Quality of Life among the Parents of Children with Hematological Malignancies: A Pilot Study

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Abstract

Background: Haematological malignancies are the most common cancer among the children in the age group of 0-14 years. Leukemia is the most prevalent cancer among these children. The diagnosis of haematological malignancy in a child is a frightening situation for the parents as well as the family, as they are the primary caregivers of the children. The aim of the present study was to assess quality of life (QoL) among parents of children with haematological malignancies.

Methods: The cross-sectional pilot study included 30 parents of children between 0-14 years of age taking treatment at the two tertiary cancer care centres of Kerala, India. The data regarding QoL was obtained through Parents a validated Malayalam version of parent's quality of life inventory (P-QLI). Descriptive statistics was used to identify quality of life of the parents.

Results: An equal distribution of fathers and mothers were maintained in the study (15 mothers and 15 fathers). The average age of the parents was 26± 2 years (for mothers) and 34± 3 years (for the fathers). Majority (73.3%) of children had Acute Lymphocytic Leukemia (ALL), and their mean age was 6±4 years. The statistical analysis showed that 33.3% of the parents had a poor quality of life after the diagnosis of haematological malignancy for their children. In addition, the mean QoL scores among the parents of children with haematological malignancies were less thatn50% of the total score of the P-QLI .The haematological malignancies among the children had a negative impact on physiological, psychological, social, vocational, economic, and spiritual dimensions of parent's quality of life.

Conclusions: This study showed that QoL measured by QLI-PCL in parents of children with haematological malignancies were poor, and the present study put forward the need strengthening parent support services among the parents of children with cancer.

Key words: *Quality of Life, parents, children with haematological malignancies*

Introduction

Diagnosis of cancer is a distressing event at any moment in life, but the agony is more if the patient is child. According to the recent reports of the National Institute of Health, it has been estimated that approximately more than 10,000 new cancer cases were reported among the children (0-14 years of age) in United States. But at the same time there is a drastic decline in the death rates among the children with the diagnosis of cancer. The most common types of cancer seen among the children are; leukemia, lymphoma, and CNS tumours[1]. The data from CANKID India portrayed that nearly 30,000 new cancer cases are reporting among the children in India[2] and nearly 1.6 to 4.8% of all cancers reported in India

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is among the children less than 15 years of age, but the cure rate is more (approximately 70-90%) among the childhood cancer patients. The overall incidence of childhood cancers in India rages from 38 to 124 per/ million/ year[3].The data received from the Population Based Cancer Registries (PBCRs) in India during the period 0f 2012-16 , shows that the percentage of childhood cancers compare to the overall cancer burden is mottled, and it was reported between 0.7%-3.7%. The relative proportion of childhood cancers was more at Delhi, Hyderabad, Aurangabad, and Barshi PBCR [4]. It was 1.4-1.6 % among the two PBCR located of Kerala state.

The overall childhood cancer burden is mainly occupied by the haematological malignancies such as leukemia and lymphoma. According to the PBCR report of year 2020, childhood leukemia comprises 5947 cases, and it is more among the boys (46.4%). The lymphomas are the second most common cancer (n=1720) among the children between 0-14 years. Same pattern of dominance is seen among the age group of 0-19 years. The Age Adjusted Incidence Rates (AAR per Million) of leukemia is more in Delhi (77.3) among the northern registries, and in Trivandrum (55.2) among the southern registries of India. Childhood lymphoma incidence also more in Delhi (30.7) in the more in northern region, and in Chennai (26.5) among the southern region [5]. Among the haematological malignancies in the children, the Acute Lymphoid Leukemias (ALL) is the most common variety and Hodgkins Disease is more among the childhood lymphomas. This escalating incidence rate of the haematological malignancies among the children needs an active and time-lapsed line of attack to confirming diagnosis and initiation of treatment. The early diagnosis opens a bounteous chance to improve the survival rates among the children[6].

Childhood cancers remain a fear factor among the parents and family, even though it has a low death rates and increased survival rates. The parents are experiencing serious sufferings in their daily life after the diagnosis of cancer for their children. Children and their parents are facing numerous protracted qualms in their life along with the complications of treatment and hospitalization[7]. The consternations of the cancer diagnosis of the child are more among the parents, and most of them were experiencing a high level of anxiety. These anxieties and its associated impacts are debilitating the quality of life of the parents [8]. The waves of childhood cancer will influence all the domains of family functioning, and it makes the parents life full of sufferings and agonies. According to World Health Organization(WHO) Quality of Life is defined as "the individuals' perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. " QoL is considered as the strategic aim in the modern health care[9]. Quality of life is considered as a purely subjective entity, hence the individual differences may influence when assessing the quality of life. So, direct subject interview is required to gain reliable information regarding the quality of life.

The overall survival rate of haematological malignancies among children is good in the lower income and developing countries. But at the same time, the factors like; acute and long-term effects of treatment and diagnosis, chance for recurrence, developmental delay of the child, and cognitive deterioration in the child, family disorganization and functional limitations are shackling the tranquillity of the parent's life[10]. Haematological malignancies are the most prominent forms of childhood cancer and the investigators could not found any comprehensive study to identify the life quality of the parents of parents of children with leukemia and lymphoma. The purpose of this pilot study was to identify the quality of life status of the parents of children with the diagnosis of haematological malignancies. This study aimed to describe the quality of life among the parents during the diagnosis and treatment of their child.

Materials and Methods

Study design

A cross-sectional survey design was used to identify the quality of life of parents of children with haematological malignancies.

Study sample and setting

The study was conducted in two tertiary cancer centres in Kerala, South India. The parents of children with the diagnosis of leukemia or lymphoma were included to in this study. A total enumeration method was used to recruit the participants for the study, because the available cases during the study period were comparatively low.

Participants

The parents of children aged between 0-14 years of age with the recent diagnosis (≤ 6 weeks) of haematological malignancies (leukemia & lymphoma), who are taking treatment from the selected cancer centres were recruited for the present study. Parents of critically ill children were excluded from the present study. All, the eligible participants were recruited.

Sample size

According to PBCR reports of the southern and northern registries of India, a total of 14698 parents of children with active haematological malignancies were identified [5]. Based on this data, the sample size of the present study was derived. The calculated sample size was 375 with 5% margin of error (absolute error) and 95% confidence interval. As the present study is a piloting project, hence the investigators were selected 35 samples for the present study.

Recruitment & Ethical Considerations

The investigators were sent a letter for seeking permission to the administrative heads of selected cancer centres. After getting the official approval from the concerned authorities, the investigators were visited the facility and conducted the baseline line assessment to recruit the samples for the present study. Following approval of the protocol by the Doctoral Research Committee (DRC) of Shri Jagdishprasad Jhabarmal Tibrewala University, India (Reference No.JJTU/R&D/DAL/3725), parents were approached to participate in the study. An Informed consent was obtained from the study participants and their family after explaining the study procedure. After the parents completed the questionnaires provided by the investigator. The study was conducted according to the principles of Declaration of Helsinki. An assurance was given regarding confidentiality before the data collection procedure. Also, the participants were informed of their right to withdraw from the study at any time.

Instruments and Data collection

The data collection was initiated after getting the formal approval from the administrative heads of the selected tertiary cancer. The questionnaire was distributed among the study participants during their stay at the selected cancer centres for the treatment of the child. For reasons of validity, parents were not allowed to meet with their spouses during time of administration of the questionnaire and the data were collected from both the parents at a single point of time. If a question was not understood for the study participants, their non-comprehension was recorded by the investigators.

For identifying the quality of life of the parents of children with haematological malignancies, the investigators developed a "parent's Quality of Life Inventory (P-QLI)", and they were established the validity and reliability of the measurement instrument through a systematic approach. The quality of inventory touches all the domains of QoL of the parents, and the questions were categorized based on the subdomains of quality of life such as, physical, psychological, socio-economic, and spiritual. There were twelve questions dealing with socio-demographic data, ten questions were related with the clinical profile of the child, and the remaining forty one questions were assessing the quality of life in the above stated subdomains. The options to the answers of the questions in the quality of life section were mostly on a sliding scale, so, it will help the study participants to express their subjective feelings more precisely. The final two questions in the inventory were comparing the present quality of life with the previous one.

Statistical Methods

The statistical analysis was performed by using SPSS (SPSS v25) . All instruments were scored as per each tool's instructions. As it is a pilot study with limited number of sample the Descriptive statistics form the basis of analysis.

Results

From November 2018 to December 2018, 18 children (aged between 0-14 years) were admitted two tertiary cancer centres in southern part of Kerala. Of these, 2 children became critically ill during the study period and 1 has shifted the trertenment centre before the data collection. So, total of 30 parents (both father and mother) were available for data collection and analysis.

In the present study, among the 30 participants, study there is an equal distribution (n=15) of fathers and mothers of the children with haematological malignancies were established. The mean age of study participants were 26± 2 (for mothers) and 34± 3 (for the fathers).Majority (80%) of the study participants were residing in rural area. 19 of 30 stated they were belongs to Hindu religion, and 2 had no religious affiliation. 66.6% of the study subjects were graduates, and 60% were employed. The results showed that most of the mothers (40%) were unemployed. Majority of the study participants had an income Rs.10000-20000 per month. 76.6% were belonged to a nuclear family, and most (93.3%) of the study participants had two children. 60 % of the fathers had unhealthy habits, alcoholism (44.4%) and smoking (55.5%) are the main unhealthy habits. There was no history of chronic illness among the study participants.

The mean age of the child was 6± 4, and majority (80%) were boys. 73.3% of the children had the diagnosis of Acute Lymphocytic Leukemia (ALL), 26.6 % had Hodgkins Disease, and one child had the diagnosis of Juvenile Myleo monocytic Leukemia. Most (60%) of the children were the first child of their parents, and they have been diagnosed with haematological malignancy since last 3 weeks. The average length of hospitalization was 6 ± 3 days.

The total scores on inventory was divided as domain scores, for the easy understanding , and the higher scores noting higher or better quality of life. The consolidated score was calculated from the domain scores and the study participants who scored less than or equal to 25th percentile is considered as poor quality of life, score above 25th - 50th percentile had average quality of life, an score above 50th -75th percentile had a better quality of life, and a score above 75 th percentile is considered as good quality of life. Table 1 presents the quality of life in the various sub domains of the QoL inventory.

Table 1: Quality of life scores of the study participants (domain wise)

Domain	**Mean Score**	**Standard deviation**	**Poor QoL (n)**	**Average QoL (n)**	**Better QoL (n)**	**Good QoL(n)**
Physiological domain	14.1	3.2	7	4	13	6
Psychological domain	36.3	9	15	10	1	4
Social domain	23.2	3.9	14	15	0	1
Vocational & Economic domain	13.5	2.9	11	17	0	2
Spiritual domain	4.2	1.0	7	8	15	0
Total QoL	89.1	9.5	10	5	8	7

The table depicts that majority (43.33%) of the study participants possess a better quality of in terms of their physical health. Half of the study participants had a poor quality of life in the psychological domain and an average quality of life (50%) in the social domain. More than half (56.7%) of the study participants had an average quality of life in the vocational & economic domain, but at the same time a better quality of life is seen among 50% of the study participants in the spiritual domain. When identifying the total quality of life of the study participants majority (n=10) had a poor quality of life.

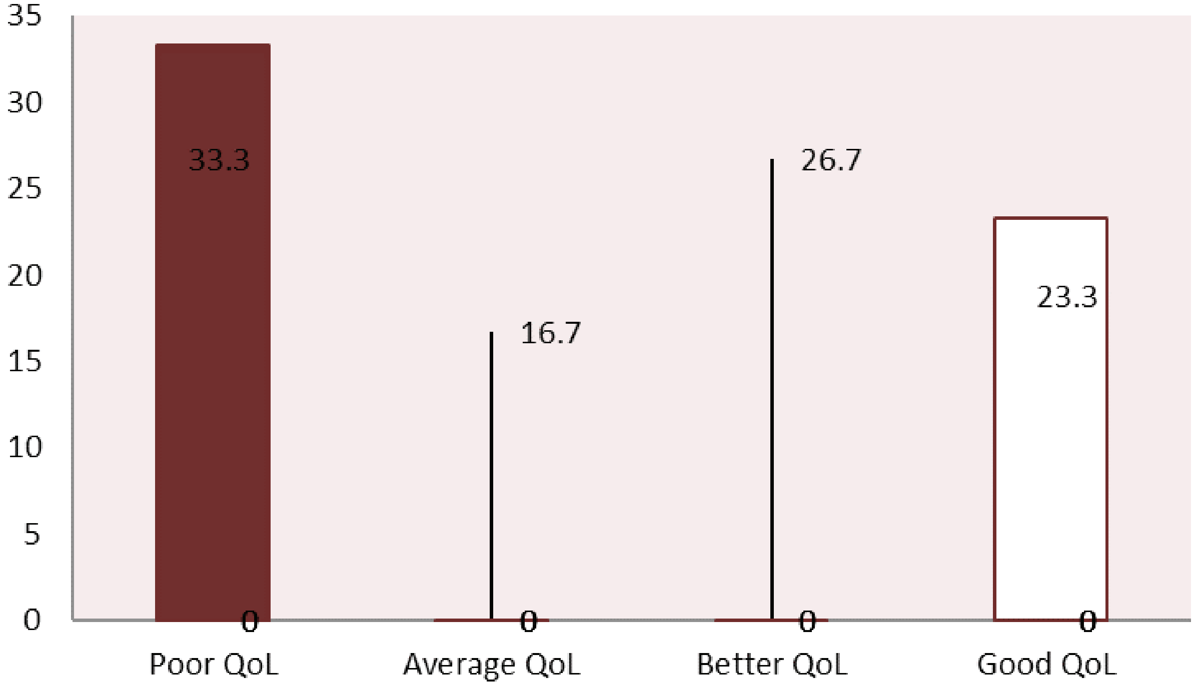

Figure 1: Quality of life distribution of the study participants

The figure portrays that, 33.3 % of the study participants had poor overall quality of life and 26.7% possess a better overall quality of life. When comparing the quality of life of the study participants before and after the diagnosis of haematological malignancy for their children, it has been shown that the study participants with poor quality of life are increased from 16.6 % to 33.3 %.

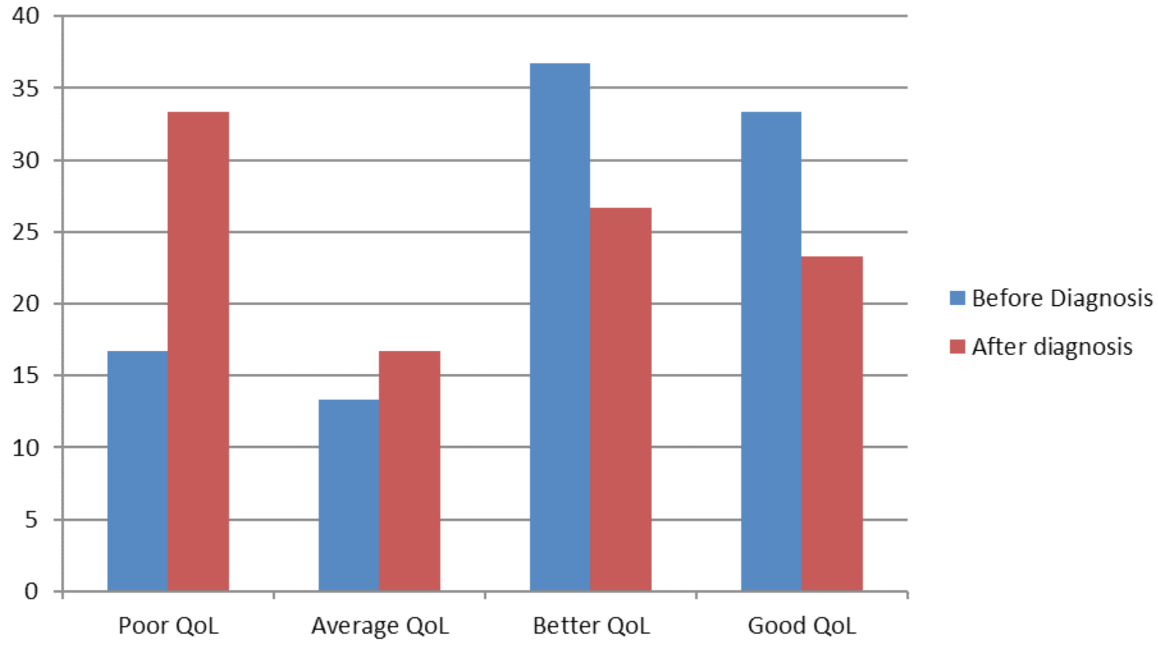

Figure 2: Comparison of parent's quality of life before and after the diagnosis of haematological malignancy for the child

Discussion

This pilot study reveals that it is possible to acquire valid facts about QOL of the parents of children with haematological malignancies. The investigators have noticed factors that should be investigated further and validated statistically in larger samples because of its practical significance.

In the present study the investigators have identified one case of juvenile myelomonocytic leukemia the incidence of juvenile myelomonocytic leukemia was 1·35 per million (age adjusted rate) in UK [11] and this is rare variety of leukemia seen among the children below 14 years of age[12]. The present study is a piloting project with a small sample size, the investigators faced difficulty in recruiting subjects to the study as the number of cases available in the selected centres were comparatively low, and many samples were exclude from the project due to their personal problems, critical conditions of the child, shifting of the treatment centres etc. Conceding the above stated limitations the investigators were made following conclusions from the results of the present study.

The overall qualities of life of the majority of the parents were categorized as poor in the present study. This finding contrasts with results among parents of children with cancer or brain tumours. The poor parental quality of life was seen among the parents of children with cancer and brain tumour, and its impact was arbitrated by parental stress and primary caregiver burden[13]. The study results also pointed out that there was a drastic decrease in the quality of life of the after the diagnosis of haematological malignancies for their children. A study conducted in Canada highlights that more caregiver support is needed for the parents during the first year of diagnosis, because the self-esteem is low among the parents and they are suffering from lots of emotional and behavioural problems[14]. Leukemia as the most common childhood cancer, the mean QoL scores among the parents of children with leukemia was less thatn50% of the total score[15]. The same pattern of quality of life scores also seen among the parents of children with haematological malignancies (mean QoL score is 45.7% of the total QoL score).

A poor quality of life seen in the psychological, social, vocational and economic domains among the parents of children with haematological malignancies, this is in line with the findings of Shin Yamazaki., et al; describes that a poor health related quality of life is seen in psychological health and social functioning among the mother of children with diagnosis of leukemia[16]. The financial constrains among the parents of children with cancers are large[17], and the vocational and economic quality of life is poor among the parents of children suffering from haematological malignancies. Parents of children with cancer have higher levels of physiological symptoms of stress [18], but in the present study the parents are maintain a better quality of life in the physiological domain of QoL. Spirituality is a coping strategy for the parents of children with cancer; moreover it is a source of comfort and hope for the parents and the families. A better spiritual quality of life is seen among the parents of children with haematological malignancies[19]. The impact of the diagnosis and of treatment of haematological malignancies among the children on parents QoL is a key concern of the health care taskforce, the current results shows, and a significant difference in the quality of life among the parents before and after the cancer diagnosis for the child. The literatures were pointed out that the strain, coping behaviours, and resources of the families were affected by the cancer treatment[20-21].

The important implication drawn from the present study is to initiate support care activities for the parents of children with haematological malignancies, as they have a low quality of life after the diagnosis of their child's disease. The findings also implicated to strengthen the psychosocial services provided by the health care tem to the children and their family during the time of hospitalization and treatment, because the parents psychosocial QoL is poor as well as they have more caregiver burden. The study also warrants the need for effective QoL assessment tools for the parents of children with leukemia and lymphoma, so, early detection will help to reduce the perceived impact of haematological malignancies on the life quality. As nurses are the key persons of health care team, the study suggested to form a nurse guided clinic or self-help group for the parents of children with leukemia and lymphoma. Because, these are the leading cancer among the children and the parents were afraid of leukemia than that of other cancers. Moreover, there no structured gatherings for the parents of children with haematological malignancies to ventilate their problems, the self-help group will provide a resort for them.

Conclusion

The present pilot study highlights that the quality of life among the parents of children with haematological malignancies are poor. The parents have quality of life problems in all the domains such as; physiological, psychological, social, economic, vocational, and spiritual. The stressful nature of childhood haematological malignancies on the parent's life warrants a comprehensive support system for the parents throughout the treatment and recovery. The findings of the present study will reinforce the health care task force to customize the childhood cancer care in a holistic manner.

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