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# The Life Situation of Parents of Children with Cancer in Kerala

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***Abstract***

Childhood cancer has a devastating impact on the entire family. A cancer diagnosis of the child disturbs every unit of the family. The life situation of every family member changes and new roles and responsibilities need to be assumed by the parents themselves for which they are often unprepared. The primary aim of this study was to understand the socio-demographic profile of parents of children with cancer and their life situation. Being a quantitative study, a descriptive research design was adopted. This study was done with 50 parents of children who are currently undergoing treatment for the management of cancer. They were selected through a snowball sampling procedure. The data was collected using a questionnaire and the tool used for understanding life situations was the Life Situation Scale for Parents (LSS-P) developed by Enskär and colleagues (1997a, 1997b). The findings of the study suggest that parents from joint families have a better living situation than parents from nuclear families, even though both groups perceive their life situation as good. The care dimension of the scale underlines the quality of health care facilities available from both private and government hospitals chosen for the treatment of the child. The psycho-social needs of the family need to be addressed and it is not possible for the oncologists to attend to this in an effective manner as they have a large adult population to cater to in Kerala. It is here the oncology social workers have to step in to aid these families. Social work is a profession which uses the empathetic relationship to touch the lives of the suffering. Oncology social work is an emerging field in India, but it has a long way to go.

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**Keywords**
cancer, childhood cancer, parents of children with cancer, life situation, cancer care, pediatric oncology

## Introduction and Background to the Study

Cancer has become one of the leading causes of death in both developed and developing countries. Many studies have identified Denmark and Niger as having highest and lowest cancer incidences in the world respectively (Dana-Farber Cancer Institute, 2015; World Cancer Research Fund International, 2018). A number of risk factors are identified as "cancer causators" from lifestyles changes to a westernized diet. The World Health Organization has reported that cancer is seen as the second leading cause of death in the world and 8.8 million deaths were estimated to be from cancer in 2015. This indicates that one in six deaths is due to cancer. One-third of cancer-related deaths are caused due to five prominent behavioural as well as dietary risks such as obesity, reduced intake of fruit and vegetables, increased use of tobacco and alcohol along with a lack of physical activity. Infections like hepatitis and the human papilloma virus (HPV) contribute to 25 per cent of the total cancer incidences reported from low and middle-income nations (World Health Organization, 2018). India has more adult cancer incidences than of childhood cancer. However, there has been an increase in the reported cases of childhood cancer over the years. The main objectives of this study were to understand the patterns and incidence of childhood cancer in the state of Kerala along with the socio-demographic profile of the families of children with cancer and to discover the perceptions of parents about their life situation.

### Childhood Cancer – Around the Globe

The report of the World Health Organization on childhood cancer states that, on a yearly basis, more than 215,000 children are diagnosed with cancer. It is a disease that affests families and communities in all regions of the world (World Health Organization, 2017). Accessibility and affordability of quality healthcare ensure the survival and healthy lives for 80 per cent of pediatric cancer patients. Nevertheless, children from low and middle-income countries are not able to access adequate healthcare facilities and thus over 90 per cent of childhood cancer deaths happen in these countries (World Health Organization, 2017). The onset of childhood cancer is characterized by non-specific signs and symptoms and, as a consequence, its late detection. Close parental as well as medical scrutiny in the high-income countries increases the chance of the early detection of childhood cancer. However, less access to health care services and inaccurate diagnostic methods pose hindrances to early detection in low-income countries (World Health Organization, 2018).

Among the reported incidence of childhood cancer, approximately 80,000 cancer-related deaths occur annually. These estimates are based on data collected by more than 100 population-based cancer registries (PBCRs) in 68 countries around the world in 2001–2010 (World Health Organization, 2016).

## Childhood Cancer: The Indian Scenario

In India, cancer is the 9th most common cause of death among children between 5 and 14 years of age (Registrar General, 2003). Mortality statistics in India 2006, a report published by the Central Bureau of Health Intelligence reports that in India, other than neonatal deaths, infectious and parasitic diseases are the leading causes of death in children. Only 2 per cent of all deaths in this group are cancer-related. Even though there is a greater percentage of childhood cancer in India when compared to the developed world, it has not become a priority in health care. This might be due to the perception related to its contribution to overall childhood mortality (Arora et al., 2009). Childhood cancer contributes to less than 5per cent of the total cancer burden in India, with approximately 45,000 children being diagnosed with cancer every year (Arora and Kanvar, 2009).

In India, there is a gap in adequately quantifying the burden of childhood cancer across the nation as well as by the states and the union territories. It must start from the reported cases of incidence from the Population Based Cancer Registries (PBCRs) as well as from the Hospital Based Cancer Registries (HBCRs). The other barrier to quantifying the burden of childhood cancer is a lack of awareness about childhood cancer among the parents. They may not recognize the signs and symptoms or may not avail themselves of the resources to provide the child with a better diagnostic medical facility. Even when cancer is diagnosed, the families may lack the funds to pursue treatment and decide to abandon the treatment before the patient is registered. The actual abandonment rates for childhood cancer patients in India are unidentified and range from 10–63% (Arora et al., 2007).

## Childhood Cancer in Kerala

In Kerala, the Regional Cancer Centre (RCC), Thiruvananthapuram, has maintained an institutional report of pediatric cancer incidence reported from 2012 to 2015. Table 1 projects the data. A recent report published in the Deccan Chronicle stated that in the state of Kerala nearly 1000 new pediatric cancer incidences are reported and nearly 600 of them approached the RCC for the treatment. Less than 100 patients were able to afford costly treatment and choose a private super-speciality hospital inside or outside Kerala. The rest falls onto government medical colleges (Mili, 2018).

Table 1. Reported incidence of childhood cancer in RCC, Thiruvananthapuram

| *Year* | *New cases* | *Review cases* |
|---|---|---|
| 2014 - 2015 | 631 | 23,424 |
| 2013 - 2014 | 592 | 23,197 |
| 2012 – 2013 | 649 | 24,984 |

Source: Regional Cancer Centre, 2013, 2014 & 2015.

Leukemia is the most common childhood cancer in India with the relative proportion varying between 25 and 40 per cent. Sixty to 85 per cent of all leukemia reported is Acute Lymphoblastic Leukemia (ALL) and it is the leading type of cancer among both male and female children (Arora et al., 2009). The same trends are identified in Kerala among childhood cancer patients. The districts of Thiruvananthapuram and Kollam have the highest incidences of leukemia after Delhi among the children aged between 0–14 years of age in the year 2012–2014 (Indian Council of Medical Research, 2016).

## The Families of Children with Cancer

Childhood cancer is an illness that affects not only the child but every unit in the family. Alderfer and Kazak (2006) have identified the impact on the families of childhood patients based on the four phases of treatment such as diagnosis, treatment initiation, illness stabilization and the end of treatment.

In the diagnostic phase, parents express guilt and anxiety. Parents tend to overlook the initial symptoms expressed by the child and might have misinterpreted them. As a result, they might have sought the usual home remedies or waited for a while to take the child to a speciality hospital treating cancer. Once they have visited the hospital, they suffer watching the child undergoing painful and invasive diagnostic procedures. Meeting with the multi-disciplinary healthcare professionals, discussion over the diagnostic results and listening to enormous information about cancer from them leaves them in a state of anxiety. Similarly, the siblings of the sick child also face disruption in matters related to them due to the illness and they tend to worry about the health and subsequent illness of their brother or sister. They may also feel left out as the attention of the parents is on the sick child. Very often parents may not disclose all the details to their other children, considering their age and ability to grasp the information shared as preventing them from understanding the experiences of their sick sibling. This may result in a fear developing in those children (Havermans and Eiser, 1994).

In the treatment initiation phase, the family routine tends to be influenced by the treatment. The side effects and the pain associated with the treatment modalities deepen the feelings of guilt and anxiety for the entire family and they suffer watching the child going through painful experiences (Enskär et al., 1997b). The illness stabilization phase is characterized by full involvement of the family in the treatment of the child and this also can be seen as an adaptation phase. The daily life patterns of the family tend to accommodate to the hospital visits and other alternative arrangements made (Hosoda, 2014). The end of the treatment phase is a time for periodical follow-up visits. This is a time of reduced burden on the family. This is a phase characterized by both anxiety and joy. The former is due to the feeling of the family about its decreased dependency on the medical care staff which had provided them with a sense of security and protection while the child was in constant care. In addition, they may face the challenge of falling back into the earlier routine of the family prior to the diagnosis of the illness. The fear of relapse, death, growth disorder and infertility and lasting side effects of treatment can disturb the family.

In the period immediately after the diagnosis, parents tend to experience a high level of strain, anxiety loss of appetite and sleep loss but the distress declines and stabilizes over the first year. Other emotional experiences of parents include fearfulness, desperation and guilt. The diagnosis of cancer in a child brings shock, disbelief fear, guilt, sadness, anxiety and anger for parents. Some studies have identified in parents low self-esteem, strained relationships, problems in relation to work and an increased financial burden (Enskär et al., 1997a; Ow, 2003). Parents view the support from social workers and medical professionals as helpful in finding out more about the illness and the treatment protocol and coping with the side effects of treatment (Ow, 2003).The present study was undertaken to understand how the parents respond to the cancer diagnosis of their child and their life situation after the diagnosis.

## Method

### Participants

This study was based upon a descriptive research design using the snowball sampling method. This resulted in the selection of 50 parents of children diagnosed with cancer and presently undergoing treatment for the management of cancer. The geographical location of the study was limited to the state of Kerala. Eligibility criteria for the participants were selected for the child and parent. The child would be within the limits of 0 to 18 years of age and should not be a cancer survivor. The parents who are able to communicate in Malayalam and are willing to complete the research instrument were selected as eligible participants for the study. The researcher identified institutions and organizations that provided accommodation as well as other support for the parents of children undergoing treatment at hospitals in the districts of Trivandrum and Ernakulam. Permission was obtained from the respective managing trusts and bodies of these institutions and organizations to meet with the parents for the purpose of the study.

### Instruments

***Socio-demographic Index:*** A socio-demographic index of the family was prepared based on the variables that are under investigation. The index had 23 items which described the social, demographic, educational, and occupational background of the family along with the details of the illness of the child, referring to the type of cancer, the duration of the illness, when treated first for the management of the illness and the present place of treatment.

***The Life Situation Scale for Parents (LSS-P):*** This instrument was developed by Karin Enskär and colleagues in 1997 in Sweden to assess the life situation of parents of children with cancer through a qualitative study (Enskar et al., 1997b). The instrument consisted of 37 questions to be answered by the respondents on a five-point Likert scale and the total life situation score could vary between 37 and 185, with higher values indicating a more positive living situation. The instrument ends with a free space to note factors that are unique to their life situation. The instrument had four dimensions to be assessed such as care, well-being, social life and preparedness. The scale had the reliability coefficient, Cronbach's alpha, and was found to be 0.69 for the whole of LSS-P. The researchers had the instrument translated into Malayalam, the local language spoken by the respondents. Its validity was ensured by forward and back translations and these were subjected to the examination of an expert panel. A pre-test of the instrument was performed before setting the final version of the translated instrument of LSS-P.

### Procedure

The researchers approached the parents who accompanied the child to the hospital. The initial session with them helped the researchers to ensure that they fulfilled the inclusion criteria.

The purpose of the study was explained and a brief description of the study was given to them. The session would end with obtaining their consent to participate in the study or their decision to withdraw from it. Those parents who consented to participate in the study would be met in the next session and their written consent obtained. We used the interview method to collect the data from the participants. The results of the study were statistically analyzed using SPSS version 18 (PASW). The 13 negative statements of the instrument were recorded to positive values before the analysis. It was decided that missing values would be calculated by using the mean substitution. For the description of the frequency variables, the mean and standard deviation were used. Group differences were analyzed using the independent s ample t-test.

## Results

### Socio-demographic Index of the Respondents

The response rate to the statements of the instrument was high and there were no items left out by the participants as unanswered. The socio-demographic profiles of the families of the respondents are given in Table 2 and the socio-demographic and clinical variables related to the sick child have been placed in Tables 3 and 4.

The participants in the present study were 50 parents (Fathers (n=25) and Mothers (n=25)) of children undergoing treatment for the management of cancer in various hospitals of the Trivandrum and Ernakulam districts. Thirty-four respondents in the study fall into the early adulthood phase of their life and 16 are in the middle adulthood stage. Forty-two respondents stated that their family had other children as siblings of the sick child and 8 parents reported that their family had no other children other than the one treated for malignancy. The respondents from joint families (n=27) outnumbered the respondents from nuclear families (n=23). The respondents from 24 families have Hinduism as their family religion, 7 respondents have Islam as their religion and 19 respondents belong to the Christian faith.

Table 2. Socio-demographic variables of the families, n 50

| *Characteristics* | *n* |
|---|---|
| Parent answering | |
| Father | 25 |
| Mother | 25 |
| Lifespan stages of respondents | |
| Early Adulthood | 34 |
| Middle Adulthood | 16 |
| Siblings of the child | |
| Yes | 42 |
| No | 8 |
| Type of family | |
| Joint family | 27 |
| Nuclear family | 23 |
| Religion | |
| Hinduism | 24 |
| Islam | 7 |
| Christianity | 19 |
| Working situation-Father | |
| Working | 24 |
| Unemployed | 22 |
| On leave | 4 |
| Working situation-Mother | |
| Working | 3 |
| Unemployed | 4 |
| On leave | 2 |
| Homemaker | 41 |

| | |
|---|---|
| Monthly Income of the family | |
| Range | ? 5,500 - ? 40,000 |
| Mean | ? 13,878 |
| SD | 8877.15 |
| Economic categorization | |
| APL | 24 |
| BPL | 26 |
| Health insurance for the children | |
| Yes | 4 |
| No | 46 |

Table 3. Socio-demographic and clinical variables of the sick child, n 50

| *Characteristics* | *n* |
|---|---|
| Gender of the sick child | |
| Male | 25 |
| Female | 25 |
| Lifespan - Child | |
| Infancy and Toddlerhood | 13 |
| Early Childhood | 11 |
| Late Childhood | 13 |
| Adolescence | 13 |
| Type of cancer | |
| Acute Lymphocytic Leukemia | 23 |
| Retinoblastoma | 1 |
| Rhabdomyosarcoma | 5 |
| Wilms Tumor | 3 |
| Acute Myeloid Leukemia | 1 |
| Ewing Sarcoma | 2 |
| Glioma | 1 |
| Hodgkin Lymphoma | 1 |
| Liver Tumor | 2 |
| Lymphoma | 1 |
| Medulloblastoma | 1 |
| Neuroblastoma | 4 |
| Osteosarcoma | 5 |
| Diagnosis - Months | |
| Less than 6 months | 23 |
| More than 6 months | 27 |
| Treatment given | |
| Chemotherapy | 48 |

| | |
|---|---|
| Operation | 1 |
| Radiation | 1 |
| Now being treated | |
| Government Hospital | 39 |
| Private Hospital | 11 |

The working situations of the respondents and their spouses indicate their sources of income and how the illness of the child has affected the family economically. Of the fathers (n=24) are working, (n=22) are unemployed and (n=4) are on leave. Of the mothers (n=41) are homemakers, (n=3) are still working, (n=2) are on leave and (n=4) are unemployed. From the monthly income reported by the respondents, the mean income of the family was calculated and amounted to Rs. 13,878 (SD=8877.15). Families that fall under the BPL (Below Poverty Line) (n=26) outstripped the families above the poverty line (APL) (n=24). The families that have taken out health insurance for the children are fewer (n=4) than the families (n=46) with no health insurance schemes.

The gender of the sick child numbered 25 male and 25 female children. The age of the children ranged from 1 year to 18 years and the mean age was 8 years (SD=5.24). The lifespan stages of the children were diverse, ranging from Infancy and Toddlerhood (n=13), Early Childhood (n=11), Late Childhood (n=13), and Adolescence (n=13). The most common type of cancer identified in this study is Leukemia (n=23) and its subtype B-cell ALL. It is followed by Rhabdomyosarcoma (n=5), Osteosarcoma (n=5), Neuroblastoma (n=4) and Wilms Tumour (n=3). Chemotherapy is the most prescribed mode of treatment given to the sick child (n=48). Most of the respondents (n=39) have chosen government hospitals for the treatment needs of their child and others (n=11) are receiving treatment from private hospitals.

The status of education of the sick child is presented in Table 4. The education of the sick child varied from pre-school to technical education. Children who have not yet started schooling numbered 17. All the children who have started schooling (n=32) have also missed schooling due to the treatment except in the case of a child who began schooling after the treatment.

Table 4. Education of the sick child, n 50

| *Characteristics* | *n* |
|---|---|
| Type of education | |
| Pre - School | 6 |
| Primary Education | 14 |
| Secondary Education | 11 |
| Higher Secondary Education | 1 |
| Technical Education | 1 |
| Not yet started schooling | 17 |
| Missed Schooling | |
| Yes | 32 |
| No | 1 |
| Not Applicable | 17 |

### The Life Situation Scale for Parents (LSS-P)

The response rate to the statements of LSS-P was high and no statement was left unanswered. The sum of the instrument varied between 107 and 154 with a mean score of 133.42 (SD=10.51).

Table 5. Scoring of the Life Situation Scale for Parents (LSS-P)

| *Dimension* | *Scoring of the dimension of LSS-P* | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | *Low* | | *Average* | | *High* | | *Very High* | |
| | *Min.* | *Max.* | *Min.* | *Max.* | *Min.* | *Max.* | *Min.* | *Max.* |
| Care | 12 | 24 | 25 | 36 | 37 | 48 | 49 | 60 |
| Preparedness | 02 | 04 | 05 | 06 | 07 | 08 | 09 | 10 |
| Social life | 06 | 12 | 13 | 18 | 19 | 24 | 25 | 30 |
| Well-being | 17 | 34 | 35 | 51 | 52 | 68 | 69 | 85 |
| Total LSS-P | 37 | 74 | 75 | 111 | 112 | 148 | 149 | 185 |

The calculation of the total score of the LSS-P and its dimensions are shown in Table 5. The dimension of care will have a score ranging from 12 to 60, preparedness from 02 to 10, social life from 06 to 30 and well-being from 17 to 85 respectively. Thus the total score of LSS-P is fixed from 37 to 185. The highest and the lowest scored items of the instrument are care and preparedness.

The life situation of the parents of the present study is shown in Table 6. The computed score for the dimension of care from the response of parents had 39 and 60 as the minimum and maximum scores respectively. Preparedness had 02 and 10, social life 14 and 29, and well-being 40 and 72 as the minimum and maximum scores respectively. The total life situation of the parents reflected 107 as the minimum score and 154 as the maximum score, with a mean score of 133.42 (SD=10.51).

Table 6. The life situation of the parents of children with cancer

| *Dimension* | *Scoring by the Parents* | | *Mean Score* | *SD* | *Life Situation* |
|---|---|---|---|---|---|
| | *Minimum* | *Maximum* | | | |
| Care | 39 | 60 | 52.00 | 4.62 | Very High |
| Preparedness | 02 | 10 | 6.08 | 1.61 | Average |
| Social life | 14 | 29 | 22.66 | 3.43 | High |
| Well-being | 40 | 72 | 52.68 | 6.75 | High |
| LSS - P | 107 | 154 | 133.42 | 10.51 | High |

The interpretation of the scores of the **LSS-P** reveals that parents (n=38) perceive the quality of care dimension of their life situation as very high and the remaining parents (n=12) consider this dimension as high. The mean score 52 (SD=4.62) of this dimension is from the category of very high. The perception of parents in relation to the quality of social life has the following clusters, very high (n=19), high (n=25) and average (n=6). The mean score 22.66 (SD=3.43) of this dimension falls in the cluster of high. The dimension of well-being projects the perception of the parents on its quality from average (n=24), high (n=25) to high (n=1) with a mean score of 52.68 (SD=6.75) falling in the category of high. The dimension of preparedness had representation in all the clusters starting from low (n=6), average (n=31), high (n=8) to very high (n=5), with a mean score of 6.08 (SD=1.61) fixing its quality to average. Thus the perceptions of the quality of life of parents are projected from average (n=2), high (n=43) to very high (n=5), with a mean score of 133.42 (SD=10.51), as high.

## Group Differences

The independent sample *t*-test was used to examine the group differences in relation to the dependent variables. The details are given in Table 6. The respondents of the study, both fathers and mothers, did not show any differences in their life situations irrespective of their gender ($t_{(df=48)} = .387$; $p > .05$). The results point to the fact that the life situation of the parents of children with cancer is the same in the population and across the gender of the parents. The respondents who had either male or female children

Table 7. Independent sample t-test for comparing the Life Situation of Parents across the groups

| *Groups* | *n* | *Mean* | *SD* | *t value* | *df* | *Sig. (2-tailed)* |
|---|---|---|---|---|---|---|
| Life Situation and the gender of the respondent | | | | | | |
| Father | 25 | 134.00 | 10.03 | .387 | 48 | .701 |
| Mother | 25 | 132.84 | 11.14 | | | |
| Life Situation and the gender of the child of the respondent | | | | | | |
| Male | 25 | 133.32 | 10.13 | -.067 | 48 | .947 |
| Female | 25 | 133.52 | 11.10 | | | |
| Life Situation and the lifespan stage of the respondent | | | | | | |
| Early Adulthood | 34 | 132.85 | 10.51 | -.552 | 48 | .584 |
| Middle Adulthood | 16 | 134.63 | 10.76 | | | |
| Life Situation and the economic categorization of the respondent | | | | | | |
| APL | 24 | 135.58 | 10.74 | 1.412 | 48 | .164 |
| BPL | 26 | 131.42 | 10.10 | | | |
| Life Situation and the type of family of the respondent | | | | | | |
| Joint family | 27 | 136.30 | 9.74 | 2.174 | 48 | .035<br>$P$=<.05 |
| Nuclear family | 23 | 130.04 | 10.59 | | | |
| Life Situation and the type of cancer of the child | | | | | | |
| ALL | 23 | 134.09 | 11.47 | .410 | 48 | .683 |
| Other types of Cancer | 27 | 132.85 | 9.81 | | | |
| Life Situation and the time of diagnosis of the child | | | | | | |
| Less than 6 months | 23 | 135.57 | 9.88 | 1.342 | 48 | .186 |
| More than 6 months | 27 | 131.59 | 10.87 | | | |

with cancer did not exhibit any differences in their life situations ($t_{(df=48)}$ =-.067; $p$>.05), indicating that the gender of the sick child does not influence the life situation of the parents. Another difference examined was the influence of lifespan stages on the life situation of parents. The comparison was done with respondents falling into the early and middle adulthood stages of their lives ($t_{(df=48)}$ = -.552; $p$>.05). The results indicated that the lifespan stages did not influence the life situation of the population. In comparing the economic categorization of the family with its life situation, the respondents were grouped into APL and BPL. The results ($t_{(df=48)}$ = 1.412; $p$>.05), indicated that regardless of whether or not the family falls above the poverty line or below, the life situation of the family remains the same. The influence of the type of family on the life situation of the parents and the results ($t_{(df=48)} = 2.412; p<.05$), indicated that there was a significant difference between the parents from the joint family and those from the nuclear family. Parents from the joint family (mean score 136.30) reported a significantly better living situation than the parents from the nuclear family (mean score 130.04). The mean difference was 6.25.

In comparing the type of cancer and life situation, types of cancer were grouped into two, ALL (Acute Lymphocytic Leukemia), which is the most common childhood cancer, and other types of cancer. The results ($t_{(df=48)} =.410; p>.05$) indicated that there is no difference in the life situation of parents of children with ALL or other types of cancer. Another difference examined was the influence of the time of diagnosis in the life situation of the parents. The time of diagnosis reported by the parents was converted to months and it was grouped into two categories of less than six months and more than six months. The results ($t_{(df=48)} = 1.342; p>.05$), displayed that the life situation of the parents was the same at the time of diagnosis.

### Comments by the Parents

Free space was provided in the tool to record the views, difficulties or opinions which were not reflected in the statements. Few respondents had expressed their views. One parent stated, "My father's (respondent's father) smoking is creating a lot of tension in the family, as I learned that passive smoking can injure the health of others... I do not want to happen anymore bad things to my daughter. This has led to discords in the family number of times..."A statement from two parents reflected how the illness has affected every unit in the family. The former stated that "my wife lost her job. My eldest daughter cannot concentrate on her studies. I had to change my job recently to another company as I failed to meet the target set for me. We need more psychological support". The latter commented, "It is a very difficult experience. I am not able to go for job everyday due to frequent hospital visits. My family has a lot of financial strains too and I really do not know where this is taking us to..." About the financial burden, a parent remarked, "The treatment has become expensive and I find it difficult to manage."

## Discussion

The aim of the present study was to understand the life situation of parents of children with cancer in the state of Kerala. The respondents of the study fall in the lifespan stages of early and middle adulthood, meaning that the illness of the child has become a major crisis in the respective phases of their lives. The lifespan stages considered for both respondents and their children were based on the Ericksonian classification of life stages. These stages are crucial to an individual as a parent as he/she forms her family and moves towards the accomplishment of his or her life tasks. At this stage, they are faced with a major challenge in the illness of the child. In the study, there were respondents who had no other children other than the sick child and this crisis was thus very severe for them.

In spite of the fact that joint families are declining in number and nuclear families are increasing, the present study had more respondents from joint families. These respondents perceive their life situation as high due to the quality of support they receive from their kinsfolk. Analysis of the working situation of the parents revealed that the father continues to be the breadwinner and the fathers who are unemployed have left their jobs to give support to the mother for looking after the child, especially when they are in the hospitalization phase. The respondents in the study were from low income and low middle-income families. The mothers of the children with cancer have taken the role of caregivers and homemakers.

One of the highlighted findings of this study was the absence of health insurance for the children where 46 respondents had taken out no insurance. This might be due to lack of awareness about health insurance policies that are provided by the private or government institutions or it might be due to negligence on the part of parents. Considering the rising hospital expenditure in the state of Kerala and its vulnerability to different types of illness, it is high time awareness of health insurance to all sections of society was provided. Even though the public health system of Kerala is adequate, for better satisfaction people tend to use more private healthcare facilities. Despite this, the treatment for cancer being free for children from 0–18 years, under the scheme of 'Thaloalam' by the Kerala Social Security Mission (Thalolam, 2018), it would be very difficult to continue the treatment for children nearing 18 years of age.

The occurrence of childhood cancer is becoming relatively common in Kerala and much more systematic studies have to be undertaken to understand its prevalence across the districts of Kerala. Similar to the findings in many studies done in India and in Kerala and supporting the data cited in the National Cancer Registry, this study also had the majority of children (N=23) diagnosed with Acute Lymphocytic Leukemia (ALL).

The majority of the respondents opted to use the healthcare facilities at government hospitals in comparison to the private hospitals for the management of the illness of the child, thus underlining the availability of free treatment under the Thalolam scheme. The respondents also reported that due to the prolonged duration of the treatment the children had breaks in continuing their education and also shared their concern over the weakened academic performance of the child.

In this study, parents reported high values in relation to their life situations. Previous studies done also support this finding (Enskär et al., 1997; John, 2013; Wright, 1993). It can be further explained that parents view the quality of their lives as very poor immediately after the diagnosis and for a few days thereafter. Gradually they become accustomed to their changed life situation and the support received from every resource within and outside their family reduces the fear of the loss of their child. Another factor associated with it would be the perception of care received from the healthcare professionals which increases their hope to save the child on completion of the treatment. Similarly, the care dimension of LSS-P received scoring with very high values from the parents. The interaction with other parents of children with cancer also enhances their social life and well-being. The lowest scored dimension in the scale was preparedness, relating to how well they were prepared to face the crisis. Oncology social workers have a definite role to play in this dimension. The empathy and the communication skills of the oncology social workers are essential for the parents to overcome the shock and fear exhibited by them immediately after the diagnosis.

The study was undertaken with a limited number of people in the sample, hence further studies should be undertaken with larger sample sizes to find out the extent of generalization of the findings of the study. The study focused on respondents from lower and middle-class families of economic stratification. Further studies should include the upper strata to have a more divergent population. The sample selected for the study had their child's diagnosis starting from one month to 65 months and further studies could be restricted to the initial months of diagnosis to obtain an understanding of changes in the life situation immediately after diagnosis.

## Conclusion

Childhood cancer is an illness that not only affects the child but the entire family. As the treatment for the management of the illness progresses, the psycho-social needs of the family also need to be addressed. It is not possible for oncologists to attend to these in an effective manner as they have a large adult population to cater to in Kerala and there is a dearth of oncologists. It is here that oncology social workers have to step in to aid these families. Their intervention can help families to cope effectively with every stage of cancer treatment. Social work is a profession which uses the empathetic relationship to touch the lives of the suffering. Oncology social work is an emerging field in India, but it has a long way still to go. This study was an effort towards understanding where the families need assistance in the process of providing quality healthcare for their little ones.

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