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Effectiveness of Nurse-led Intervention to Improve Quality of life for family caregivers of Children with Leukemia: A Quasi-Experimental Study from Karachi Pakistan

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Effectiveness of Nurse-led Intervention to Improve Quality of life for Family Caregivers of Children with Leukemia: A Quasi-Experimental Study from Karachi Pakistan

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ABSTRACT

Background: Acute lymphoblastic leukemia accounts for 25% of all cancers in children less than 15 years old. The treatment phase of leukemia is lengthy and takes 2-3 years. Due to prolonged treatment, family caregivers often become exhausted, highly distressed with low quality of life and unsatisfactory patient outcomes. Thus, caregivers need interventions such as adaptation strategies and access to support groups that enhance their wellbeing and improves their quality of life (QoL).

Objectives: To determine the effectiveness of nurse-led structured educational intervention for family caregivers having a child diagnosed with leukemia and to examine the association between socio-demographic variables and quality of life of leukemia child caregiver.

Methodology: A Quasi-Experimental pre-post-test design was applied at the tertiary care hospital of Karachi. A total of 74 family caregivers of leukemia children were recruited from outpatient and inpatient oncology departments using purposive sampling. The data was collected pre-intervention and post-intervention using QoL-FV. Intervention of educational session given in 30-45 minutes for 4 days and after 1month of intervention, posttest done by same questionnaire to estimate the effect of nurse-led education

Results: Study findings revealed that mean score of overall QoL improved after one-month of nurse-led educational intervention 95 ± 23 and had a significant difference in post-test QOL (<0.001). The sub-dimensions of QoL such as physical wellbeing, psychological wellbeing, and social concern improved significantly in posttest interventions group ($P < 0.01$). Spiritual wellbeing was found insignificant after interventions ($p > 0.080$).

Recommendation: Nurse-Led education program is helpful to improve family caregivers' quality of life during the treatment journey of their leukemia patient. It must be considered and acknowledged with prime importance and caregivers should be supported by health care professionals. It should be an important aspect to include counseling sessions of families to improve their coping, problem solving and awareness.

Keywords: *Children with Leukemia, Family caregivers, Quality of life, Nurse-led education interventions.*

INTRODUCTION

Among all non-communicable diseases, Acute Lymphoblastic Leukemia (ALL) is the most common cancer and accounts for 25% of other cancers worldwide. It is highly prevalent in below the age of 15 years (1, 2). The high-income countries account for 18% of the global DALYs of childhood leukemia whereas the low and middle-income countries account for 60 per cent of the global DALYS (3). Fortunately, with the help of medical advancement, the recovery rate of Acute Lymphoblastic Leukemia in children has improved from 97 to 99% (4). Whereas the treatment journey of ALL takes approximately 2–3 years, which is a prominent feature of leukemia treatment (5). During this aggressive and prolonged treatment, the children affected with this disease are highly dependent upon their family caregivers (2, 6). National Alliance for Caregiving statistics of 2015 suggested that approximately 2.8 million people are involved in providing care to cancer patients informally in the United States of America and they fulfill about 50% of cancer patients' needs at home where their efforts are unpaid and not acknowledged (6, 7). Providing comprehensive care to cancer children is quite a challenging job for family caregivers as they are supposed to extend multidimensional care such as giving medication, managing symptoms, rehabilitation, physical and psychosocial care, coordinating with health care services to notify them of a change in the health status of the patient and being a partner with the health care team, and so on (8, 9). However, most caregivers of cancer children do not have adequate knowledge, skills, and self-reliance to fulfill such sophisticated duties as it is both emotionally and physically draining (10).

Family caregivers of cancer patients are quite stressed when they are required to balance their responsibilities as caregivers and their essential personal needs (6). These multiple roles and responsibilities of caregivers cause an imbalance in their life and impact on their physical, mental, social, and spiritual health adversely. Also, Eiser (11) reported that many caregivers end up losing their job for caregiving commitments, which intensifies the financial burden and cost of treatment on the family suffering from chronic conditions such as cancer. The undesirable circumstances wreak havoc not only on caregivers' QoL but also make it challenging for them to deliver appropriate care to their loved ones (9). However, their role is fulfilled with rigor and vitality without knowing the prognosis of their loved ones. Yet, they do not obtain any significant help (6).

Numerous studies have documented that Childhood cancer affects negatively on the QoL of family caregivers (12, 13). So, it is highly important to assess these areas ensuring comprehensive and holistic care for family caregivers (4, 14, 15, &13).

METHODOLOGY

A Quasi-experimental (pre and post) design was employed to determine the effectiveness of nurse-led educational interventions among family caregivers of leukemia children. The study was conducted at 300 hundred bedded tertiary care hospital of Karachi, Pakistan. The duration of the study was from August to October 2020, which included pre-test, intervention, and post-test intervention. The WHO sample size calculator was used to determine sample size using SD (± 7.8) for QoL score of Leukemia children caregivers, reported in the previous literature (10), keeping with confidence level of 95%, and 80% power, the calculated sample size was 60 but the researcher opted for 74 to account for dropouts. The non-probability purposive sampling technique was used to attain sample completion. Inclusive criteria of participants was a family

caregiver who was directly involved in the care of a child having leukemia diagnosis, both male and female above 18 years of age, signed written consent for participating in the study, caregiver whose child who was at the initial stage of diagnosis, and having 0-14-year-old child under treatment for ALL. Whereas participants who had difficulty in understanding instructions and having patient with a diagnosis other than leukemia were not included in the study.

Data Collection tool

The Quality of Life-Family version (QoL-FV) instrument was used in this study. It was adapted from quality of life of the patient version developed by Ferrell and Grant (16). The internal consistency on total sample was measured by Cronbach's alpha and had a reliability as $r=0.77$. However, the face validity for the content of the questionnaire, in English and Urdu translation was done by subject experts in one of the renowned oncology hospitals of Pakistan. The questionnaire comprised of two sections. Section 1 contained sociodemographic data, whereas section 2 included 37 questions based on four dimensions: physical, psychological, spiritual wellbeing, and social concern. Each dimension was assessed on a scale of 0-10. Study was divided into three phases:

Phase-I: Pre-Test

A pre-test questionnaire was given as a baseline data to participants

Phase-II: Intervention

After data collection by the nurse researcher, all participants were given a structured teaching session through presentations consuming 30-45 minutes during hospitalization or outpatient department visits; Educational sessions were conducted in four days. In addition, pictorial brochure in English or Urdu language was also provided to caregivers.

Phase-III: Post-Test

After one month of nurse-led intervention, the same questionnaire (Quality of life-Family version) was administered as a post-test.

Data Analysis

After data collection, data was entered and analyzed using Statistical Package for Social Science (SPSS) version 20. Mean \pm SD was calculated for continuous variables, while frequency and percentages were used for the categorical variables QoL of caregivers is based on four dimensions: Physical, Psychological, Spiritual wellbeing, and Social Concern. All dimensions were presented in terms of Mean \pm SD.

To find out the mean differences in QoL, scores including four dimensions were examined by paired T-test and p-value ≤ 0.05 was considered as statistically significant. Moreover, linear regression analysis was also applied to check all independent variables' effect on the outcome variable, i.e., the post-test QoL scores. Cut-off P-value ≤ 0.25 was considered a significant value at the univariate level. Variable under significant p-value at univariate level; were taken forward for Multivariable regression analysis. Multivariable linear regression was applied using a stepwise model considered P-value ≤ 0.05 significant.

Ethical Consideration

The data collection was initiated after the approval from Clinical Review Committee (CRC), Ethical Review Committee (ERC), and Board of Advance Studies and Research (BASR) of Ziauddin University.

RESULTS

Socio-Demographic variables are summarized in Table 1. Out of 74 participants, 69 (93.24%) were married, and 5 (6.76%) were unmarried; 47 (63.51%) male responders, and 27 (36.49%) were females. The relationship of the subject to the patient was found as 39 (52.70%) were fathers, 25 (33.78%) were mothers, 5 (6.8%) were siblings, and 5 (6.8%) were having other relationships. Regarding the education of study participants, 12 (16.2%) were uneducated, 20 (27%) had a primary level, 30 (40.5%) had secondary, 8 (10.8%) were Intermediate, and 4 (5.4%) were graduates. Approximately all 73 (98.65%) participants belonged to the religion of Islam, and only 1 (1.35%) was from another religion. About one-third of participants 22 (29.7%) were unemployed, 12 (16.2%) had their business, 32 (43.2%) were skilled laborers, and remaining 8 (10.8%) were doing other jobs. The mean± SD age of the participants was 33.91±8.12 (years); the numbers of family members of the sick child were 10.45 ±8.031, and the duration of care was 14.32 ±7.93 (hours).

Table 1: Socio-demographic characteristics of study participants (N= 74)

Variables	(N = 74)	%
Relationship with patient		
Father	39	52.70
Mother	25	33.78
Sibling	5	6.8
Other	5	6.8
Marital Status		
Married	69	93.24
Unmarried	5	6.76
Gender		
Male	47	63.51
Female	27	36.49
Qualification		
No Education	12	16.2
Primary	20	27
Secondary	30	40.5
Intermediate	8	10.8
Graduate	4	5.4
Occupation		
Unemployed	22	29.7
Business	12	16.2
Skilled labor	32	43.8
Other	28	37.84

Continuous Variables	* Mean	±	SD
Age (years)	*33.91	±	8.12
Number of family members	* 10.45	±	8.031
Duration of care (hours)	* 14.32	±	7.93

Participants scores on QoL domains and overall QoL before and after Intervention

Paired T-test was applied to examine the effect of nurse-led structured education on participants (Table 2). Quality of life-family version questionnaire was given to the subject before nurse-led intervention. In accordance with the findings of the pretest, the mean scores and standard deviation of psychological wellbeing were 92±6, spiritual wellbeing 55±08, social concern 44±1, and physical wellbeing was 22±09; and the overall Pre-test QoL mean score was 215±30. Subjects were administered the same instrument after receiving nurse-led education as posttest QOL. Study participants had significant progress in psychological wellbeing 84±11, social concern 38±10, and physical wellbeing 16±09 (P<0.001). Whereas the mean score of spiritual wellbeing 57±05 remained insignificant after receiving the intervention (p<0.08).

Table 2: Participants scores on QoL domains before and after Intervention

S.NO	Variables	Before Mean & SD	After Mean & SD	P value
1	Physical wellbeing	22 ± 9	16 ± 9	<0.001
2	Psychological wellbeing	92 ± 16	84 ± 11	<0.001
3	Social wellbeing	44 ± 11	38 ± 10	<0.001
4	Spiritual wellbeing	55 ± 8	57 ± 5	0.080

*P values calculated by Paired T Test

Table 3: Participants Overall QoL before and after Intervention

S.NO	Variables	Before Mean & SD	After Mean & SD	P value
1	Overall QoL	215 ± 30	195 ± 23	<0.001

*P values calculated by Paired T Test

There has been some evidence of better QoL in female caregivers and this factor was also found significant in the present study. However, the number of family members and the duration of care negatively predicted the QoL scores which was much of an expected finding as we assumed that these parameters mostly predicted the overall lack of resources and financial limitation.

Table 4: Multivariable linear regression reporting adjusted Beta Coefficients (n=74)

Covariates	β (SE)	95% CI		P-value
		Lower limit	Upper limit	
Total pre-QoL score	0.002 (0.0003)	0.001	0.003	<0.001
Gender	-			
Male	0.04 (0.02)	0.01	0.05	<0.001
Female				
Number of family members & Duration of care (hours)	-0.0004 (0.0001)	-0.0007	-	<0.001
			0.00002	

DISCUSSION

The analysis of study findings indicated that caregivers of ALL children experience compromised quality of life throughout treatment journey. In the current study, caregivers' have reported overall low QoL scores in dimensions like physical, psychological, social, and spiritual wellbeing. Several studies have been reported similar issues among caregivers because of their burden of care (14, 17, 18). With the projecting prevalence of ALL, the quality of life of caregivers is equally important to alleviate issues of leukemia children; therefore, QoL must be considered and acknowledged by health care professionals with prime importance. In this study, spiritual wellbeing of caregivers did not show a significant improvement ($p < 0.080$) in post-test intervention. However, the overall QoL for caregiver is enhanced as a result of teaching provided to them which is evident through the p-value applied. In contrast, previous study suggested that interventional teaching session on spiritual coping found to be effective in lowering the caregivers' stress ($P < 0.001$) (19). This difference can be result of difference in sample size.

In current study, association between nurse-led educational intervention and caregivers' QoL scores showed a significant enhancement in overall QoL following the nurse-led teaching intervention (< 0.001). The results are in line with the studies conducted in Iran (10, 12). It highlights the importance of education for caregivers of ALL children as leukemia has greater mortality risk than any other chronic illness, and lead to caregivers' life more challenging. Therefore, support interventions rendered to caregivers of ALL children can bring significant improvement in minimizing caregiver role strain among caregivers of ALL. The demographic characteristics have also major influence on the quality of life of the caregiver. About the relationship of caregivers with the patient, more than three quarters 64 (86.48%) of participants in current study were parents such as father and mother who play a crucial role in providing care to the sick child. This result is concurrent with findings (5, 20). This shows that parents are primary stakeholders, and they are closely bonded with their children and can better provide support to their sick children.

In this study, the participant's mean age was 33.91 ± 8.12 (years). This finding is coherent with the previous studies conducted in China, and Iran (.9, 12). It suggested that caregivers in their

middle age are more understanding, better in problem solving, and they can provide better care to their sick children and their family too. Based on the education level of the participant, this study found that only 5 % of caregivers fell into the category of graduate level education and majority were secondary or below, which is concurrent with the study conducted in Indonesia (13). Findings also reported that a lower level of education is significantly associated with the physical symptoms of caregivers who care for ALL children. It highlights the issue that usually caregivers with low literacy have less motivation and willingness to practice healthy activities and they are reluctant to change their routines which ultimately affects their health issues and risks.

Gender is another predictor of caregivers' QoL. In this study, majority (63.51%) caregivers were males. The findings were consistent with the study done in India (5). In-contrast, study conducted in Iran reported that 66.8% were female caregivers in their study. The difference in study findings can be interpreted as in terms of cultural context, where due to lack of accessibility of medical facility and financial issues, participants have to travel far away for free treatment. Since females have many other responsibilities at home so man travel with children in this case. Therefore, males especially fathers were staying in hospital or economic rental residence temporarily. Moreover, due to covid situation and patient safety, two parents were not allowed to stay with child. In this study, the female caregivers showed better QoL (<0.001) after nurse intervention as compared to male caregivers. These findings were consistent with study done in Indonesia (13). It could be due to males having paternal role along with multi responsibilities of a family is exaggerated due to caregiving burden and end up with a decrease in their QoL and makes their life challenging and tougher to handle both situations.

In this study, caregivers belonged to low socio-economic background which was evident in the findings as 28% of participants were jobless, and 43% laborers, and only a few (16.2%) had their businesses. The more time spent on caring for a cancer patient limits caregivers from earning, leading to a financial crisis in the family. The unfortunate circumstances such as the pandemic Coronavirus was also a confounding factor that affected their economic condition. The economic situation of caregivers is concurrent with several other studies done in Turkey (19), & Iran (23). In addition, caregiving families with chronic illnesses have a higher economic burden by giving an average of ten hours in a day to the patient may cause job losses, out-of-pocket expenses, and other sustainability issues. In the current study, it became evident that increasing the number of caregiving hours and adding more family members to the caregiving of a single person leading to decreased post QoL scores and the study result has a weak positive correlation between duration of care and QoL ($P\text{-value}<0.001$). These results are in-line with a previous study conducted in Iran (10).

Strengths and limitations of the study

Strengths of study include that it is first of its kind in Pakistan so, this study can serve as a baseline or pilot study for the large-scale prospective research, and which can be generalizable in Pakistan. Furthermore, this pre -post-study has used a robust statistical measure to check the association between different factors with QoL scores. In addition, this study has tried to assess various predictors such as age factor, different educational backgrounds, and diverse socioeconomic groups, which enhance the validity of the study.

There were few limitations of this study such as participants were recruited from a single tertiary care hospital in a province, so the generalization of the findings is questionable. Moreover, the possibility of wish bias cannot be excluded because there is tendency that participants may respond based on their own scheme of thoughts for subjectivity.

CONCLUSION

Provided that usual caregivers of leukemia children turnout to be parents, and parents of cancer children need more care and assistance as compared to children with other diseases usually. Since it is revealed from many studies discussed QoL improves in many dimensions including mental health of the families. Enhancing QoL of caregivers will positively impact the family of child diagnosed with leukemia and eventually patient also. Additionally, nurses need to talk about the support system which is rare in our region and specifically public settings. Physical, mental, spiritual, and social support should be considered for leukemia children as well as for their caregivers.

RECOMMENDATIONS

- Decreased QoL of caregivers is a global issue therefore, it must be considered and acknowledged with prime importance and caregivers should be supported by health care professionals to ensure their physical, psychological, social, and spiritual well-being.
- This study pointed out many areas that can be explored further. such as how this caregiver role is affecting other role and relationships of the family. This could be implemented as counseling sessions of families to improve their coping, problem solving and awareness.
- Such interventional studies should be promoted in various parts of the country so that the implication of intervention can be generalizable to the local population.
- In–depth interviews and exploratory studies can further highlight the issues of physical, psychological, social, and spiritual wellbeing faced by caregivers, which will eventually help nursing services and health care system in planning a better holistic care of cancer patients and their families.
- QoL among caregiver of ALL should be explored in different Socio-economic status and comparing care provided in private versus public setting to identify health and care related factors affecting QoL.
- Prospective research should be done by recruiting participants from Children of acute leukemia and chronic leukemia settings.

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