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Exploring burden experience among parents of child with cancer child-A mixed method

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Abstract: *Cancer is a group of diseases involving abnormal cell growth with the potential to invade or spread to other parts of the body. Cancer is still the second leading cause death among children aged between 5 and 14 years old. Caregivers have several problems such as social problems, relationships with relatives and psychological distress including stress, depression, anxiety etc.*

Objectives of the study *1.To assess the level of burden among the parents of cancer child.2.To associate the level of burden and Burden experiences among the parents of cancer child with selected demographic variables.3.To exploring burden experiences among the parents of cancer child.*

Methodology*: This study was conducted with 50 parents in Mixed study and the study design is QUAN-QUAL. Non- probability-purposive sampling technique was applied in quantitative study. Convenient sampling was applied qualitative study. The study was conducted in Haematology ward and op at ICH &HC, Egmore, and Chennai – 08.*

Results: Quantitative Study *Parent's burden score among the parents of cancer children. On an average, generalization of 70% of parents of cancer children having burden. Differences and generalization of burden score was calculated using proportion with 95% CI.*

Qualitative Study: *Content analysis for coding process revealed ten subthemes are follows: 1. Initial stage 2. Financial, 3. Balancing dual responsibility, 4. Physical, 5. Social, 6. Altruism, 7. Accepting reality, 8. Being positive, 9. Family support and then10. Spiritual. The first five subthemes were related to protection against physical stress, and final five ones were related to coping mechanism.*

Conclusion: *Exploring burden experience among parents of child burden score about the disease and treatment regimen can improve decision making among parents of child with cancer and provide them with coping mechanisms. Nurses have a pivotal role in educating clients about the importance of treatment regimens and providing necessary information about treatment and physical and psychological needs. Evidence-based practice allows nurses to build their knowledge and skills and practice new ideas and techniques. Nurses can incorporate aerobic exercises, yoga, meditation, and music to comfort psychological trauma and side effects due to anticancer drug interactions.*

Key words*: cancer, QUAN-QUAL, Non- probability-purposive sampling, Financial, Initial stage*

1. Introduction

Biologically, a baby could be a creature between the stages of birth and time of life, or between the biological process amount of infancy and time of life. The legal definition of kid typically refers to a minor, otherwise referred to as someone younger than the age of majority. Kids typically have fewer rights and fewer responsibilities than adults.They classed as unable to create serious selections and wrongfully should be below the care of their oldsters or another accountable caregiver. Child may additionally describe a relationship with a parent (such as sons and daughters of any age) or, metaphorically, associate authority or signify cluster membership in tribe, or religion; it may also signify being powerfully plagued by a selected time, place, or circumstance, as in "a kid of nature or a kid of the Sixties"Achild'sdevelopment,Since every amount couldbea time withindividual variations concerning begin ning and ending.Some age-related development periods and samples of defined intervals include: newborn (ages 0–4 weeks) baby (ages four weeks one year); (ages twelve months-24 months), fry (ages 2–5 years); school-aged kid (ages 6–13 years); adolescent (ages11_19). Promoting kid development through parental coaching, among different factors, promotes wonderful rates of kid development. Oldest play an outsized role in a very child's activities, socialization, and development.

Cancer is a group of diseases involving abnormal cell growth with the potential to invade or spread to other parts of the body. Cancer is still the second leading cause death among children aged between 5 and 14 years old. Caregivers have several problems such as social problems, relationships with relatives and psychological distress including stress, depression, anxiety etc.

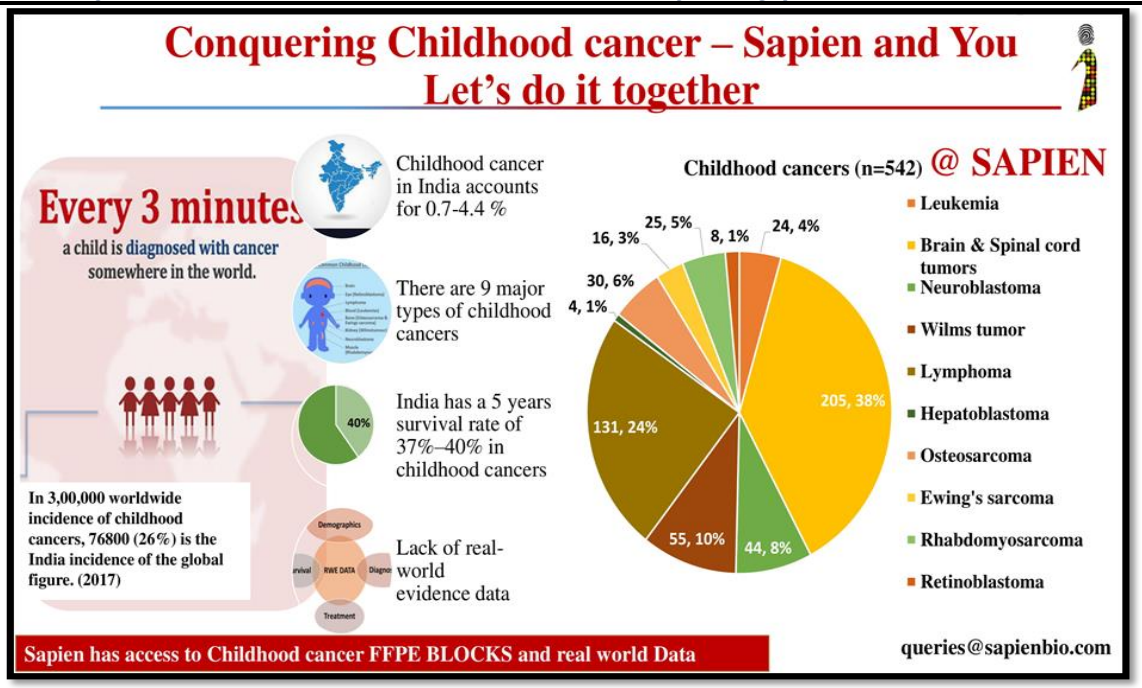
WHO reported cancer as a second leading causes of death

Most Frequent Types of Cancer in U.S. Children and Adolescents*

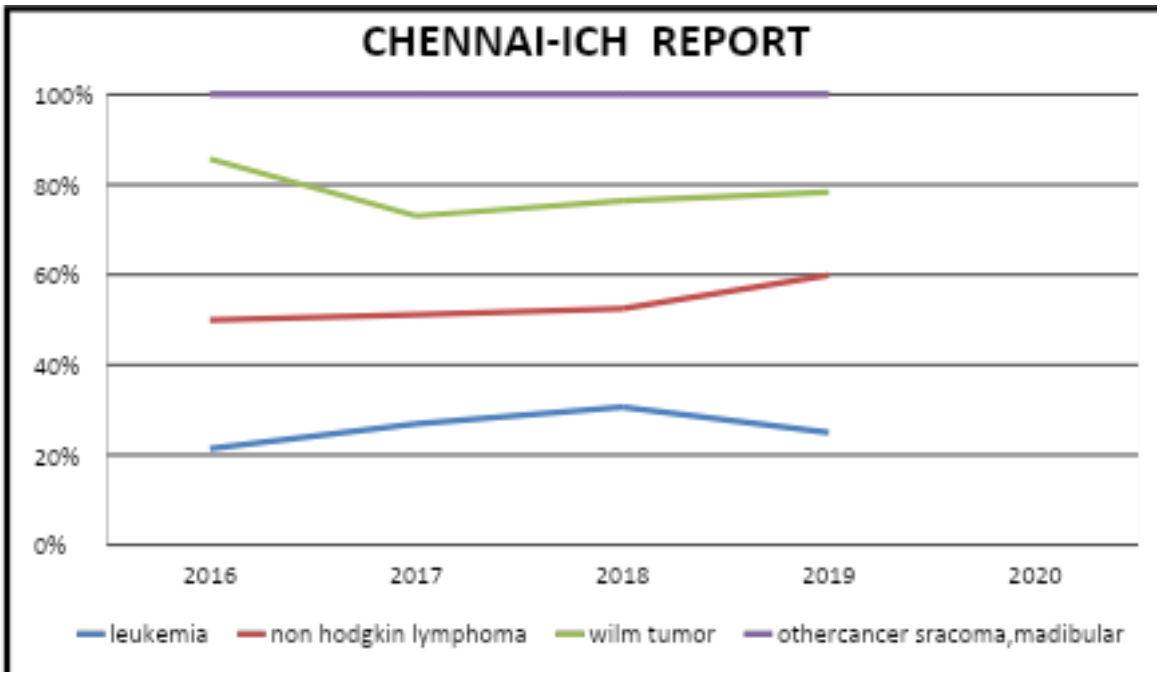
Type of Cancer	Children Birth to 14 years (approximate percentage of cases)	Adolescents 15-19 years (approximate percentage of cases)
Lymphoid leukemia (acute and chronic)	22%	7%
Acute myeloid leukemia	4%	4%
Hodgkin lymphoma	3%	12%
Non-Hodgkin lymphoma	5%	7%
Brain and other central nervous system cancer	26%	21%
Neuroblastoma & other peripheral nerve tumors	6%	<1%
Nephroblastoma & other nonepithelial renal (kidney) tumors, including Wilms' tumor	5%	<1%
Hepatic (liver) tumors	2%	<1%
Osteosarcoma	2%	3%
Ewing tumor and related bone sarcomas	1%	2%
Rhabdomyosarcoma	3%	<1%
Germ cell & gonadal tumors	3%	11%
Thyroid carcinoma	2%	11%
Malignant melanoma (skin cancer)	1%	4%
Other types of cancer (not listed above)	15%	16%

*as reported from 2011-2015

Source: Cancer Statistics, 2019 CA: A Cancer Journal for Clinicians/ Volume 69, Issue 1



Estimated number of cases of cancer in India. (2018 – 2020)



Institute of Child Health Hospital for Children, Egmore, Chennai-08 Report on 2016-2020

PREVALENCE OF BURDEN AMONG PARENTS OF CANCER CHILD:

Al Qadire et al (2020) reported on Prevalence and Predictors, was cross-sectional survey design was used to conduct the study in 2 hospitals. A sample of 264 parents of children with cancer was recruited. Data were collected using 2 instruments: the Zarit Burden Interview and the Hospital Anxiety and Depression Scale. The mean burden score was 38.1 (SD, 16.6), and 75.4% of parents experienced mild to severe levels of burden. Having a chronic disease, financial constraints, high levels of anxiety and depression, a child with advanced cancer, and a child experiencing pain, nausea, and vomiting predicted higher levels of burden.

Mehrnaz Ahmadi et al (2019) conducted the study cross-sectional descriptive study was done on 125 parents of children with cancer in oncology department of Shohada Hospital, Tehran, Iran, during March to August 2017. The result of this score of parents' care burden was 52.76 ± 10. Moreover, 17.6%, 71.2% and 11.2% of parents had low, moderate, and high care burden, respectively. Regression analyses indicated that the factors associated with care burden were cancer type (Acute myeloid leukemia (β=0.36, $p<0.001$) and Ewing sarcoma (β=0.16, $p=0.007$)), the number of hospitalization (β=0.38, $p<0.001$), duration of disease (β=-0.31, $p<0.001$), parent's age (β=-0.29, $p<0.001$), parent's income (β=-0.23, $p<0.001$), and child's age (β=0.24, $p<0.001$). These variables accounted for 65% of the variance in care burden.

According to the above study result clearly explained that the parents of cancerchild had such as,lack of knwolegde regarding disease condition,financial problem,and lack of interpersonal relationship between parents. It clearly explained that the burden of parents of cancer child are very high and also most of the studies have done in only quantitative or qualitative manner. Exploration of burden experience after the quantitative measurement is very useful &understand the problem in every aspect. The researcher got interested in "**Exploring Burden Experience Among Parents of Child with Cancer-A Mixed Method"(QUAN-QUAL).** It explore the problem to the parents in a holistic manner**.**

CONCEPTUAL FRAMEWORK

Conceptual frame work helps to express abstract ideas in a more reality understandable or precise form then the original conceptualization.this conceptual framework for this study was directed from one of the health behaviour **Theory of Health Belief Model.** The Health Belief Model was originally developed in the **1950** s by social psychologist **Irwin M.Rosenstock, Godfrey M.Hochbsum,S.Stephen Kegeles,and Howard Leventhal at the** U.S Public Health service.

Health Belief Model used to guide health promotion and prevention of disease. It focuses on individual beliefs about health condition, which predict individual health behaviors. Conceptual used for this study is based on the of burden experience among parents of child with cancer to improve skills to cope with their disease condition and also to influence health behaviors to avoid illness and get well.

MATERIAL AND METHODS: A explanatory mixed –method design was conducted among 50 cancer child parents in quantitative,5 interview face to face in depth interview in qualitative samples were chosen by convenient and purposive sampling technique respectively. The study carried out in Hematology OPD and ward in selected in tertiary care centers, Chennai. The eligibility criteria were a) Only female patients diagnosed as breast cancer b) able to understand and speak Tamil. c) Attending In-patient and Out-patient department in the selected tertiary care center.

DATA COLLECTION:Formal permission was obtained from the concerned authorities to conduct the study. Both oral and written informed consent was obtained from the participants according to their preferred language. The data collection was done with a structured Bio-socio demographic questionnaire followed by Structured questionnaire (caregiver burden scale zariet et al)-cancer in quantitative aspect. About 15 minutes were spent on each participant to elicit data using the selected tool. In the qualitative aspect, semi-structured questionnaires were used in FGDs and one-on-one interviews to collect qualitative data.

ETHICAL APPROVAL:The study was proposed and submitted to the ethical committee, Madras Medical College and the committee approved the study vide reference no., EC.Reg.NO.ECR/270/Inst/TN/2013/RR-16/0125363970.

DATA ANALYSIS

Quantitative study: Descriptive statistics were used to describe; socio- demographic and clinical variables, medication adherence, and informational need. Socio- demographic and clinical data will be averaged and tabulated with percentages. burden score given in mean, median, percentage of the mean score, and standard deviation. Association between burden score with demographic variables was analyzed using Pearson chi-square test. Inferential statistics were used to identify the relationship between burden score. The correlation between cancers burdens score has been analyzed using the Pearson coefficient. $P<0.05$ was considered significant. All statistical tests are two tailed test.

Qualitative study: The audio contents were transcribed, and the verbatim was developed, which made the researcher familiar with the data and acquire an overview of the text. Next, the transcripts were examined for content. The content corresponding to the variables was coded and categorized. Any coding issues have been discussed, and then consensus was reached. A description of each category was developed. In the mixed analysis, the individual studies' conclusions were combined in a discussion where the combined results were described next to each other according to the methods.

RESULT AND DISCUSSION:

Quantitative study

Objective 1: To assess the level of burden among the parents of cancer child

The present study illustrated level of exploring burden experience among parents of child with cancer. In the descriptive analysis 30.00% of the parents having or nil of burden score,70.00% of them having Mild to moderate burden score, none of them having Moderate to severe burden score .

The above studies exhibited that the parents of cancer child have moderate to sever burden and even some study explored high level of burden present parents of cancer child.**Hence the hypothesis:"**There will be a highest number of parents of cancer child having moderate to severe burden.H_1 was accepted($p<0.01$)(figure-24)The present study were compared study finding was supported by **Kristanti et al (2021)**. He conducted an exploratory study among 451 respondents of whom 40 were involved in the feasibility testing. Confirmatory factor analysis with the original factors of the CRA revealed that the fit was not satisfactory, and adaptation was needed. Through exploratory factor analysis, the best model fit was developed, and confirmatory factor analysis was performed again. Five factors from the original instrument were confirmed with an explained variance of 54.89%.So burden score very low. In the current study result was significant (70%)**.**Another one supportive study was conducted by **Mohammad Al Qadire et al (2019).** He conducted quantitative method using studies among 540parents are participated in this study. He is found burden score was 38.1 (SD, 16.6), and 75.4% of parents experienced mild to severe levels of burden. Having a chronic disease, financial constraints, high levels of anxiety and depression, a child with advanced cancer, and a child experiencing pain, nausea, and vomiting predicted higher levels of burden. There are significantly same in both studies.Similarly a quantitative study reported that parents of a child with cancer was **conducted by Bryan A. Sisk et al (2019).** He conducted the burden experience was Most parents preferred to share decision making with the oncologist (64% [236 of 372]); however,13% (49 of 372) preferred oncologist-led decision making. Most parents fulfilled their ideal decision-making role (66% [244 of 372]), but a notable minority were either more involved (14% [52 of 372]) or less involved than they preferred (20% [76 of 372]; P < .0001.Oncologists recognized parents' preferred roles in 49% of cases (167 of 341); 24% (82 of 341) of parents preferred more active roles than the oncologist recognized, and 27% (92 of 341) preferred less active roles than recognized.

The above studies revealed that majority of parents of child had significant high level burden and low quality of life score.

Objective 2: To associate the level of burden and Burden experiences among the parents of cancer child with selected demographic variables

Finding: parents demographic variables:

In the current study report was association the level of burden and experience among the parents of cancer child Monthly income and it is statistically significant with **$\chi 2=1.23$ p=0.27DF=1(s)** types of family and it is statistically significant with **$\chi 2=5.50$ p=0.02* DF=1(S)** residential place, and it is statistically significant with **$\chi 2=3.89$ p=0.05* DF=1(S)**, are having more scores than others. It was confirmed using the chi square test. **Finding for child demographic variables:** The association between level of burden and birth order it is statistically significant with **$\chi 2=8.65$ at P=0.01*** level. **$\chi 2=7.88$ p=0.02* DF=2(S),** number of children and it is statistically significant with **$\chi 2=9.53$ p=0.01* DF=2(S) are** having burden score than others. It was confirmed using the chi square test.

The above studies indicated that the demographic variables influence the burden among parents of child with cancer. **Hence the hypothesis (H_2)**: stated earlier that "there is significant association between the demographic variables and burden among parents of child with cancer, the H2 accepted($p\leq 0.05$)significant.table-4.4-

To summarise parenting burden has an association with certain demographic variables among parents of child with cancer.

The above finding study was supported by **MehrnazAhmadi PhD et al (2019).** He was conducted cross sectional study and conducted among a total number of 209 parents of children with cancer at Dr. Mohammed kermanshahi hospital, Kermanshah city, in the west of Iran. The finding of this study was reported the parent's care burden has been 52.76 ± 10. Moreover, 17.6%, 71.2% and 11.2% of parents had low, moderate, and high care burden, respectively. The result of this study demonstrated that most of parents of children with cancer had moderate levels of care burden.

Another one findings supported by Filiberto **Toledano-Toleranto**, **et al (2021)** cross sectional study a total number of 446 family caregivers of children with chronic complex diagnosis were selected. Using a non probability sampling technique for convenience He analysed the anxiety and depression levels. The low percentage of family caregivers with high levels of both of these symptoms, approximately 12%, is similar to that reported in other studies with families of children with chronic diseases The findings from this study

suggested that such results may be due to the time elapsed since the child was diagnosed with cancer, given that it is relatively short (one year maximum for 68.5% of the sample), as well as the length of the hospitalization period (from one week to one month for 83.9% of the sample). Therefore, the results of this study demonstrated that, despite the adversity caused by the disease and the vulnerability to which they are exposed, family caregivers of children with cancer reported high levels of resilience and other protective factors that contribute to their psychosocial adjustment. These findings are consistent with previous data pointing to the ability of the families of children with cancer to adapt and overcome the impact of chronic illness.

From the above, it is revealed that majority of mothers of child with cancer had lack of knowledge's about medication, quality of life and stress.

Objective 3: To exploring burden experiences among the parents of cancer child

Qualitative Study

The present study illustrated exploring burden experience among the parents of cancer child for coding process revealed ten sub themes evolved follows: **Initial stage, financial, balancing dual responsibility, physical, social, altruism, accepting reality, being positive, family support, spiritual. The first five subthemes were related to protection against physical stress** and final five ones were related to coping mechanism. The above the finding was supported by **Mahin Ahmadi Pishkuh,et al (2018)** conducted as a qualitative research with phenomenological approach. Participants were selected with purposeful sampling among 13 parents at imam Khomeini hospital, cancer department, in Iran **.**He extracted content is consisted of eight main subheadings that include the parents anxiety of the death of their children, parents inability to respond to the questions of their children, parents inability to have an appropriate behavior while confronting the children angry, parents suffering of treatment side effect in their children, the pressure of economic, social, and psychological burden on family, lack of time, experienced the impact of spiritual support, and influence on the relationship between parents.

Similarly another one study report was conducted by **Jadidi et al (2019)** a qualitative study with phenomenological approach. Participants were selected with purposeful sampling among Khomeini hospital cancer department, in Iran. In this study finding medical expenses, job losses, and unemployment due to full time care of the parents child, emotional and psychological stress, and depression of the parents due to attending a hospital which their child was admitted, was one of the problems expressed by parents. In current study, the socioeconomic burden of cancer and higher cost of treatment have been noted. Some parents have pointed to loss of job opportunities, reduced income, and their loss of saving.

Similarly a qualitative study reported by **StephanieMardakis, et al (2020)** qualitative study with using purposive sampling technique among 6 care giver of children with cancer**.** He was described direct and indirect, psychological cost associated with their treatment. The primary sources of direct cost were hospital admission, medication, food, and travel expenses. Indirect cost were hospital involved their child treatment, affecting care givers ,sleep, work hours, and time spent with other family members, psychological cost included coping with the uncertainty caused by a cancer suffer. Caregivers accessed a network of suffer to cope with their Childs treatment. No families abandoned treatment or indicated that they indented to do so.

The Findings of present study was Supported by **Streubert et al (2019**) which narrated a qualitative study reported that mothers of a child with cancer are exposed to a destructive experience in their families, and when the disease is diagnosed, they suffer from shock and disbelief and are forced to live with the extra burden on their shoulders. Having a child with cancer changes the lives of parents and their mothers and families experience many physical and psychological stresses. The identification of the mothers concerns by healthcare staff and planning for therapeutic interventions based on their needs and concerns is necessary. Therefore, in order to adapt to these problems, it is necessary for mothers to be supported by more family members and nurses. Support from professionals ensures the parents confidence in conducting therapeutic and caring measures. Mothers of a child with cancer noted fear of losing a dear child on the one hand, and belief in God and the mercy of God on the other hand as their experiences. From the above, it revealed that majority parents of child with cancer had a sense of disability which disturbed the relationship between parents, they could not look after other family members, and they discontinued family and social relationships.

In addition, it disrupted their occupational, social, and experiential experiences. **Miedema et al (2019)** stated that when a child is fighting cancer, all of the family gets involved in the issue, it disrupts life patterns, job opportunities, income of parents and the healthy children of this family also experience issues in facing the needs and wants of their sick sibling. Another one study also discussed about the parents life pattern conducted by **Syse et al (2019)** qualitative study among parent of child with cancer in Iran. He also argued that cancer significantly reduced the job opportunities and income of the parents and increased their psychological stress and caring responsibilities. It has also been reported that with the diagnosis of childhood

cancer, a major change occurred in the quality of life of the family, causing marital problems and divorce among parents of children with cancer.

CONCLUSION:

Exploring burden **experience** among parents of child burden score about the disease and treatment regimen can improve decision making among parents of child with cancer and provide them with coping mechanisms. Nurses have a pivotal role in educating clients about the importance of treatment regimens and providing necessary information about treatment and physical and psychological needs. Evidence-based practice allows nurses to build their knowledge and skills and practice new ideas and techniques. Nurses can incorporate aerobic exercises, yoga, meditation, and music to comfort psychological trauma and side effects due to anticancer drug interactions.

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