acute Lymphoblastic Leukemia children

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Abstract

Acute lymphoblastic leukemia (ALL) is the most common type of childhood leukemia that is about 75-80% of all types of leukemia. In Pakistan the prevalence rate of ALL in childhood is 34% and the total patient survival is 51.06%. **Study Objective:** To assess the knowledge of primary care providers having children with ALL regarding basic home care skills.

Methods: A descriptive cross sectional survey was carried out at the out-patient department of the Pediatric Oncology at the Children Hospital, Islamabad. Census method of sampling was used to estimate 100 primary care providers of children with ALL. An adapted, modified, pilot

tested and interviewer-administered questionnaire was used to assess the knowledge of study participants regarding home care skills. Primary care provider who, spent less than 2-3 hours per day in ALL child care, health professional and cannot speak and understand Urdu, Punjabi and Pashto were excluded from study. Study was approved by IRB of Shifa International Hospital. Written informed consent from participants was taken.

Results: The study findings indicated that most of the study participants (50%) had poor knowledge level regarding home care management of ALL children, 43% were good knowledge level and only 07% has very good knowledge level. More than (80%) participants has knowledge about most of the infection control components, , while 81% participants were not encouraging their children for tooth brushing practices in oral care section and 78% of the participants were not prohibiting black tea for their children in Nutrition care section.

Conclusion: This research concluded that most of the primary care providers had deficit in knowledge regarding basic home care skills of the children with ALL.

Keywords: Home care skills, ALL children, cancer children survivors, parental knowledge and basic home care practices, primary care providers, assessment of knowledge, mother knowledge regarding home care skills of leukemia children.

Introduction:

Childhood cancer is a growing and prevailing type of chronic disease. It is estimated that more than 200,000 children and adolescents are diagnosed with cancer each year, out them 80% children belongs to developing countries, while more than 90% deaths of children are cancer related globally (Howard, 2004). The annual incidence of childhood cancer was 148000 during 2008 in children aged 0–14 years in developing countries (Satyanarayana, 2014). The expected number of childhood cancer will increase up to 30% by the end of 2020 (Mohammad, 2106).

Most of the developing countries data regarding childhood cancer is not availible becuase majority of them have no national level cancer registeration system.

Pakistan is one of the developing countries where cancer registry system does not exist; so limited data is available regarding incidence rate of cancer. A study conducted in 2008 reveals that in Pakistan 0.15 million new cancer cases will be observed each year, and out of these cancer cases 60% to 80% patients die each year (Globocan, 2008).

Leukemia is the most common type of childhood cancer and accounts for 25% of all cancer occurring before the age of 20 (Tonorezos ES, 2014). Leukemia has two main types in children, acute lymphoblastic leukemia (ALL), accounting for about three-fourths of leukemia, and acute myeloid leukemia (AML) accounting for much of the remainder of leukemia cases (Shukir, 2011). Leukemia is the second most general form of cancer after breast cancer in Pakistani population. In children, leukemia is the most common type of cancer and prevails up to 36 % of all childhood cancers (Mehwish et al., 2015) and these patients five years survival rate is 51.06% (Shabbir, 2011). Shaukat The peak incidence of ALL is observed in children aged 2 to 3 years (Smith, Gloeckler Ries, Gurney & Ross, 2010). Advancement in the treatment and competent supportive care for the children with ALL plays a key role in the management of this disease. Successful management of childhood ALL is one of the great medical sciences successes of the modern era. The five years survival rates approaching or even exceeding 90% in most of developing countries (Pui CH, et al., 2012). The burden of cancer is increasing in the developing countries as compared to developed countries because of the unavailability of resources, lack of cancer treatment centers and poor supportive care of the patients following the start of the treatment (chemotherapy). Developing countries face many barriers regarding the effective management and organizing the childhood cancer treatment programs, like lack of education and

training regarding childhood cancer for patients, their families, community and health care proffesional, and not enough oncology units or regional oncology centers. (Magrath, et al. 2013).

After admission of ALL children in hospital their primary care providers has great opportunity to closely observed the nurses for, how to perform basic skills like fever monitoring, hydration status monitoring, bedding, hand washing with soap following proper techniques, using mask, maintaining isolation protocols, traffic control and participation in different games usually indoor . They have also the opportunity to perform these tasks in front of nurses so proper guidance and knowledge are provided by the nurses to them (Afshin Fathi, 2015). Moreover primary care provider need to perform complex medical tasks at home, management of ALL child, decision making, problems solution, provide emotional support, comfort, and coordinate care of the child. Using these skills, primary care provider administer medications at home, provide nutrition according to the patients' needs, handle medical equipment, and provides direct care such as fever management at home, lifting and turning of the patients (Gaugler, et al., 2007).

Knowledge for the primary care provider about their child's diagnosis and treatment plan will help to relieve uncertainty. Primary care providers of ALL children are feel relax and more satisfied when their child's oncologist or pediatric oncology nurse provide accurate and authentic information regarding the disease, its management and about home care (Rodgers C, 2016).

Assessment of the knowledge of primary care providers of ALL children for their home care skills is very important. Only through proper assessment of their knowledge the health care professionals can plan to train them according to their needs and plan in future for better educational sessions for them. Moreover proper knowledge of the primary care providers has a significant impact on the health outcomes of cancer children, decreases the cost in terms of readmission rates, decreases the infection rate, improve the quality of nutritional intake,

encourage exercise, fever management at home and change in the use of inpatient facilities (Manal, 2013). This study aims to assess the knowledge of primary care provider regarding basic home care skills of the ALL children's.

Methodology:

A descriptive cross sectional study was carried out on primary care providers of acute lymphoblastic leukemia (ALL) children. The study population for this research study included all the primary care providers (age more than 18 years) of ALL children's, visited outpatient department at children hospital Pakistan Institute of Medical Sciences (PIMS), Islamabad. In this study census (universal) method of sampling was used. The proposed sample size for the current research study was 130 participants but due to loss of follow up in pediatric oncology OPD, the total sample size reached to100 participants. Every primary care provider of the children with ALL was approached to participate in the study on volunteer basis.

Inclusion criteria

- Primary care providers age more than 18 years.

- Those primary care providers involved in assistance, care & support for the child at home.

- Primary care providers of the children (01 year to 12 years of age) with ALL, they received at least a single dose of chemotherapy.

Exclusion criteria

- Primary care provider who is not or less than 2-3 hours per day involved in child care since one month

- All primary care providers those are health care professionals.

- Children with any complication or visited due to any other diagnoses in hospital

- Language barrier (other than Urdu, Poshto or Punjabi).

Study Tool

In this research study data was collected with the help of an adapted, structured and modified questionnaire. This questioner is adapted from a study of Iraq (Al-Ani, 2013). Cronbach Alpha Coefficient was reported by them, the reliability of that study tool, which was 0.76.

The used study tool contains three parts:

Part 1: Demographic characteristics of ALL children;

age, sex, type of received treatment, educational status and duration of illness.

Part 2: Socio- demographic characteristics of primary care provider of children with ALL; age, sex, number of Children, level of education, residential status and monthly income.

Part 3: Assessing the knowledge of primary care providers of children with ALL regarding home care skills. This part of the questioner consisted total of 28 components and further divided in to five main components: infection control care (07 components), oral care (04 components), nutritional care (05 components), others like social care, sleep and exercise (06 components) and fever management (06 components).

Tool validity

Tool was submitted to five experts (two doctors and three nurses) in field of pediatric oncology to test the content validity. Little modifications were carried out according to the experts' suggestions regarding the clarity of sentences and appropriateness of content. The experts of pediatric oncology further identified important items not included in the questionnaire which were subsequently added.

Pilot Testing:

Total number for the pilot testing was 13 participants which was conducted at pediatric oncology unit of Children Hospital, Pakistan Institute of Medical Sciences (PIMS), Islamabad. Primary care providers of the children with cancer (except ALL children) were included in that pilot testing.

Data collection

In data collection process for this research study, an adapted, self-administered questionnaire was used and information was collected from the participants. Interview of the participants conducted in the waiting room beside the pediatric oncology clinic by the primary investigator. Each interview sheet took around 30-45 minutes to be filled by the participant. Data was collected 03 days/week (Monday, Wednesday and Friday) from March 2017 to July 2017, because on these days the more patients came to outpatient department (OPD) of the study selected setting.

Ethical consideration

This research study was approved by the Institutional Review Board (IRB) of Shifa Tameer-e-Millat University. Subjects were independent to either participate in this research or not 'voluntary participation' and they have the right to withdraw from a study any time without any penalty. The written informed consent was obtained after explaining the purpose of study. The confidentiality, anonymity and autonomy of the participants were ensured.

Data Analysis

Data analysis commenced after conducting the first interview. IBM SPSS Statistics version 21.0 was used for the analysis of the research data. Percentages were calculated for the analysis of socio-demographic characteristics and for the overall study tool as well. Tables and graphs were used to show association between variables.

Each component of the study tool given 1 score for the correct (when response 'yes') answer and 0 for incorrect answer (when responded 'no') Total score was 28. Three main categories were formulated on the basis of score secured by the participants:

- **Poor:** Participants scored 11 (≤ 40%)

- **Good:** Participants scored between12-19 (41%-70%)

- **Very Good:** Participants scored more than 19 (>70%)

Study Results and Data Analysis:

Study Result

The mean age of the children with Acute Lymphoblastic Leukemia was 6.69 years with Standard Deviation of 3.28. While the mean age of the primary care providers were 31± 7.70. Table 1 represents the demographic data of the ALL children and their primary care providers. (*Detail results are given in table 1*).

Overall knowledge Level of the Participants regarding Home Care Management

The overall results of study categorized in to three main categories according to the knowledge level poor, good and very good (as described in Chapter-3). The results showed that 50% of the participants has poor knowledge level, 43% of the participants has good knowledge level while 07% has very good knowledge level regarding basic home care for the ALL children. The results clearly signify that majority (50%) of the primary care providers of the children with ALL has deficit in knowledge regarding home care of their children. *(For detail see Pie chart-1)*

Most Significant Findings of the Study

The study results shows that majority of findings related to infection control component the study participants has very poor knowledge that was 80% or more than that as

compared to other components. The second important component of the study is oral care because only 19% of the study participants had knowledge regarding encouraging their children to practice tooth brushing. While in the component of nutritional care majority of the participants 78 (78%) were not prohibiting black tea to their children. Most of primary care providers (94%) were able to provide adequate sleep at night time for their ALL children.

The detail results of every component and primary care provider responses are given in table 2.

Discussion:

Socio-demographic characteristics of children with ALL

Regarding the socio-demographic characteristics of children with ALL, results of the current study is agreement with an Egyptian study conducted by Manal 2013, showed that 62.5% of the ALL children were boys and 37.5% were girls (Manal, 2013). Regarding children age, results of the current study is similar with the result of the study conducted by Sahar & Nahla in 2015; the mean age of ALL children was 7.07±2.56 (Muhmoud, S. & Elaziz, N. A., 2015). In relation to the educational level of child with ALL, the current study result was agreed with a study by Hasan and Ibrahim, showed that most of the leukemia children 48% were in primary school level (Hassan G, Ibrahim H., 2018).

Socio-demographic characteristics of Primary Care Providers

The result of the present study shows that majority of the primary care provider were female (99%) and their mean age and standard deviation were 31± 7.70 respectively. It may be due Pakistani cultural context that most of the females take care of their children at home, not only but at the same time they may take care of more than one child. The other most important task for rural female they performed additional activities outside home. As we know that majority of our study participants were female so their increase ratio of education may be

because most of them were residents of nearby urban areas (residents near to the twin cities). Another reason may be due to the awareness of the people regarding educating their females.

While talking about the monthly income level of the participants the results shows that only 27 (27%) has monthly income less than 10,000 rupees. It showed that most of the persons belong to the nearby areas, and has some type of job or own business.

Overall knowledge Level of the Participants regarding Home Care Management

The overall results of the current study showed that study participants has deficit in knowledge regarding basic home care skills and these results are similar with an Indian base study conducted in 2015, the result of that study showed that 43% participants (mothers) has deficit in knowledge (Purkait G, 2018). A joint workshop by the Institute of Medicine (IOM) and the American Cancer Society, conducted in March 2015 on the topic of "Comprehensive Cancer Care for Children and Their Families" and they identified, that most of the study participants has deficit in knowledge regarding home care management (Rebecca et al., 2016).

The result of the current study showed that majority of the study participants has deficit in knowledge regarding the different components of the infection control, that include hands washing, using of mask and avoidance their ALL children in contact with ill persons at home. The results of the current study were accordance to the study conducted in Erbil city, Iraq. That study result showed that 42.5% of the participants were not using proper hand wash before and after food preparation, and only 37% avoided their children from dusty and crowed areas (Al-Ani, 2013).

Regarding oral care only 39 (39%) of the study participants assess their child's mouth on daily basis, 81 (81%) were not practicing their child tooth brushing after each meal and at bed time, and this result has agreement with Al-Ain study that findings showed that only 30% of the

participants assess their child mouth on daily basis and 87.5% were not practicing their child tooth brushing after each meal and at bed time.

The study participants have also deficit in knowledge regarding other basic home care skills like not avoiding their children from direct sun light and not encouraging their children for daily exercise. Similar results were found in the study Sahar & Nahla, (2015) and Manal, (2013) both of these studies were conducted in Egypt. They found out that family caregivers of the leukemia children were deficit in knowledge regarding basic home care practices (exposure to sun light, daily exercise and adequate sleep), (Manal, 2013 & Elaziz, N. A., 2015). Majority of the participant has limited information regarding temperature taking skills and the use of non-pharmacological techniques of fever management at home. Deficit in knowledge regarding temperature taking may be lack of awareness related to health education and poor practices of the study participants inside home.

The cold towels draw heat out of the body and can lower the body temperature. Fever can lead to dehydration which can make the sufferer feel worse. Avoid dehydration by drinking plenty of water or an oral rehydration solution (Zora Degrandpre, 2017). Similar results were shown in an Indian base study only 51% of the participants have knowledge about fever symptoms and less than that has deficit in knowledge regarding fever management (Nikhitha, 2015).

Conclusion

The final conclusion reached from the current study that primary care providers of children with ALL who participated in the study had deficit in knowledge regarding basic home care skills. Majority of them were female, educated, living in rural areas, while majority of the ALL children were male. From the findings of the study and in the light of available literature it can be concluded that the primary care providers have lack of knowledge regarding basic home

care skills. Most of the study participants had deficit in knowledge especially in the component of home base fever management and infection control techniques at home.

Study Limitations

The studing findings may not be generlized because it was performed in one setting with limited sample size. It was also not ethically right for the researcher to request participants to come from their residences merely to take part in the research purposes on voluntarily bases. Whole budget was manage by the primary researcher as no grant was allocated in any means to conduct this study so this issue may be consider in future for coming badges of MSN students.

It was assume that only health care providers will be excluded from the research study but, durating the interaction with the participants at data collection time it was observed that some of the them have enough knowlegde regarding the disease and its home care management. Some of the articles in other languages (non-English) could not be included due to the lack of access to appropriate translation services.

Recommendations

Based on the findings of the study, the primary researcher made the following recommendations;

- Similar study can be conducted on a broderscale with larger sample size. Increase in the sample size will increase the generalibility of the study.

- A study can be conducted to improve knowledge of the primary care providers regarding home care skills.

- Health education program for primary care providers of children having ALL to prepare them with the needed knowledge and skills so they can provide appropriate home care for their children.

- Prepare a protocol/guidelineson home care management for the primary care providers of children with ALL to help them in appropriate home care skills.

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Table 1: Demographic data of the children with ALL and their primary care providers.

S/no	Description		Frequencies	Total number
1	Gender			
	a.	Male	63	100
	b.	Female	37	
2	Duration of Disease			
	a.	Less than one year	53	100
	b.	More than one year	47	
3	Treatment Types			

a.	Chemotherapy	94	
b.	Corticosteroid therapy	100	100
4	**Educational Status**		
a.	Pre-School	33	
b.	Primary School	56	100
c.	Elementary School	11	

Demographic data of the primary care providers

1	**Gender**		
a.	Male	01	100
b.	Female	99	
2	**Minimum Education Level**		
a.	Illiterate	27	100
b.	Primary and Below	19	
c.	Up to Secondary	27	
d.	Secondary and above	27	
3	**Monthly Income in Rupees**		
a.	Less than or equal to 10,000	27	100
b.	10,001-30,000	38	
c.	More than 30,000	35	
4	**Residence**		
a.	Urban	40	
b.	Semi Urban	09	100
c.	Rural	51	

Table 2.Responses of the Primary Care Providers r/t Hand Washing and Infection Control when Contact with ALL children.

S/no	Description	Frequencies		Total Number
		Yes	**No**	
1.	Are you washing hands			
a.	with soap?	42	58	100
b.	Are your follow the proper techniques of hand washing?	100	--	100
c.	Hand washing before and after preparing food?	48	52	100
d.	Are you washing hands after attending toilet or after changing pamper of your child?	68	32	100
2.	Avoid patient's contact with ill people.	19	81	100
3.	Avoid staying in crowded and dusty areas.	12	88	100
4.	Using masking when contact with other outside home.	02	98	100

Responses r/t mouth assessment, tooth brushing

and providing of moist diet.

1.	Check the mouth and tongue every day.	39	61	100
2.	Encourage brushing teeth, gums, and tongue after each meal and at bed time.	19	81	100
3.	Encourage brushing teeth with a very soft toothbrush.	62	38	100
4.	Provide diet that is moist, easy to chew and swallow.	61	39	100

Responses r/t the practices of the nutritional care.

1.	Give large amount of fresh fruit and vegetables.	47	53	100
2.	Encourage to 5 or 6 small meals and snacks instead 3 large meals.	40	60	100
3.	Small meals and snacks when he/she has nausea.	46	54	100
4.	Increase fluid intake.	39	61	100
5.	Limit intake of tea Black Tea intake.	22	78	100

Responses r/t fever management at Home

1.	Knowing the proper way to take a temperature	39	61	100

2.	Are you used the non-pharmacological techniques for fever control at home?	---	---	
	a. Using cold sponging techniques for managing fever at home.	47	53	100
	b. Remove clothes or apply loose and light clothes at home for fever management.	31	69	100
	c. Increased fluid intake in case of fever.	03	97	100
3.	Are you used the pharmacological techniques for fever control at home?	80	20	100
4.	Are you brought you child immediately to hospital in case of fever?	43	57	100

	Responses r/t Other Home Care Skills			
1	Encourage adequate sleep of at least 8 hour each night.	94	06	100
2	Avoid eating big meal before sleep.	55	45	100
3	Encourage social activity.	47	53	100

4	Avoid direct sunlight.	19	81	100
5	Encourage exercise.	14	86	100
6	Avoid sharp and hard material forms.	47	53	100

Pie Chart 1: *Knowledge Level of the Primary Care Providers*