

Original Research Article

# Quality of Life & Lived Experience of Mothers and Their Felt Needs of Children Diagnosed With Cancer in a Selected Hospital in Mangaluru - Pilot Study Report

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## ABSTRACT

**Background:** Family plays an important role in a child's life more so when the child is sick and diagnosed with cancer. Parents of child with cancer face several challenges during the child's sickness and affect their life.

### Objectives:

1. Quantitative To assess the Quality of life of mothers of children diagnosed with cancer
2. To describe the mothers felt needs of children with cancer during their hospitalization
3. To find association between Quality of life of mothers ,mothers felt needs of children diagnosed with cancer & selected demographic variables
4. To find correlation between Quality of life of mothers & needs of children diagnosed with cancer

### Qualitative

1. To elucidate mothers lived experience during a child's cancer treatment

**Methods:** A mixed method approach and sequential exploratory design was used. Subjects consist of 10 mothers of children with cancer for quantitative and 3 mothers for qualitative. Subjects were selected purposively and nested identical sampling was used.

**Results:** Study showed that majority (70%) of sample had their family income >Rs10,000/- & half (50%) of sample had their family member affected with cancer. (40%) of Mothers of children with cancer had moderate QOL & (30%) had poor & good QOL. QOL score was highest in the care related area (78.5%) with mean±SD of 15.7±2.5 whereas least in the area of financial & spiritual (64.37%) with mean±SD of 10.3±4.6. Mothers felt needs of their children with cancer was highest (100%) in future condition, therapeutic choices, basic needs, doctors consultation, services from hospital, spiritual advice & abandoned within the society There was a strong positive correlation between Quality of life of mothers & mothers felt needs of children diagnosed with cancer ( $r=0.78;p<0.05$ ). Meta inference showed that issues faced by the majority of the mothers of children with cancer were in areas related to Psychological (82.7%) followed by physical (80%), social relationship (75%) and spiritual (50%) related.

**Interpretation and Conclusion:** Study found that, majority of the mothers felt need about their child with cancer was 100%. in areas related to future condition, therapeutic choices, basic needs, doctors consultation, services from hospital regarding the affected child, spiritual advice & being abandoned within the society

**Keywords:** - Quality of life, lived experience, mothers felt needs and children with cancer

## INTRODUCTION

Cancer among children is the known to be a leading cause of death. With the

emerging technologies and advancements in treatment there is progressive improvement, however is very stressful for parents

influencing their quality of life. Parents are challenged to meet the demands of the child. [1]

There is increasing burden of new cancer cases among children which affects the family roles and routines. [2] Family members are worried with the fear of spread of cancer. [3,5] Thus, making it very difficult for taking care of a cancer child. [4] Several researches conducted report that caregivers suffer with physical & psychological problems. [6]

There has been limited research evaluating the relationship between child with cancer the parents QOL. Thus, the researches felt that this alarming areas need to be addressed so that parents' burden & problems can be identified. Having an understanding of these associations can help us identify the risk of parents progressing to poor quality of life & also find out measures to support the parents. [1]

Nurses play a vital role Nurses play an important role, for the early detection and management of both physical and psychological symptoms of patient as well as the caregivers. There is a need to use strategies that will empower mothers to have a greater sense of control over the illness and treatment of their dear ones especially those caregivers who are taking care of their child suffering from cancer. Keeping in view the above findings in literature, cancer can be considered as a prevalent problem, which adversely affects the life of many individuals including the life of mothers. The investigator in her personal experience realized that mothers of children with cancer experience agony, anxiety, and depression due to this illness of their child. After an extensive review of literature regarding problems of mothers and by the personal experience in this field, the investigator was interested to research on the same and has selected the present study.

### Objectives of the study

The objectives of the study are;  
Quantitative

1. To assess the Quality of life of mothers of children diagnosed with cancer
2. To describe the mothers felt needs of children with cancer during their hospitalization
3. To find association between Quality of life of mothers of children diagnosed with cancer & selected demographic variables
4. To find association between mothers felt needs of children diagnosed with cancer & selected demographic variables
5. To find correlation between Quality of life of mothers & needs of children diagnosed with cancer

### Qualitative

1. To elucidate mothers lived experience during a child's cancer treatment

## MATERIALS AND METHODS

**The study used** Mixed method research approach & Sequential exploratory design.

**QUAL → QUAN** wherein Qualitative used Phenomenological design & Quantitative adopted descriptive exploratory design.

**Source of Data** - Mothers of Children diagnosed with cancer in a selected hospitals in Mangalore.

**Population** – All mothers of children diagnosed with cancer

**Setting** – The present study will be conducted in selected Hospitals of Mangalore like father Muller medical college hospital (which is a multi-specialty hospital with 1250 beds that has a well equipped Pediatric ward with 93 bed strength. On an average there are 10-20 cases of pediatric oncology in a month etc

### Sample and Sample Size:

#### Sample size-

- a) **Qualitative** – Until data saturation
- b) **Quantitative** – 10 mothers of children diagnosed with cancer

### Sampling technique

Nested identical sampling technique will be used and subjects will be selected purposively.

### Selection Criteria

### Inclusion criteria

- Mothers of Children diagnosed with cancer and undergoing treatment in hospital
- Mothers of Children diagnosed with cancer that are availing the services of inpatient, outpatient and day care.

**Exclusion criteria**

- Mothers of Children diagnosed with cancer who are intellectually & Mentally challenged
- Mothers of Children diagnosed with cancer who are not taking care of the child

**Content Validity** – was being established by sending the tool to 12 experts from different fields like Psychiatrists, Paediatricians, oral pathologist, Pediatric nursing lecturers, Psychologist, Counsellors.

**Translation of Tool** - The tools were being translated in Kannada and discussed with the subject experts.

**Pretesting Tools-** Tool has been pretested among mothers of children with cancer.

**Reliability-** Reliability was done using Cronbach’s alpha

Tool 2-Mothers Quality of life with a child diagnosed with cancer –0.881

Tool 3-Mothers felt needs assessment checklist of child with cancer – 0.724

**Data collection process**

Prior to the data collection, the investigator obtained Ethical clearance from Father Muller Charitable Ethical Committee and Permission for the study was obtained from concerned authorities. The investigator familiarized oneself with the subjects and explained the purpose of the study to them. She assured the confidentiality of their responses. An informed written consent was taken from each subject. Lived experience of mothers of children with cancer was elucidated using interview scheduled followed by Mothers Quality of Life & Mothers felt needs assessment checklist of child with cancer was administered. The data collected was subjected to analysis and respondents were thanked for their response.

**STATISTICAL ANALYSIS**

Data obtained was analyzed on the basis of objectives and hypothesis as follows.

**Section 1:** Baseline characteristics of mother of children with cancer

**Section 2:** Baseline characteristics of mother of children with cancer mothers felt needs of children with cancer during their hospitalization

**Section 3:** Quality of life of mothers of children diagnosed with cancer

**Section 4:** Mothers felt needs of children with cancer during their hospitalization

**Section 5:** Association between Quality of life of mothers of children diagnosed with cancer & selected demographic variables

**Section 6:** Association between mothers felt needs of children diagnosed with cancer & selected demographic variables

**Section 7:** Correlation between Quality of life of mothers & needs of children diagnosed with cancer

**Section 8:** Lived experience of mothers of children with cancer

**Section 9:** Metamatrix on Quality of life & lived experience of mothers of children diagnosed with cancer

**RESULT**

**Table 1: Demographic variables of mothers of children with cancer**

Variable	Frequency	n=10 Percentage
<b>Religion</b>		
Hindu	4	40%
Muslim	2	20%
Christian	4	40%
<b>Place of residence</b>		
Urban	7	70%
Rural	3	30%
<b>Education (Self)</b>		
Secondary	3	30%
PUC	5	50%
Diploma	2	20%
<b>Education (Husband)</b>		
Secondary	2	20%
PUC	2	20%
Diploma	6	60%
<b>Number of children</b>		
1	3	30%
2	4	40%
3	3	30%
<b>Occupation ( husband)</b>		
Non Medical	10	100%
<b>Occupation (self)</b>		
Medical	1	10%
Non medical	9	90%

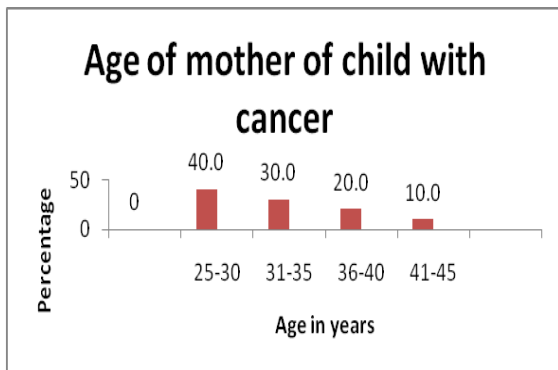


Fig 1: Age of mother of child with cancer

Data in fig 1 shows that majority (40%) of mothers were in the age group of 25-30yrs & least (10%) were in the age group of 41-15 yrs

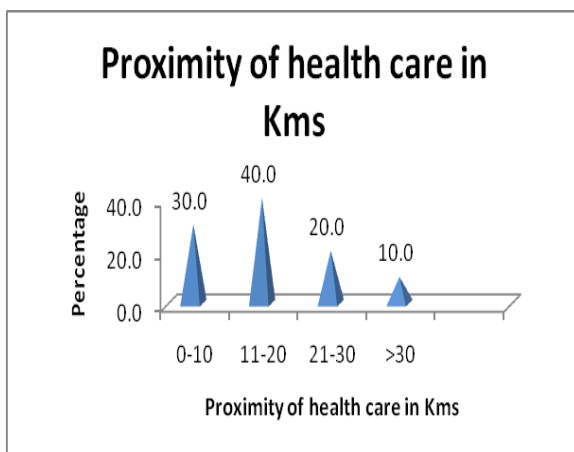


Fig 2: Proximity of health care center in kms

Data in fig 2 shows that majority (40%) of mothers were availing treatment from health care center at a distance of 11-20kms & least (10%) were mothers were availing treatment from health care center at a distance of >30kms.

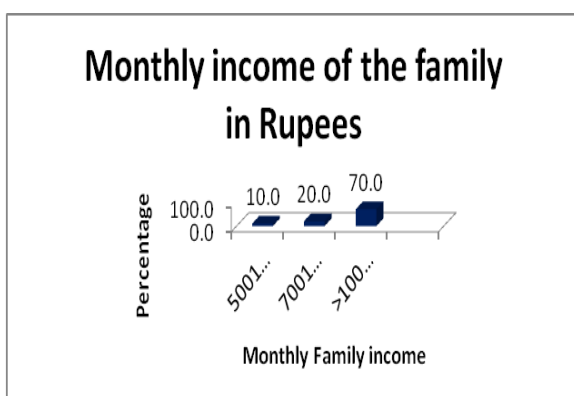


Fig 3: Monthly family income in rupees

Data in fig 3 shows that majority (70%) of sample had their family income >Rs10,000/- & least (10%) of sample had their family income Rs5,000- Rs 7000/-

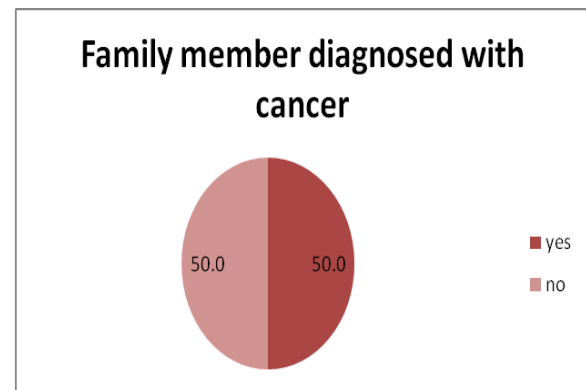


Fig 4: Family member diagnosed with cancer

Data in fig 4 shows that half (50%) of sample had their family member affected with cancer.

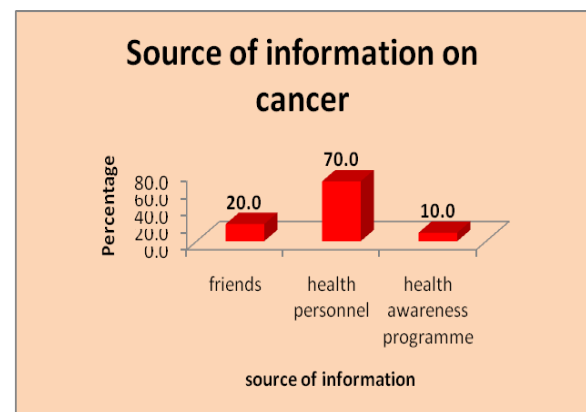


Fig 5: Source of information on cancer

Data in fig 5 shows that majority (70%) of sample had information on cancer from health personnel & least (10%) of sample had information on cancer from health awareness programs.

Table 2: Demographic proforma of children with cancer n = 10

Variables	Frequency	Percentage
<b>Birth order of child</b>		
1 <sup>st</sup> born	5	50%
2 <sup>nd</sup> born	3	30%
3 <sup>rd</sup> born	2	20%
<b>Duration of illness</b>		
Less than 6months	4	40%
6 months-1 yr	1	10%
1-2 yrs	2	20%
More than 2 yrs	3	30%
<b>School drop out</b>		
Yes	3	30%
No	7	70%

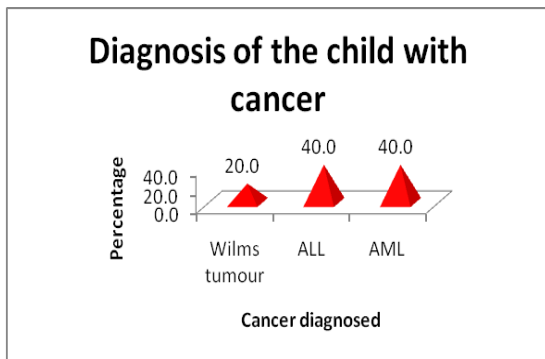


Fig 6: Diagnosis of child with cancer

Data in fig 6 shows that majority (40%) of children were diagnosed with ALL & AML & least (20%) of children were diagnosed with wilms tumor.

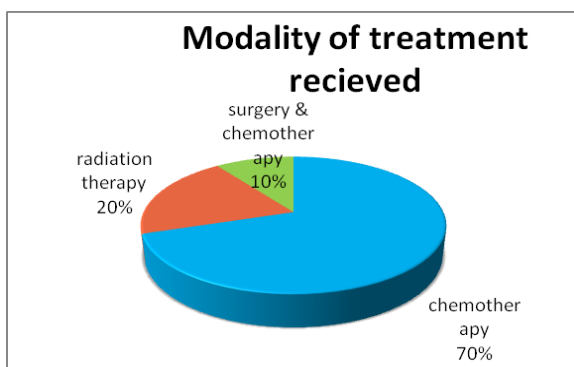


Fig 7: Modality of treatment received by child with cancer

Data in fig 7 shows that majority (70%) of children received only chemotherapy & least (10%) of children were treated with surgery and chemotherapy

Table 3: QOL of mothers of children diagnosed with cancer n=10

Grading of QOL	Frequency	Percentage
Poor	3	30.0
Moderate	4	40.0
Good	3	30.0

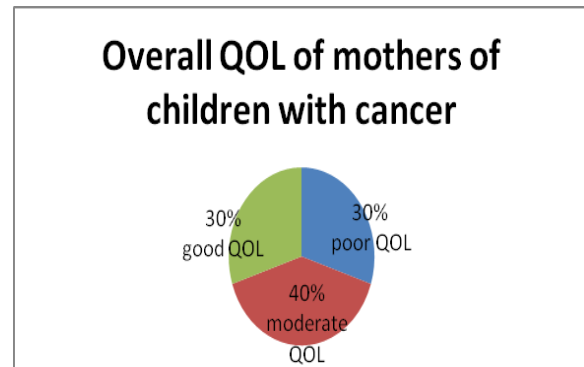


Fig 8: Overall QOL of mother of child with cancer

Data in fig 8 shows that majority (40%) of Mothers of children with cancer had moderate QOL & (30%) had poor & good QOL.

Table 4: Domain wise mean ±SD, mean percentage of QOL of mothers of children diagnosed with cancer n=10

Domain	No of items	Range of scores	Maximum scores	Mean ±SD	Mean %
Physical	9	19-30	36	24.9 ±5.8	69.16
Psychological	13	25-49	52	37.3 ±9.2	71.73
Financial & Spiritual	4	8-13	16	10.3±4.6	64.37
Social	4	7-16	16	11.5±1.9	71.87
Care related	5	11-20	20	15.7±2.5	78.5

**Interpretation:** The data presented in Table 3 shows that the QOL score is highest in the care related area (78.5%) with mean±SD of 15.7±2.5 whereas least in the area of financial & spiritual (64.37%) with mean±SD of 10.3±4.6 .

### Mothers felt needs of children with cancer during their hospitalization

Table 5: Item wise analysis of Mothers felt needs of children with cancer during their hospitalization n=10

SNo	Items	Frequency	Percentage
1.	need more information about my child's diagnosis	9	90
2.	need more information about my child's future condition	10	100
3.	need more explanations of my child's treatments	8	80
4.	need to be more involved in the therapeutic choices of my child	10	100
5.	need doctors to be more honest about my child's outcome	8	80
6.	need my child's symptoms (pain, nausea, insomnia, etc.) to be better controlled	9	90
7.	need more help with managing basic needs of my child like eating, dressing, hygienic needs etc	10	100
8.	need better respect for my child's intimacy	9	90
9.	need better attention from nurses	9	90
10.	need to be more reassured by the doctors	10	100
11.	need better services from the hospital (bathrooms, meals, cleaning)	10	100
12.	need to have more economic-insurance information	9	90
13.	need economic help	7	70
14.	need to speak with a psychologist	8	80
15.	need to speak with a spiritual advisor	10	100
16.	need to speak with people who have this same experience	9	90
17.	need to be more reassured by my relatives	8	80
18.	need my child to be better accepted within my family	9	90
19.	need my child to feel, less abandoned within the society	10	100
20.	need to receive less commiseration from other people	9	90

The data in table 5 shows that the majority of mothers felt needs of their children with cancer was highest (100%) in future condition, therapeutic choices, basic needs, doctors consultation, services from hospital, spiritual advice & abandoned within the society & least (70%) in need of economic help.

**Table 6: Association between QOL of mothers of children with cancer and selected demographic variable**

H<sub>01</sub>- There is no significant association between Quality of life of mothers of children diagnosed with cancer & selected demographic variables

Variables	QOL		Chi square value
	<Median	>Median	
			n=10
<b>Age of mothers</b>			
25-30	2	2	
30-35	1	2	0.72
36-40	1	1	
40-45	1	0	
<b>Religion</b>			
Hindu	3	1	0.22
Christian	0	2	
Muslim	2	2	
<b>Education (Self)</b>			
secondary	2	1	0.28
PUC	3	2	
diploma	0	2	
<b>Education (husband)</b>			
secondary	2	0	0.13
PUC	0	2	
diploma	3	3	
<b>Occupation (Self)</b>			
un employed	1	1	0.64
skilled labour	1	0	
unskilled labour	0	1	
self employed	1	1	
professional	1	2	
others	0	1	
<b>Occupation (Self)</b>			
un employed	0	1	0.32
skilled labour	1	2	
unskilled labour	0	1	
self employed	2	0	
professional	2	1	
others	0	1	
<b>Income per month</b>			
5001-7000	0	1	0.2
7001-10000	2	0	
>10000	3	4	
<b>Family member diagnosed with cancer</b>			
Yes	1	4	0.1
No	4	1	
<b>Place of residence</b>			
Urban	3	4	1.0
Rural	2	1	
<b>Proximity to health care centre (in kms)</b>			
0-10	1	2	0.5
11-20	3	1	
21-30	1	1	
>30	0	1	
0-10	1	2	
11-20	3	1	

**Interpretation:** The data presented in table 6 shows that the calculated ‘p’ value is more than 0.05 hence we accept the null hypothesis and conclude that there is no significant association between QOL and selected demographic variables

**Table 7: Association between mothers felt needs of children with cancer & selected demographic variables**

H<sub>02</sub>- There is no significant association between mothers felt needs of children with cancer and selected baseline variables

Variables	Mothers felt needs		Chi square value
	<Median	>Median	
			n=10
<b>Age of mothers</b>			
25-30	2	2	
30-35	1	2	0.57
36-40	1	1	
40-45	1	0	
<b>Religion</b>			
Hindu	3	1	0.43
Christian	0	2	
Muslim	2	2	
<b>Education (Self)</b>			
secondary	2	1	0.32
PUC	3	2	
diploma	0	2	
<b>Education (husband)</b>			
secondary	2	0	0.45
PUC	0	2	
diploma	3	3	
<b>Occupation (Self)</b>			
un employed	1	1	0.69
skilled labour	1	0	
unskilled labour	0	1	
self employed	1	1	
professional	1	2	
others	0	1	
<b>Occupation (Self)</b>			
un employed	0	1	0.34
skilled labour	1	2	
unskilled labour	0	1	
self employed	2	0	
professional	2	1	
others	0	1	
<b>Income per month</b>			
5001-7000	0	1	0.13
7001-10000	2	0	
>10000	3	4	
<b>Family member diagnosed with cancer</b>			
Yes	1	4	0.26
No	4	1	
<b>Place of residence</b>			
Urban	3	4	0.66
Rural	2	1	
<b>Proximity to health care centre (in kms)</b>			
0-10	1	2	0.8
11-20	3	1	
21-30	1	1	
>30	0	1	
0-10	1	2	
11-20	3	1	

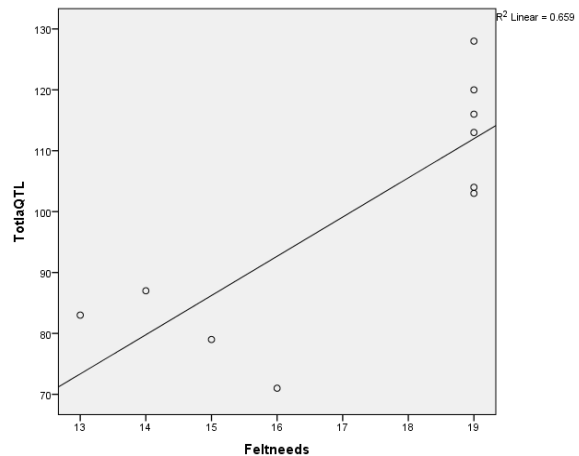
**Interpretation:** The data presented in table 7 shows that the calculated ‘p’ value is more than 0.05 hence we accept the null hypothesis and conclude that there is no significant association between mothers felt needs of children with cancer and selected demographic variables

and conclude that there is a strong positive correlation between Quality of life of mothers & mothers felt needs of children diagnosed with cancer

**Table 8: correlation between Quality of life of mothers & mothers felt needs of children diagnosed with cancer**

H<sub>03</sub>: There will be no significant correlation between Quality of life of mothers & needs of children diagnosed with cancer  
n=10

Variable	Mean ±SD	Mean%	r value	p value
Quality of life of mothers	100.4±19.4	71.71	0.77	<0.01
mothers felt needs	17.2± 2.4	86.0		



The data in table 8 shows that r is 0.77 at p<0.01.Hence we reject the null hypothesis

**Table 9: Lived experience of mothers of children with cancer**

LEAD QUESTIONS	SIGNIFICANT STATEMENT	FORMULATED MEANING	SUBTHEME S	THEMES
<b>Q.No: 1.</b> What are your feelings when your child was diagnosed with cancer?	“I couldn’t accept my child’s condition.” [ Participants 1] “My feelings was not good. I hated this world. I thought I don’t want this life.” [participant 2] “ I was tensed and worried. I was angry with my husband and family members.” [participant 3]	The participants reported that they were unable to accept the child’s diagnosis and felt sad & worried	Non acceptance Hopelessness Anxiety	Negative attitude towards life
<b>Q.No 2</b> What was your experience in accepting the diagnosis and adapting to the situation?	I accepted it as the will of god and surrendered everything to him. [participant 1] I cannot accept this diagnosis because this is my child. How can I accept this.[participant 2] First I didn’t accept this diagnosis after that with the help of my family members....I accepted this situation, even now I am not able to think about my child’s diagnosis. [participant 3.]	The participants reported that although they found it difficult to accept the diagnosis initially they accepted it gradually and believed in gods will.	Faith in god Acceptance	Positive attitude towards life
<b>Q.No:3</b> How did you feel when your child was undergoing cancer treatment?	First, I could not accepted the cancer treatment. After I thought this treatment will help my child. [participant 1] What I will tell....what the condition was.....vomiting....crying....my god!!!!!! I was too sad. [participant 2] I am afraid even to mind about the treatment. [participant 3]	The participants expressed fear about prognosis and the sadness	Disappointment Fear	Negative attitude towards life
<b>Q.No: 4</b> What was your experience with managing financial aspects of treatment?	I am a rich person therefore I have no problems with financial aspects of treatment. [participant 1,2,3]	The participants did not have any financial constraints	Well financed	
<b>Q.No: 5</b> What was your experience with managing family during treatment of your child?	My family members were very sad especially my husband, he couldn’t accepting the treatment. [participant 1] My mother helped me. [participant 2] My family is a joint family. So we were one in all things. [participant 3]	The participants expressed the support they received from the family members during their crisis	Good Family support	Family support
<b>Q.No: 6</b> What was your experience with family members relatives and neighbours after your child was diagnosed with cancer?	Our family members recognized our child cancer. There for everybody accepted the situation. [participant 1,2] My family is my strength , so I had no bad experience. [participant 3]			

Table 9 to be continued...				
<b>Q.No:7</b> How was your experience of attending any social gathering and mingling with people after your child was diagnosed with cancer?	I couldn't participate in any the social gathering and mingling with people in that situation. [participant 1] I was not liking any gathering ; without happiness .....what is social gathering????????? [participant 2,3]	The participants reported that they remained aloof from the society and were unhappy.	Isolation Unhappy	Life style changes
<b>Q.No:8</b> How your faith in god was after your child was diagnosed with cancer?	I believed in God at all times. [participant 1] My faith is same not increased ....not less. [participant 2] I was not interested in prayer. [participant 3]	The participants reported their faith in god was same , however some lost faith in god	Lost faith in god Believe in god	Negative attitude towards life
<b>Q.No:9</b> What was your feeling about your child's future after your child was diagnosed with cancer?	I know that he may not have long life and in future. I decided to provide all the possibilities to grow. [participant 1] I hope that my child will be cured. [participant 2] I don't know. [participant 3]	The participants expressed their uncertainties about prognosis of the child however were hopeful of a miracle	Uncertain about future Hopeful	Psychological issues
<b>Q.No:10</b> Have you ever experienced being hopeless and giving up on life because your child was diagnosed with cancer?	At that situation, I thought.... I don't want to live properly. [participant 1] At first I felt that hopelessness then I became to normal life. [participant 2,3]	The participants expressed that they did not want to live however gradually accepted the reality.	Acceptance of reality	Positive attitude towards life

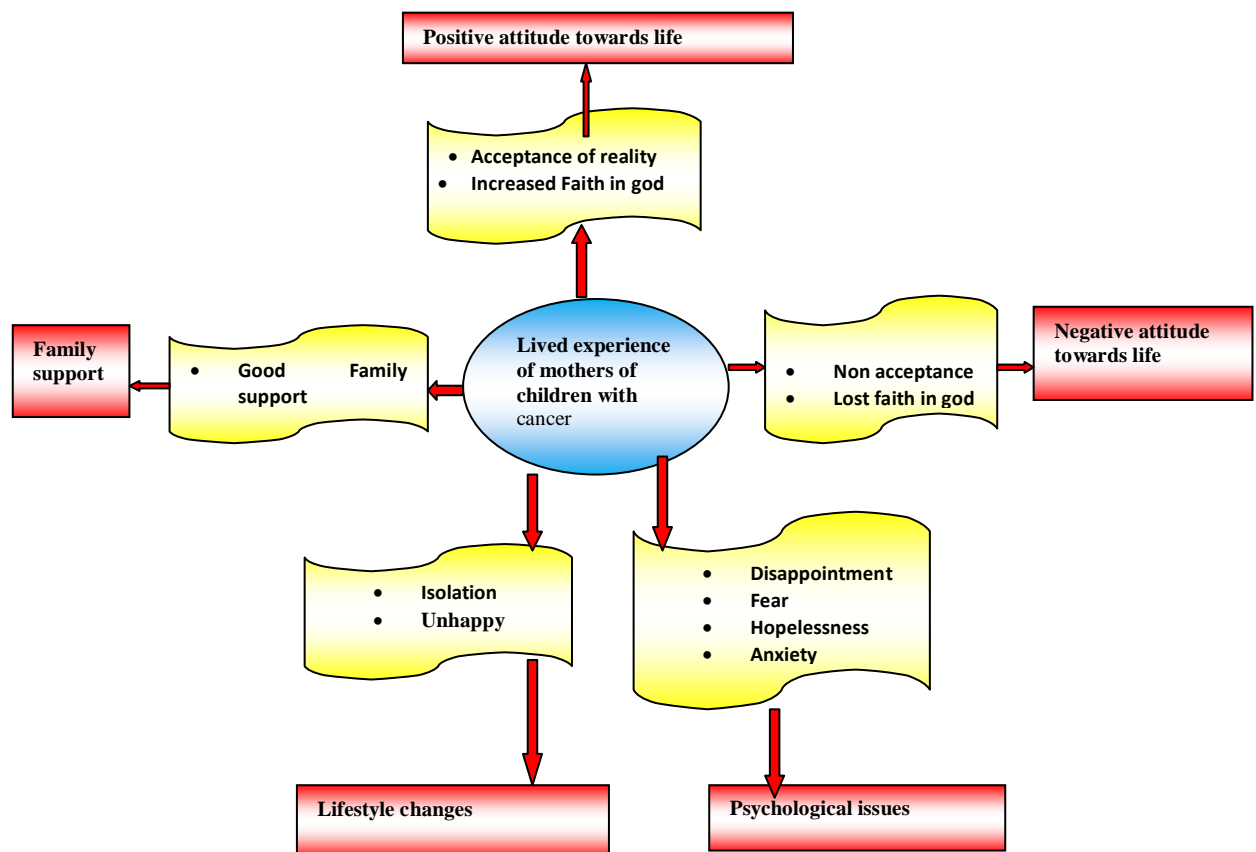


Figure 9: Derivation of themes and subthemes



**Table 10: Metamatrix on Quality of life & lived experience of mothers of children diagnosed with cancer**

Name	Age in yrs	Family monthly income	Duration of illness	Quantitative: QOL		% of Mothers felt need score	Qualitative: Lived Experience	Themes and subthemes (Lived Experience)				
				DOMAINS	%			Positive attitude towards life	Negative attitude towards life	Psychological issues	Lifestyle changes	Family support
<b>Participant 1</b>	32	Rs 8000/-	< 6 months	Psychological Physical Spiritual	82.7% 75% 50%	100%	“I couldn’t accept my child’s condition.” I accepted it as the will of god and surrendered everything to him. First, I could not accepted the cancer treatment. After I thought this treatment will help my child. I am a rich person there for I have no problems with financial aspects of treatment. My family members were very sad especially my husband, he couldn’t accepting the treatment. Our family members recognized our child cancer. There for everybody accepted the situation. I couldn’t participate in any the social gathering and mingling with people in that situation. I believed in God at all times. I know that he may not have long life and in future. I decided to provide all the possibilities to grow. At that situation, I thought..... I don’t want to live properly.	Acceptance of reality Increased Faith in god	Non acceptance Lost faith in god	Disappointment Fear Hopelessness Anxiety  Fear Hopelessness	Isolation Unhappy	Good Family support
<b>Participant 2</b>	43	Rs >10000/-	>2 yrs	Psychological Physical Social	82.7% 80.6% 75%	90%	“My feelings was not good. I hated this world. I thought I don’t want this life.” I cannot accept this diagnosis because this is my child. How can I accept this. What I will tell.....what was the condition.....vomiting....crying....my god!!!!!!! I was too sad. I am a rich person there for I have no problems with financial aspects of treatment. My mother helped me. Our family members recognized our child cancer. There for everybody accepted the situation. I was not liking any gathering ; without happiness .....what is social gathering????????? My faith is same not increased ....not less. I hope that my child will be cured. At first I felt that hopelessness then I became to normal life.					
<b>Participant 3</b>	34	Rs 4000/-	6 months – 1 year	Psychological Physical Social	69.2% 83.33% 31.3%	100%	“ I was tensed and worried. I was angry with my husband and family members.” First I didn’t accept this diagnosis after that with the help of my family members.....I accepted this situation, even now I am not able to think about my child’s diagnosis. I am afraid even to it to my mind about the treatment. I am a rich person there for I have no problems with financial aspects of treatment. My family is a joint family. So we were one in all things. My family is my strength , so I had no bad experience. I was not liking any gathering ; without happiness .....what is social gathering????????? I was not interested in prayer. I don’t know. At first I felt that hopelessness then I became to normal life.					

**Interpretation:** A meta-matrix approach was used for analytic integration of quantitative and qualitative strands. Data from qualitative and quantitative strands were arrayed in the form of a 12×3 column vs. row outline matrix. The rows represented each subjects (3) and columns(12) represented qualitative and quantitative variables.

### Meta inference

In this study Meta inference of 3 samples are included. All mothers of children with cancer are facing problems in the area of physical, psychological, social relationships and spiritual. Based on the semi structured interview it was found that all the mothers (3) lived experience was poor (30%). Psychological (82.7%) was faced by the majority of the mothers of children with cancer followed by physical problem (80%), social relationship (75%) and spiritual (50%) problems. Lived experience of primary care givers was collected through audio recording and analysed. Different themes and subthemes were formed. The themes were as follows, life style changes positive attitude towards life, negative attitude towards life, psychological issues and family support . It was also found that majority of the mothers felt need about their child with cancer was 100%.

From this study we found that, having child with cancer and caring for the child is a very stressful job for the mothers. Psychologically the mothers go through various emotional turmoil. The mothers felt need, needs to be assessed and addressed accordingly & she needs to be supported psychologically. Additionally information on care of child with cancer should be provided adequately to reduce the burden on the mothers

### DISCUSSION

In the present study, almost subjects had belongs to age group of(40%) of mothers were in the age group of 25-30yrs & least (10%) were in the age group of 41-

15 yrs . (40%) of mothers were availing treatment from health care center at a distance of 11-20kms & least (10%) were mothers were availing treatment from health care center at a distance of >30kms. Majority (70%) of sample had their family income >Rs10,000/- & least (10%) of sample had their family income Rs5,000- Rs 7000/-. half (50%) of sample had their family member affected with cancer. Majority (70%) of sample had information on cancer from health personnel & least (10%) of sample had information on cancer from health awareness programs.

Majority (40%) of children were diagnosed with ALL & AML & least (20%) of children were diagnosed with wilms tumor. (70%) of children received only chemotherapy & least (10%) of children were treated with surgery and chemotherapy. 30% of the children with cancer reported to have school dropouts.

Korean studied reported that 56.5% of the mothers of children with cancer were in their 30's with an average age of 34.7yrs. 97% were married & well educated. 85% reported to be full time housewives. Their level of income ranged from \$ 318 to \$ 4545. 45% of children with cancer were diagnosed to have leukaemia & 90% of them received chemotherapy. This study was found to be consistent with the current study.<sup>[7]</sup>

In the present study shows that majority (40%) of Mothers of children with cancer had moderate QOL & (30%) had poor & good QOL. QOL score is highest in the care related area (78.5%) with mean±SD of 15.7±2.5 whereas least in the area of financial & spiritual (64.37%) with mean±SD of 10.3±4.6 . majority of mothers felt needs of their children with cancer was highest (100%) in future condition, therapeutic choices, basic needs, doctors consultation, services from hospital, spiritual advice & abandoned within the society & least (70%) in need of economic help.

A descriptive correlational study was conducted in Tabriz children's hospital Iran

. The study evaluated resilience and its predictors among 400 parents of children with cancer. A demographic questionnaire and Connor Davidson resilience scale were used to collect the data which was analysed using SPSS 16. The results showed that mean score of parents resilience was  $66.83 \pm 14.28$ . The study concluded that mothers of children with cancer had low resilience & may be at risk for different physical & mental health problems. Health care providers need to identify at risk parents & provide psychological & educational support. [8]

Psychological distress among mothers of children with cancer was assessed in Chennai which reported 47.9% of mothers to have moderate intrusion, 49.3% to have severe & 2.8% to have extreme intrusion. [9]

A study was conducted to assess the Impact of Caring for a Child with Cancer on Parents' Health-Related Quality of Life in Canadians among 411 respondents recruited from five pediatric oncology centers. Parents completed a questionnaire on adult QOL (SF-36), a measure of child health status (functional status IIR), and questions to assess health-promoting self-care actions (eg, sleep, diet, and exercise habits) and child characteristics with cancer (eg, relapse status, time since diagnosis, prognosis, treatment intensity). Parents of children with cancer reported poor physical and psychosocial QOL in all psychosocial domains (effect sizes range,  $-0.71$  to  $-1.58$ ) and in most physical health domains (effect sizes range,  $-0.08$  to  $-0.63$ ). Parent reported better parental QOL in better eating, exercise and sleep habits, younger age, and higher income. Child reported better parental QOL with better child health status (functional status IIR scores), lower treatment intensity, and longer time since diagnosis. [10]

Present study shows that there was no significant association between QOL and selected demographic variables & mothers felt needs of children with cancer and selected demographic variables. However  $r$  was 0.77 at  $p < 0.01$  which concludes that

there was a strong positive correlation between Quality of life of mothers & mothers felt needs of children diagnosed with cancer

A study conducted in Asia Pacific, shows that there were no significant association between the problems of mothers of children with cancer (caregivers strains such as; social, economic, cultural and medical) and selected demographic variables. [3]

In the present study lived experience of mothers of children with cancer was identified by with the help of semi structured interview. Through the thematic analysis the themes were life style changes positive attitude towards life, negative attitude towards life, psychological issues and family support. It was also found that majority of the mothers felt need about their child with cancer was 100%.

All mothers of children with cancer are facing problems in the area of physical, psychological, social relationships and spiritual. Based on the semi structured interview it was found that all the mothers (3) lived experience was poor (30%). Psychological (82.7%) was faced by the majority of the mothers of children with cancer followed by physical problem (80%), social relationship (75%) and spiritual (50%) problems. Lived experience of primary care givers was collected through audio recording and analysed. Different themes and subthemes were formed. The themes were as follows, life style changes positive attitude towards life, negative attitude towards life , psychological issues and family support . It was also found that majority of the mothers felt need about their child with cancer was 100%.

A study on Stressors and Coping Strategies of Mothers Having Children with Cancer in Mansoura found that most of mothers of cancer children (86.4%) suffered from psychological stressors followed by financial stressors, stressors related to treatment, physical stressors and social stressors (83.5%, 74. 74.8%, 52.4%, 5.8% respectively), most of them (68.9%) used

emotional coping strategies and highest percentage of them (78.6%) used problem solving coping strategies. <sup>[11]</sup>

Results of a study conducted in Pune, coping strategy used by the mothers of children with leukaemia showed 71.7 % of the mothers of children with leukaemia are having poor coping strategies. The mothers have used both problem solving and emotional coping strategy equally as follows, seeking support (5.33±0.75), then emotive coping strategy (4.8±1.30), Acceptance (2.9±0.51), Avoidance (2.5±0.64) Distancing (1.9±0.87) then positive action (1.6±1.2). <sup>[12]</sup>

## CONCLUSION

The study concluded that around 40% of mothers had moderate & 30% of mothers had poor quality of life. Study also highlighted the mothers felt needs which clearly indicate the need to take up interventions to address their concerns.

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