TO ASSESS THE QUALITY OF LIFE IN THE PEDIATRIC LEUKEMIC PATIENTS

K. Sushanth Sekhar[1]*, B. Geethika Reddy[2], B. Viswanadha Reddy[3], K. Anupama Priyadarshini[4], Dr. Thangabalan Boovizhikannan[5]

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[1*,2,3]Department of Pharmacy practice, Sims college of Pharmacy, Mangaldas Nagar, Guntur, Andhra Pradesh, Pin-522509.
[4]Asst.Professor, Department of Pharmacy practice, Sims college of Pharmacy, Mangaldas Nagar, Guntur, Andhra Pradesh, Pin-522509.
[5]Principal, Department of Pharmaceutical analysis, Sims college of Pharmacy, Mangaldas Nagar, Guntur, Andhra Pradesh, Pin-522509.

***Corresponding Author:** K. Sushanth Sekhar
*Department of Pharmacy practice, Sims college of Pharmacy, Mangaldas Nagar, Guntur, Andhra Pradesh, Pin-522509.

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INTRODUCTION:

Cancer

Cancer is the name given to a complex of diseases. [(1)] The Greeks are said to be the first discoverers of cancer way back in the 4th or 5th Century BCE. The oldest proof of the presence of cancer was found by Louis Leakey in Kenya in 1932. Leakey found a mandible with tumour. [(2)]
Cancer begins in the cells, which are the building blocks of body. Normally, body forms new cells as needed, replacing old cells that die.[(3)] In cancer cells the normal control system that prevent cell overgrowth and the invasion of other tissues are disabled. These altered cells divide and grow in the presence of signals that normally inhibit cell growth; therefore, they no longer require special signals to induce cell growth and proliferation. If proliferation is allowed to continue and spread, it can be fatal. In fact, almost 90% of cancer - related deaths are due to tumour spreading – a process called metastasis. [(3 - 4)]

Gene changes within cells (mutations)

Mutations can happen in the genes when a cell divides. The change is called a mutation. It means that a gene has been damaged or lost or copied twice. Some mutations mean that the cell no longer understands its instructions and starts to grow out of control. There have to be about half a dozen different mutations before a normal cell turns into a cancer cell.

Mutations in particular genes may mean that too many proteins are produced that trigger a cell to divide. Or a protein that normally inhibits cell division may not be produced. Abnormal proteins may be produced that work differently to normal. It can take many years for a damaged cell to divide and grow and form a tumour big enough to cause symptoms or shows up on a scan. [(7)]

PURPOSE OF STUDY:

QOL assessment has become increasingly common in the field of cancer and has been identified as the second most important outcome with survival being the most important. For patients and their family, a diagnosis of cancer brings challenges to many aspects of daily life, with a major concern being maintaining the highest quality of life possible during and after the experience. This study was carried out with the objective of measuring the quality of life of pediatric leukemic patients during their cancer treatment. The study was carried out using a standard validated questionnaire called (Peds QL) which of 4.0 version

METHODOLOGY:

Study Site:

The study was conducted from the Department of Oncology, Manipal Hospitals, Guntur, Andhra Pradesh.

Study Design:

The study was a non- interventional retrospective observational study.

Study Period:

The study was conducted over a period of three months from November 2018 to January 2019.

Inclusion criteria:

- Patients who are undergoning the chemotherapy.
- Newly diagnosed with leukemia by pathology report.
- Parents who are willing and able to provide, signed informed consent.

Exclusion criteria:

- Concomitant major psychiatric disorders or cognitive dysfunctions that would interfere with a self-reported evaluation.
- Parents who are not willing to provide, signed informed consent.
- Patients below age of 8 years and above age of 12 years.

Sample Size:

A total of 49 pediatric patients form the Oncology Department were taken in the study.

Source of data:

The Patient's demographic details, clinical findings, laboratory and therapeutic data were collected from following source.

- Patient's case notes/direct interviewing of patient.
- Treatment chart/Medication chart.
- Lab data reports.
- Patient discharge cards.

METHODS:

The study was carried out using a standard validated questionnaire called (Peds QL) which of 4.0 version. It comprises of different parameters that are used to estimate quality of life in cancer patients. It major comprises of 23 questions which depicts physical functioning, emotional functioning, social functioning, school functioning. The questionnaire are directly made to be filled by interviewing patient's parent. The scores are given as per the guidelines given.

All the data is manually collected in Peds QL forms and next entered in the Google Forms electronically for the output of the data in graphical form . All this data is exported into the Google sheets where the data is in form of the excel format. From this the whole data is imported into the SPSS software. The data was statistically analysed by using SPSS (Statistical Package for Social Sciences) with version 24.0 (SPSS Inc, Bangalore). All the continuous variables of normal distribution were presented in the form of mean with standard deviation. The *Independent sample t test* and *One way Anova* were performed.

Peds QL:

The Peds QL Measurement Model is a modular approach to measuring health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions. The Peds QL Measurement Model integrates seamlessly both generic core scales and disease-specific modules into one measurement system.

The Peds QL Generic Core Scales are: Brief, Practical, Flexible (Designed for use with community, school, and clinical pediatric populations), Developmentally Appropriate, Multidimensional (Physical, Emotional, Social, School Functioning), Reliable (Total Scale Score: 0.88 Child Self-Report; 0.90 Parent Proxy-Report), Valid (Distinguishes between healthy children and children with acute and chronic health conditions; distinguishes disease severity within a chronic health condition), Responsive to clinical change over time.

The 23-item Peds QL Generic Core Scales were designed to measure the core dimensions of health as delineated by the World Health Organization, as well as role (school) functioning. The 4 Multidimensional Scales and 3 Summary Scores are:

- ✓ **Scales**: Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), School Functioning (5 items)
- ✓ **Summary Scores**: Total Scale Score (23 items), Physical Health Summary Score (8 items), Psychosocial Health Summary Score (15 items)

SPSS:

SPSS Statistics is a software package used for interactive, or batched, statistical analysis. Long produced by SPSS Inc., it was acquired by IBM in 2009. The current version are named IBM SPSS Statistics. The software name originally stood for Statistical Package for the Social Sciences (SPSS), reflecting the original market, although the software is now popular in other fields as well, including the health sciences and marketing.

SPSS is a widely used program for statistical analysis in social science. It is also used by market researchers, health researchers, survey companies, government, education researchers, marketing organizations, data miners and others.. In addition to statistical analysis, data management (case selection, file reshaping, creating derived data) and data documentation (a metadata dictionary is stored in the datafile) are features of the base software.

Statistics included in the base software:

- Descriptive statistics: Cross tabulation, Frequencies, Descriptives, Explore, Descriptive Ratio Statistics.
- Bivariate statistics: Means, t-test, ANOVA, Correlation (bivariate, partial, distances), Non parametric tests, Bayesian.
- Prediction for numerical outcomes: Linear regression.
- Prediction for identifying groups: Factor analysis, cluster analysis (two-step, K-means, hierarchical), Discriminant.
- Geo spatial analysis, simulation.

GOOGLE FORMS:

This is a tool that allows collecting information from users via a personalized survey. The information is then collected and automatically connected to a spreadsheet. The spreadsheet is populated with the survey responses. New features include, but are not limited to, menu search, shuffle of questions for randomized order, limiting responses to once per person, shorter URLs, custom themes, automatically generating answer suggestions when creating forms, and an "Upload file" option for users answering questions that require them to share content or files from their computer or Google Drive. "Intelligent response validation" is capable of detecting text input in form fields to identify what is written and ask the user to correct the information if wrongly input. Depending on file-sharing settings in Google Drive, users can request file uploads from individuals outside their respective company, with the storage cap initially set at 1 GB, which can be changed to 1 TB. A new checkbox grid enables multi-option answers in a table. In Settings, users can make changes that affect all new forms, such as always collecting email addresses.

GOOGLE SHEETS:

This is a spreadsheet program included as part of a free, web-based software office suite offered by

Google within its Google Drive service. The service also includes Google Docs and Google Slides , a word processor and presentation program respectively. Google Sheets is available as a web application, mobile app for Android, iOS, Windows, BlackBerry, and as a desktop application on Google's ChromeOS. The app is compatible with Microsoft Excel file formats. The app allows users to create and edit files online while collaborating with other users in real- time. Edits are tracked by user with a revision history presenting changes.

RESULTS:

Table 5.1 Age wise Distribution Pediatric Leukemic Patients

AGE WISE DISTRIBUTION		
S.no	Age (years)	Percentage
1	8	20.4 %
2	9	18.4%
3	10	22.4%
4	11	20.4%
5	12	18.4%

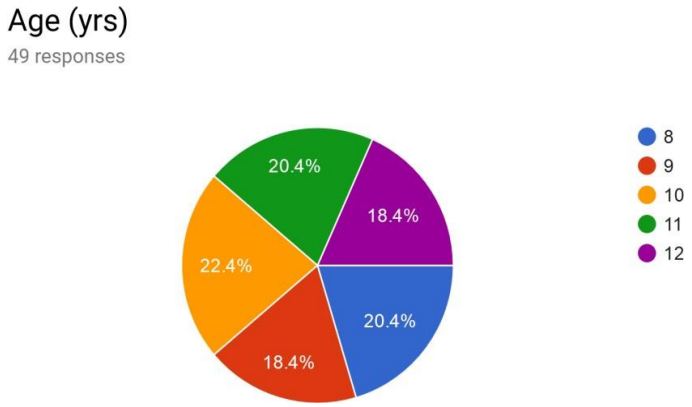

Figure 5.1 Age wise distribution of Pediatric Leukemic Patients (n=49)

The Age group Analysis in the above figure shows that out of 49 patients, 20.4% are of age 8years, 18.4% are of age 9 years, 22.4% are of age 10 years, 20.4% are of age 11years,18.4% are of 12 years.

Table 5.2 Gender wise distribution of Pediatric Leukemic Patients (n=49)

GENDER WISE DISTRIBUTION		
S.no	Gender	Percentages
1	Male	57.1 %
2	Female	42.9 %

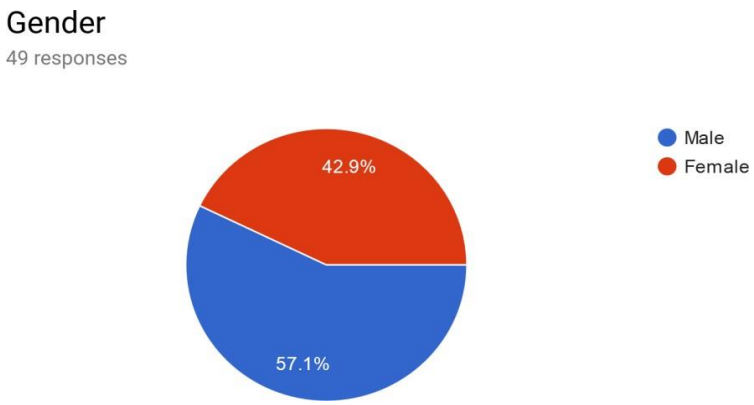

Figure 5.2 Gender wise distribution of Pediatric Leukemic Patients (n=49)

The Gender group Analysis in the above figure shows that out of 49 patients, 57.1 % are male,42.9% are female.

PHYSICAL FUNCTIONING

Table 5.3 Distribution patients having problem with walking more than a block

	No. of Patients	Percentages
Never	**0**	**0%**
Almost Never	**20**	**40.8%**
Sometimes	**22**	**44.9%**
Often	**6**	**12.2%**
Almost Always	**1**	**2%**

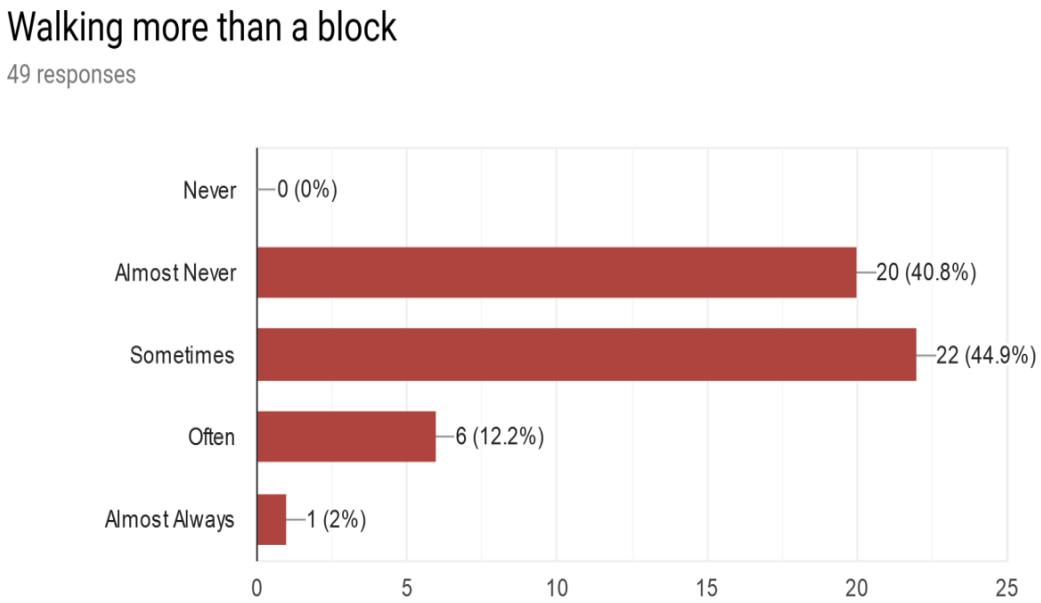

Figure 5.3: Distribution patients having problem with walking more than a block

Table 5.4 Distribution patients having problem with running

	No. of Patients	Percentages
Never	**0**	**0%**
Almost Never	**22**	**44.9%**
Sometimes	**18**	**36.7%**
Often	**8**	**16.3%**
Almost Always	**1**	**2%**

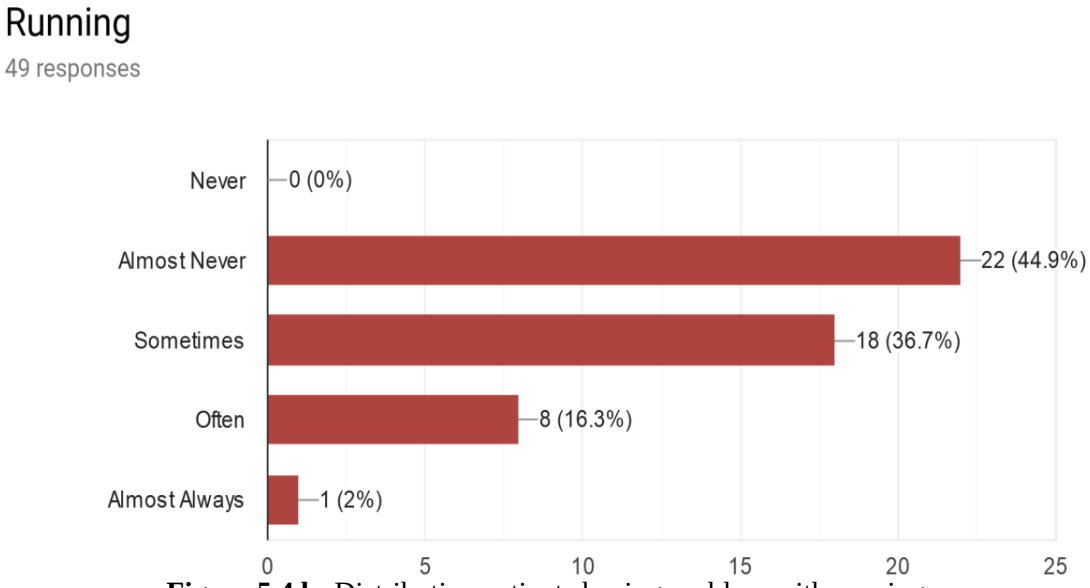

Figure 5.4.b: Distribution patients having problem with running

Table 5.5.a: Distribution patients having problem with participating in sports activity orexcercise

	No. of Patients	Percentages
Never	**0**	**0%**
Almost Never	**20**	**40.8%**
Sometimes	**17**	**34.7%**
Often	**12**	**24.5%**
Almost Always	**0**	**0%**

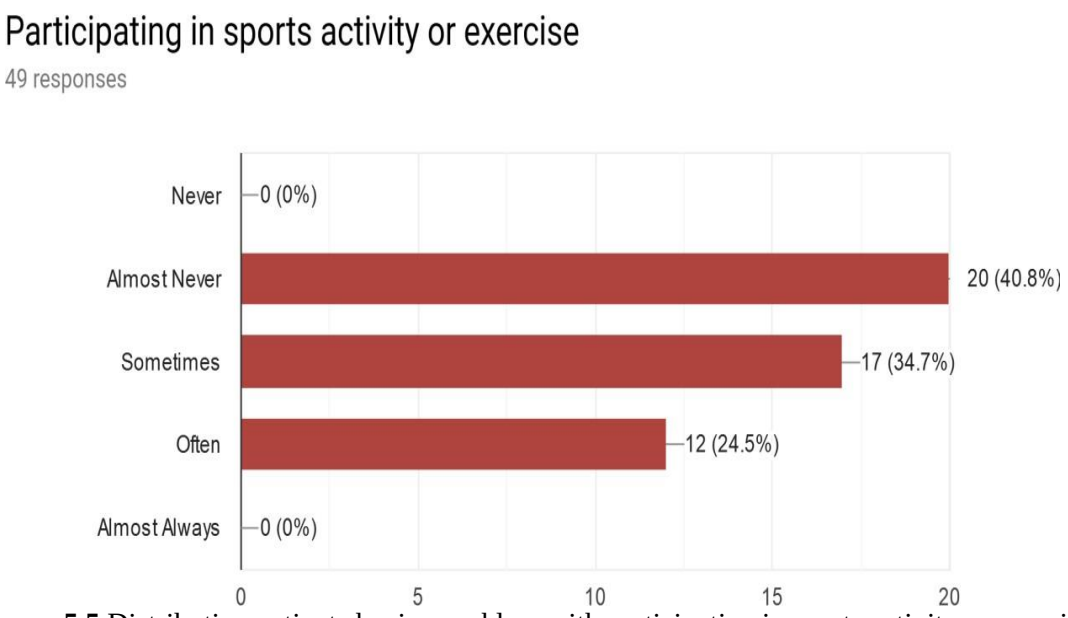

Figure 5.5 Distribution patients having problem with participating in sports activity or exercise

Table 5.6 : Distribution patients having problem with lifting something heavy

	No. of Patients	Percentages
Never	**0**	**0%**
Almost Never	**6**	**12.2%**
Sometimes	**33**	**67.3%**
Often	**10**	**20.4%**
Almost Always	**0**	**0%**

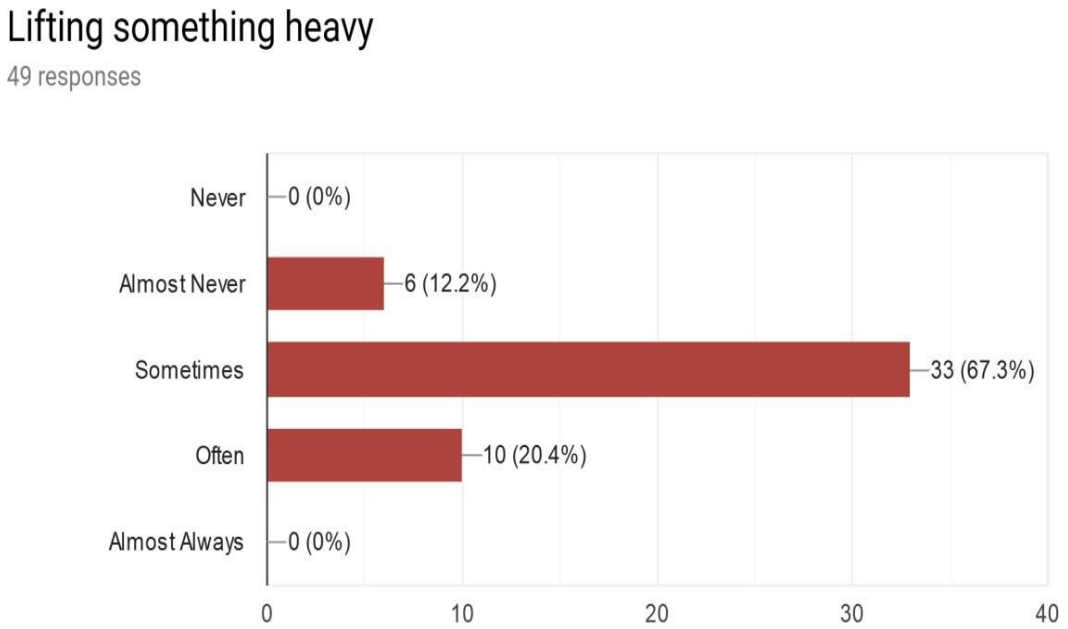

Figure 5.6 Distribution patients having problem with lifting something heavy

Table 5.7 : Distribution patients having problem with taking bath or shower by him or herself

	No. of Patients	Percentages
Never	**0**	**0%**
Almost Never	**6**	**12.2%**
Sometimes	**14**	**28.6%**
Often	**27**	**55.1%**
Almost Always	**2**	**4.1%**

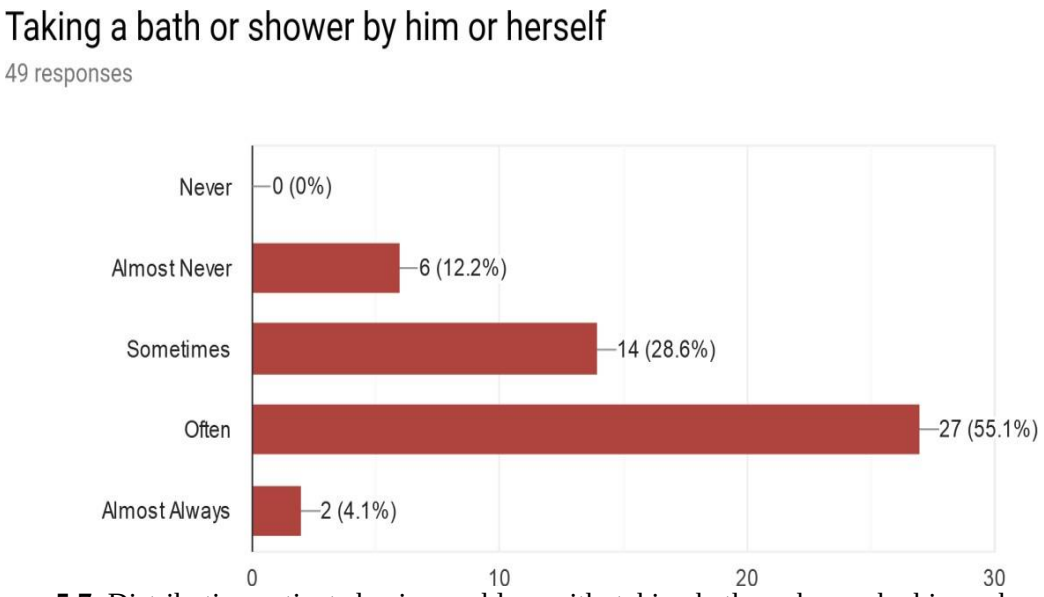

Figure 5.7 Distribution patients having problem with taking bath or shower by him or herself

Table 5.8 Distribution patients having problem with doing chores around house

	No. of Patients	Percentages
Never	**0**	**0%**
Almost Never	**17**	**34.7%**
Sometimes	**11**	**22.4%**
Often	**20**	**40.8%**
Almost Always	**1**	**2%**

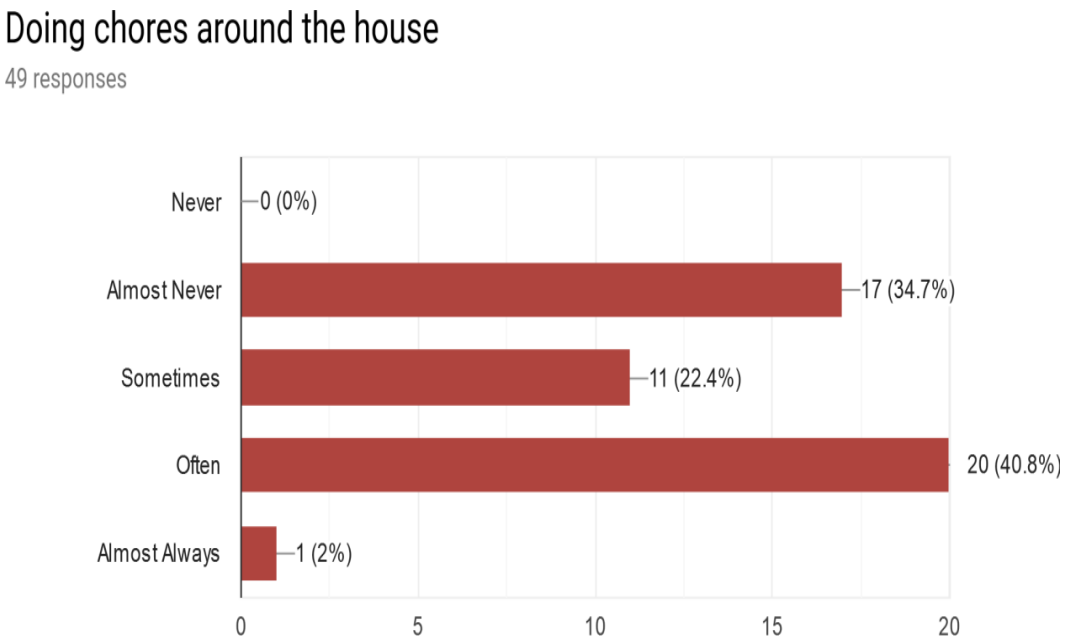

Figure 5.8 Distribution patients having problem with doing chores around house

Table 5.9 Distribution patients having low energy level

	No. of Patients	Percentages
Never	**0**	**0%**
Almost Never	**15**	**30.6%**
Sometimes	**16**	**32.7%**
Often	**17**	**34.7%**
Almost Always	**1**	**2%**

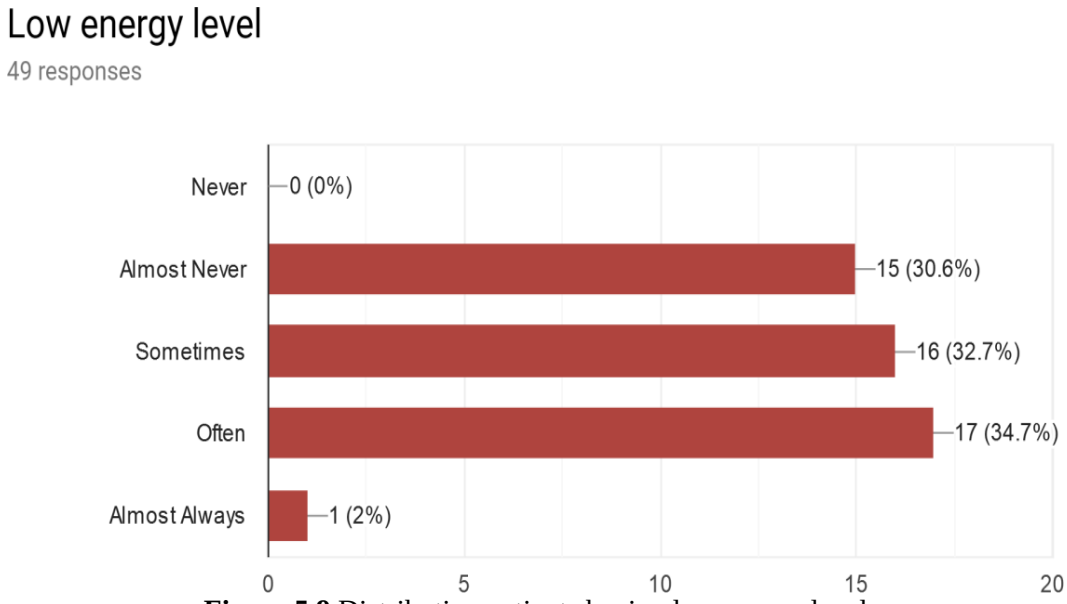

Figure 5.9 Distribution patients having low energy level

Table 5.10 Distribution patients having hurts or aches

	No. of Patients	Percentages
Never	**0**	**0%**
Almost Never	**3**	**6.1%**
Sometimes	**26**	**53.1%**
Often	**18**	**36.7%**
Almost Always	**2**	**4.1%**

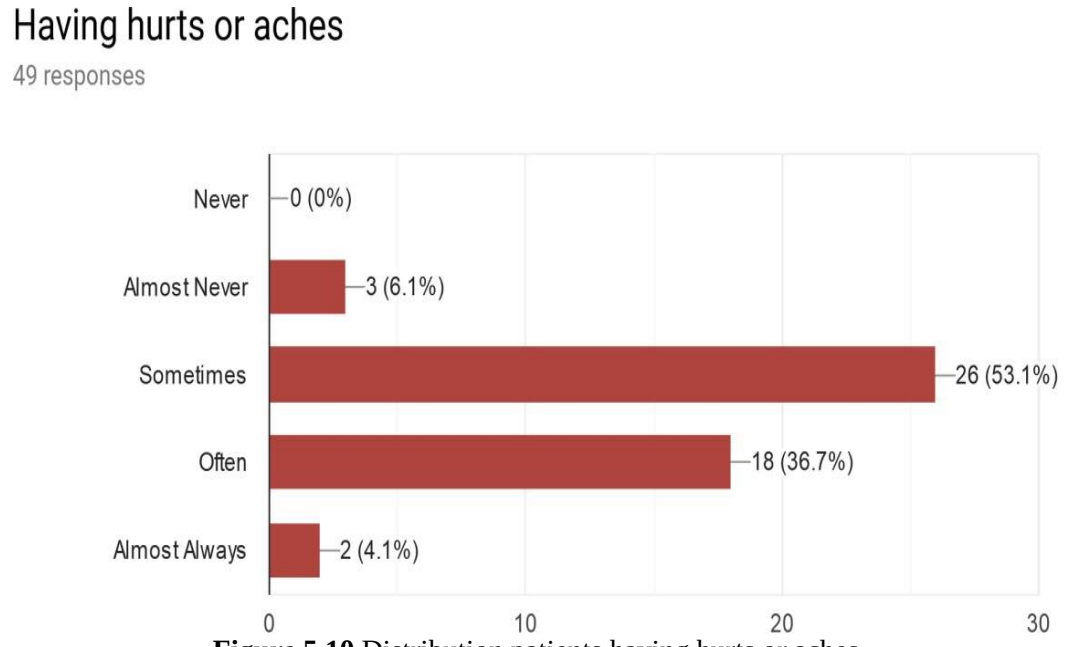

Figure 5.10 Distribution patients having hurts or aches

EMOTIONAL FUNCTIONING

Table 5.11 Distribution of patients feeling afraid or scared

	No. of Patients	Percentages
Never	**0**	**0%**
Almost Never	**10**	**20.4%**
Sometimes	**33**	**67.3%**
Often	**5**	**10.2%**
Almost Always	**1**	**2%**

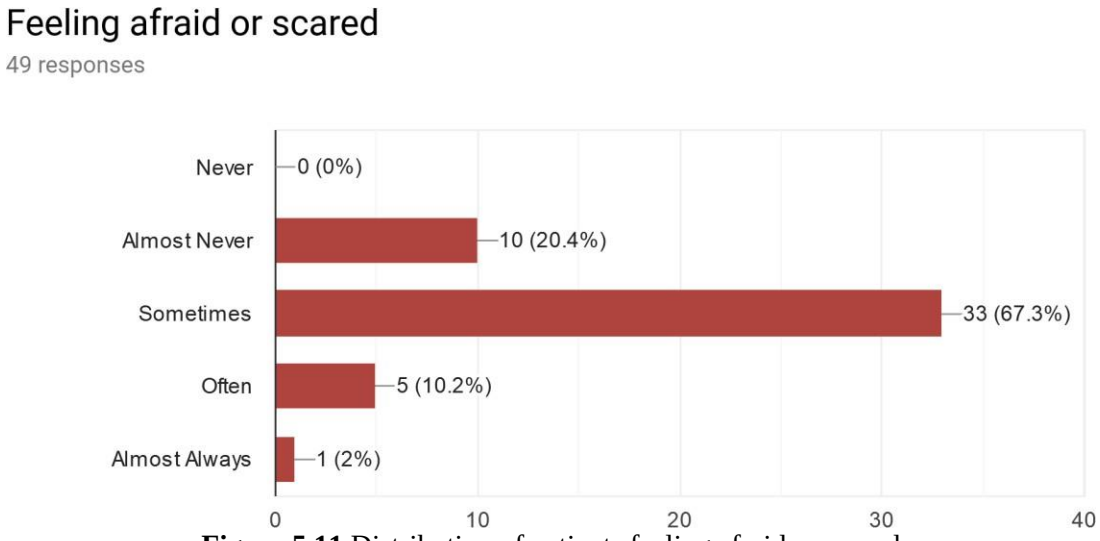

Figure 5.11 Distribution of patients feeling afraid or scared

Table 5.12 Distribution of patients feeling sad or blue

	No. of patients	Percentages
Never	**0**	**0%**
Almost Never	**4**	**8.2%**
Sometimes	**27**	**55.1%**
Often	**17**	**34.7%**
Almost Always	**1**	**2%**

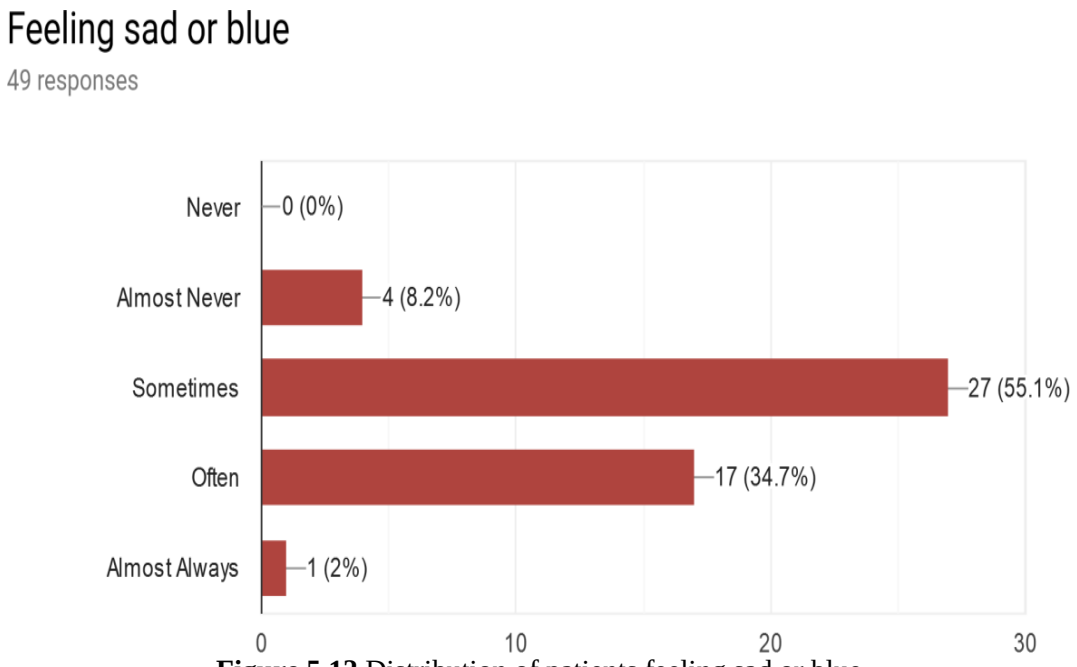

Figure 5.12 Distribution of patients feeling sad or blue

Table 5.13 Distribution of patients feeling angry

	No. of patients	Percentages
Never	**0**	**0%**
Almost Never	**1**	**2%**
Sometimes	**15**	**30.6%**
Often	**13**	**26.5%**
Almost Always	**20**	**40.8%**

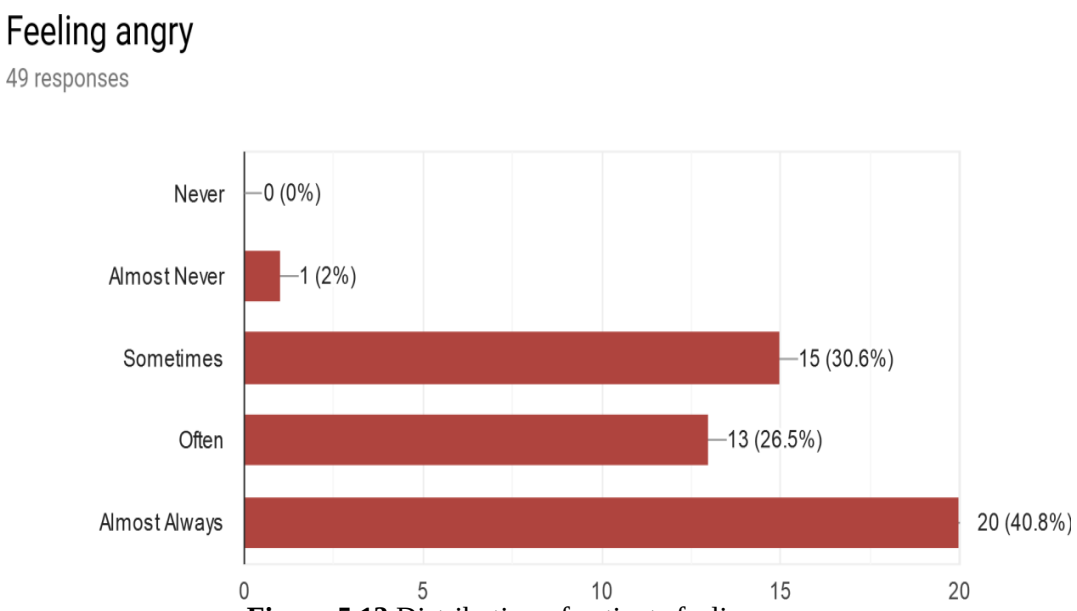

Figure 5.13 Distribution of patients feeling angry

Table 5.14 Distribution of patients having trouble sleeping

	No. of Patients	Percentages
Never	**0**	**0%**
Almost Never	**3**	**6.1%**
Sometimes	**20**	**40.8%**
Often	**24**	**49%**
Almost Always	**2**	**4.1%**

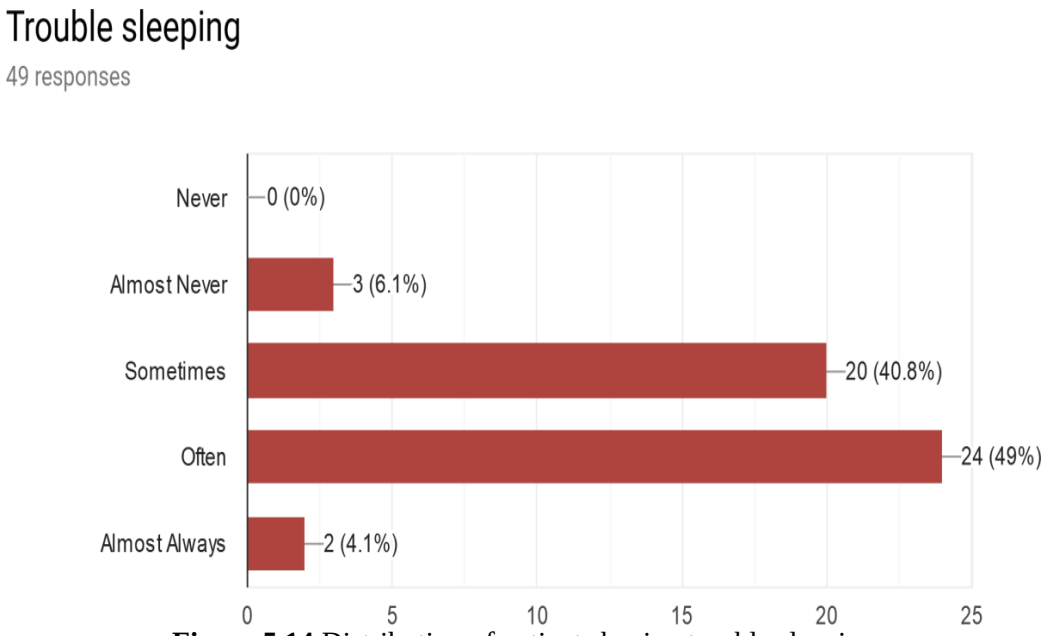

Figure 5.14 Distribution of patients having trouble sleeping

Table 5.15 Distribution of patients worrying about what will happen to him or her

	No. of patients	Percentages
Never	**0**	**0%**
Almost Never	**13**	**26.5%**
Sometimes	**24**	**49%**
Often	**12**	**24.5%**
Almost Always	**0**	**0%**

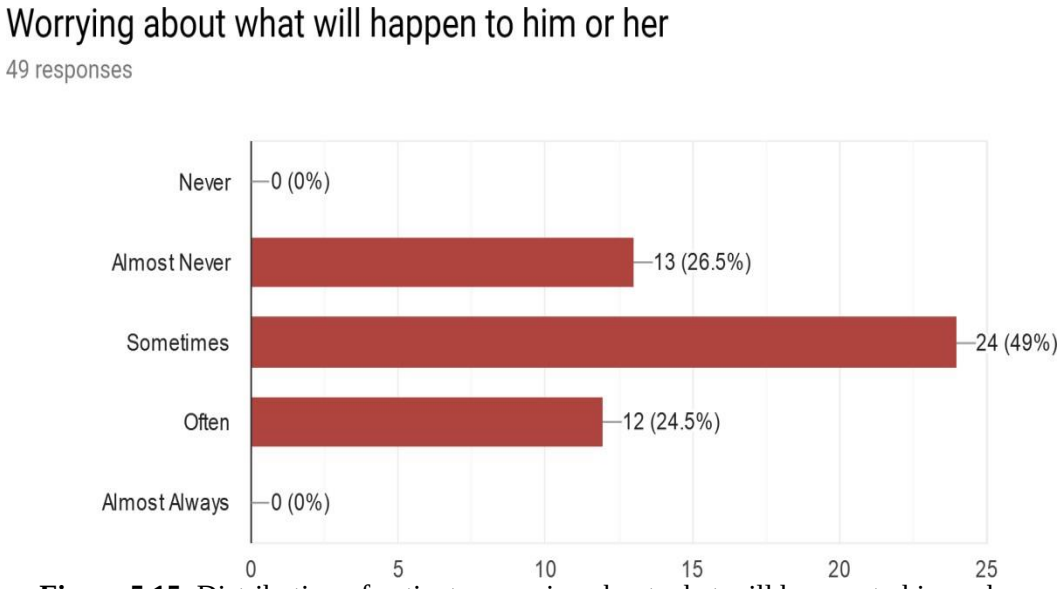

Figure 5.15 Distribution of patients worrying about what will happen to him or her

DISCUSSION

Quality of life is the state of well-being that is a composite of two components: the ability to perform everyday activities that reflect physical, psychological, and social wellbeing; and patient satisfaction with the levels of functioning and control of the disease. Until recently, extremely less attention was paid to cancer patients' quality of life. Clinical trials have suggested that one can measure quality of life as an independent predictor of survival. QOL assessment has become increasingly common in the field of cancer. The trend reflects a growing appreciation of the need to evaluate cancer treatments more broadly than just by tumor response or survival. In cancer treatment, survival is the most important outcome and QOL assessment has demonstrated clear research value as a secondary outcome measure**.**

Multidimensional approach of QOL assessment reflects the patient's situation and presents important information for the process of treatment evaluation. Regarding quality of life, it was found that the Social and Physical domains were the most affected and the best preserved was the Environment domain. In a similar study with patients affected by colorectal cancer, the most affected domain was the Environment, and the least effected is the psychological parameters in the cancer patients. It was observed that the Physical and Psychological domains showed the highest co- relation with each other and with other domains, suggesting the inter-relationship.

Regarding the facets that influenced the Physical domain the most, the following was found in order of higher to lower: energy and fatigue, daily activities, pain and discomfort and mobility. It is proposed that these four facets are very well related between them.

CONCLUSION

According to the present results, it seems that some demographic factors affect QoL have a tangible relationship among them as well. QoL in pediatric patients with leukemia is the most common and serious problem that can dramatically affect their QoL. Therefore, it is important for the medical staff to consider the demographic information and Physical, Emotional, Social, School function ing in these pediatric patients to improve their QoL. It helps them in organizing their activities to promote health and QoL of the patients.

Based on the study findings in chemotherapy centers, health care providers, especially Clinical Pharmacist, are key members of the care team and they should pay special attention to the phenomenon of QoL in pediatric patients

undergoing chemotherapy with leukemia, and have strategies to eliminate or alleviate it. It is recommended, as an aid in assessing the patient's recovery and also in the assessment of different treatment outcomes, the QoL in all patients with leukemia to be assessed; so, based on our findings, the best treatment method for the patients can be chosen.

Anxiety, irritability, worries, depression, and aggression were also sometimes a barrier to communicate with the patients and for them to complete the questionnaire. It should be noted that the approximate time to enter the study for this number of subjects (n = 49) was 3 months. Another limitation was the limited environment of the study; due to this limitation, studying patients with leukemia ad mitted in other hospitals at the same time was not possible. Based on the limitations of this study, including the small number of subjects, applying the study only in one hospital, and in only one section, and the problems of generalizability, it is recommended for further similar studies to be conducted in other hospitals with larger sample size. Also, to improve the quality of data analysis, it is suggested that in future, researches with similar methodology using multivariate tests also must be considered.

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