

A Study to Extrapolate the Lived in Experience of Parents of Children with Chronic Illness in SRM General Hospital, Kattankulathur

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ABSTRACT

A study to extrapolate the lived in experience of parents of children with chronic illness was conducted to explore the lived in experience of parents of children with chronic illness in hospital and to extrapolate the various dimensions of parents of children with chronic illness. Research design was qualitative in nature, and the research approach adopted was phenomenological approach. The tool used for data collection had 2 parts, part A Demographic variables and Part B Interview schedule with open ended question. The main study was conducted in S.R.M General Hospital and Research Centre, Kattankulathur on 10 samples who fulfilled the inclusion criteria. Under the dimension of physical well being, majority of the parents had sleep pattern disturbance, irregular dietary intake and altered health maintenance. Under the psychological dimension majority of parents fear about child's future and expressed anxiety regarding pain underwent by child. Under the behavioral dimension, the data reported that most of parents gets angry either at work place or home, and irritable. Under the spiritual dimension all the parents have faith in god, and conduct prayer. Under the social dimension most of parents have good and normal social relationship, receives emotional support from the relatives. Regarding economical dimension majority of parents had financial difficulties and of them are selling valuables for the treatment. Under dimension of health service, most of the parents are satisfied with the hospital service. Nursing professionals are the first line response to parents. This study allowed the participants to express their feelings and problems. At the end of the study investigator motivated participants to go for periodic counselling.

Keywords: chronic illness

INTRODUCTION

Chronic illnesses are disease that persists for a long time. A chronic condition is a human health condition or disease that is persistent or otherwise long lasting in its effects or a disease that comes with time¹. Chronic condition is an "umbrella" term. Children with chronic illnesses may be ill or well at any given time, but they are always living with their condition. Chronic illnesses includes diabetes, cerebral palsy, epilepsy, down's syndrome, chronic renal insufficiency and other inherited chromosomal anomalies includes asthma, cancer, juvenile arthritis, dermatitis, leukaemia, cystic fibrosis etc.². There is an increased prevalence of speech and learning difficulties, sensory dysfunction, behavioural problems. The diagnosis of chronic illness causes emotional havoc in the family leading to shock, anger, sorrow etc and for child it is a big challenge. This study investigated the experience of parents who resided in the ward with their child from their perspective. Chronic diseases constitutes a major cause of mortality and the World Health Organisation (WHO) reports chronic non communicable conditions to be by far the leading cause of mortality in the world representing 35 million deaths in 2005 and 60% of all. It was found that in 2012 about 15% to 18% of children in the United States live with chronic health condition. The rate of chronic health conditions among children in the United States

increased from 12.8% in 1994 to 26.6% in 2006, particularly for asthma, obesity and behaviour and learning problems, according to a study published in February 17th issue of the Journal of the American Medical Association⁵. In Chile, a national survey of pediatric nephrologists estimated an incidence of Chronic Kidney Disease (Glomerular Filtration Rate < 30 ml/min/1.73m²) in children aged less than 18 years of 5.7 per million age related population and a prevalence of 42.5 pmparp in 1996. A study on the epidemiology of CKD conducted in several Latin American countries (Argentina, Brazil, Chile, Colombia, Mexico, Uruguay, and Venezuela) showed a wide variation in incidence that ranged from 2.8 to 15.8 new cases per million age related population⁶.

METHODS AND MATERIALS

This study was conducted to explore the lived in experience of parents with chronically ill child and to extrapolate the various dimensions of lived in experience of parents living with chronically ill child. Research Approach was phenomenological approach. Qualitative research design was used. The setting for the study was in paediatric medical and surgical ward of S.R.M General Hospital and Research Centre, Kattankulathur a 1200 bedded hospital. The study population comprised of

parents of children diagnosed with chronic illness. The sample consisted of parents of children with chronic illness

Frequency and percentage distribution of demographic variable of parents of children with chronic illness. N=10

S. No	Age in years	Frequency	Distribution
1	a.15-20	-	
	b.21-25	2	20%
	c.26-30	3	30%
	d.31-35	1	10%
	e.36-40	1	10%
	f.41 and above	3	30%
2	Sex		
	a .Male	3	30%
	b. Female	7	70%
3	Educational status		
	a .Illiterate	-	
	b. Primary school	-	
	c. Middle school	3	30%
	d. High school	4	40%
	e. Intermediate	1	10%
	f. Graduate or post graduate	2	20%
	g. Profession or honours	-	-
4	Occupational status		
	a. Unemployed	4	40%
	b. Unskilled worker	2	20%
	c. Skilled worker	4	40%
	d. Clerical, shop owner, farmer	-	-
	e. Semi profession	-	-
	f. Profession	-	-
5	Income		
	a.Rs.-1520	-	-
	b. Rs. 1521-4555	3	30%
	c.Rs.4556-7593	2	20%
	d.Rs.7594-11361	3	30%
	e.Rs.11362-15187	2	20%
	f. Rs. 15188-30374	-	-
	g. Rs. 30375-	-	-
6	Socio economic status		
	a. Lower	3	30%
	b. Upper class	-	-
	c. Lower middle	6	60%
	d. Upper middle	1	10%
	e. Upper	-	-
7	Religion		
	a. Hindu	7	70%
	b. Christian	2	20%
	c. Muslim	1	10%
	d. Others	-	-
8.	Type of family		
	a. Nuclear	6	60%
	b. Joint	3	30%
	c. Extended	-	-
	d. Broken	1	10%
9	No. Of children		
	a.1	4	40%
	b.2	5	50%
	c.3	1	10%
	d.4 and above	-	-
10	Age of the child		
	a.>1 year	1	10%
	b.1-3 years	4	40%

	c.3-6 years	3	30%
	d.6-12 years	2	20%
	e.12-16 years	-	-
11	Sex of child		
	a. Male	6	60%
	b. Female	4	40%
12	Duration of illness		
	a.>6 months	6	60%
	b.6 months-1 year	2	20%
	c.1-3 years	1	10%
	d.>3 years	-	-
13	Marital status		
	a. Married	9	90%
	b. Unmarried	-	-
	c. Divorced	1	10%
14	Relationship with child		
	a. Father	3	30%
	b. Mother	7	70%
	c. Caretaker	-	-

Frequency and percentage distribution of the physical dimension of parents of children with chronic illness. N=10

S.no	Themes	Subthemes	Respondents (n)	Percentage (%)
1	Sleep pattern	Disturbed	8	80%
		Not disturbed	2	20%
2	Dietary pattern	Regular	3	60%
		Irregular	7	30%
3	Altered health maintenance	Fatigue	5	50%
		Pain (headache, body pain)	2	20%
		Other illness	-	-
		No alteration	3	30%

Frequency and percentage distribution of psychological dimension of parents of children with chronic illness. N=10

S.No	Themes	Sub themes	Respondents(n)	Percentage (%)
1	Fear	Child's future	6	60%
		Education	3	30%
		Losing child	1	10%
2	Anxiety	Chronic illness	4	40%
		Child in pain	4	40%
		Prolonged treatment	2	20%

Frequency and percentage distribution of behavioural dimension of parents of children with chronic illness. N=10

S.no	Themes	Sub themes	Respondents(n)	Percentage (%)
1	Anger	Present	5	50%
		a)family members	1	10%
		b)hospital staffs		
		Absent	4	40%
2	Irritability	Present	7	70%
		Absent	3	30%

who fulfilled inclusion criteria. Non probability-purposive sampling technique was used. The sample size for the study is 10.

The tool used for data collection was interview schedule with open-ended question. It consists of 2 sections. Section A - Structured questionnaire to elicit demographic data of parents of children with chronic illness. It was used to find out the demographic variables of parents of children with chronic illness. Section B - An interview schedule with

open-ended questions were used to explore the lived in experience of parents of children with chronic illness. The proposed study was approved by the dissertation committee of S.R.M College of Nursing, S.R.M University, Kattankulatur. Permission was obtained from the college and setting where the study was conducted. Informed consent was obtained from each participant for the study before starting data collection.

Frequency and distribution of spiritual belief of parents of children with chronic illness. N=10

S. no	Themes	Sub themes	Respondent(n)	Percentage (%)
1	Faith in god	Yes	10	100%
		No	-	-
2	Prayers	Conducted	9	90%
		Not conducted	1	10%

Practical difficulties were identified. The experience of pilot study assured the investigator's confidence to move with the final study. The investigator had collected data within three days with effect from 25.04.2015 to 30.04.2015. Formal approval was obtained from concerned department. 10 parents of children with chronic illness who fulfilled the inclusion criteria were selected as samples by using non probability purposive sampling technique. The procedure was explained to each study participants individually with comfort. Each study participants were explained about the purpose of study. The informed consent was obtained from parents to use audiotape to record their lived in experience during the interview. Audiotaped interview were listened to and transcribed into verbatim as soon as possible. The collected data were analysed using Colaizzi's seven-step methodological interpretation approach. The viewpoint of parents were retained. The model selected for this study is Colaizzi's analysis framework.

RESULTS AND DISCUSSIONS

Assessment of demographic variables of parents of children with chronic illness.

This chapter deals with the discussion of results of the data analysed based on the objectives and purpose of the study. The problem stated is "A study to extrapolate the lived in experience of parents of children with chronic illness in hospital". The study was conducted with 10 parents of children with chronic illness admitted at S.R.M General Hospital, Kattankulathur, and Tamil Nadu.

Regarding the demographic variables

Regarding the age distribution of parents of chronically ill child 2(20%) of them are between the age of 21-25, 3(30%) of them between 26-30, 1(10%) between 31-35, 1(10%) between 36-40 and 3(30%) of 40 and above. Regarding the sex of the parents, 3(30%) of the parents are male and 7(70%) of them are female. Considering education, 2(20%) of parents are illiterate, 1(10%) among them had middle school education, 4(40%) among them had high school education, 1(10%) had intermediate education and 1(10%) did graduate and postgraduate education. Considering the occupational status, 4(40%) of them are unemployed, 2(20%) are unskilled worker and 4(40%) of them are skilled worker. Regarding the monthly income, 3(30%) of them are between Rs.1521-4555, 3(30%) between Rs 7594-11361 and 2(20%) between Rs 11362-15187. Considering the socio economic status, 6(60%) of them belong to lower class, 3(30%) belong to lower middle class and 1(10%) belong to upper middle class. With respect to religion, 7(70%) of them are Hindu, 2(20%) of

them are Christian and 1(10%) of them is Muslim. The data revealed that, 6(60%) of them belongs to nuclear family, 3(30%) of them belong to joint family and 1(10%) belong to a broken family. Data revealed that 4(40%) of them have 1 child, 5(50%) of them have 2 children and 1(10%) of them have 3 children. Considering the age of the child, 1(10%) among them is less than 1 year, 4(40%) of them are between age group of 1-3 years, 3(30%) of them are between 3-6 years of age and 2(20%) of them are between 6-12 years of age. Regarding sex of the child, 6(60%) of them were male and 4(40%) of them were female. Considering the duration of illness, 6(60%) of them are sick for less than 6 months, 2(20%) of them for 6 months to 1 year and 2(20%) of them for 1-3 years. Considering the duration of marriage, 9(90%) of them are married and 1(10%) of them are divorced.

Considering the relationship with child, 7(70%) of them are mother and 3(30%) of them are father.

The first objective of the study was to explore the lived in experience of parents of children with chronic illness

The investigator explored the lived in experience of parents of children with chronic illness by conducting audio taped interview. The investigator identified various dimensions such as physical, psychological, behavioural, spiritual, social, economical and health care services. Under each dimension, Sub themes were formulated based on their lived in experience.

Under the physical dimension, sleep pattern disturbance, irregular dietary pattern and altered health maintenance were identified as major stressors for the parents. Regarding to psychological dimension, fear and anxiety were present among parents of children with chronic illness. With regard to changes in behaviour, and anger and irritability were identified as stressor for the parents.

Regarding to spiritual dimension sub themes like faith in god and conduction of prayer were identified by investigator. Under social dimension investigator identified that, there is good social relationship and the relationship with relatives are also satisfactory. Under economical dimension majority of parents had financial difficulty, sold valuables. Under dimension of health service rendered majority of parents were satisfied.

The second objective of the study was to extrapolate the lived in experience of parents of children with chronic illness.

Physical Dimension

The sub themes are sleep disturbance, irregular dietary pattern and altered health maintenance.

Majority 8(80%) of the parents had disturbed sleep pattern and 2(20%) of them have undisturbed sleep. Majority of parents 7(70%) of them have irregular sleep pattern and 3(30%) of them have regular sleep pattern. Majority of the parents 7(70%) reported altered health maintenance, out of which 5(50%) of them had fatigue, 2(20%) of them had pain (headache, body pain) and 3(30%) of them had no alteration in their health. The common statements described by parents were,

Frequency and percentage distribution of social dimension of parents of children with chronic illness.

N=10

S.no	Themes	Sub themes	Respondent(n)	Percentage (%)
1	Social relationship	Good	5	50%
		Normal	2	20%
		Poor	3	30%
2	Support from relatives	Financial support	2	20%
		Emotional support	6	60%
		No support		
			2	20%

Frequency and percentage distribution of economical dimension of parents of children with chronic illness.

N=10

S.no	Themes	Sub themes	Respondents(n)	Percentage (%)
1	Financial difficulty	Present	7	70%
		Absent	3	30%
2	Monetary loss	Selling valuables	3	30%
		Not selling valuables	7	70%
3	Debts	Present	5	50%
			5	50%

Frequency and percentage distribution of dimension of health services of parents of children with chronic illness.

N=10

S.no	Themes	Sub themes	Frequency(n)	Percentage (%)
1	Satisfaction	Satisfied	8	80%
		Somewhat satisfied		
		Not satisfied	1	10%
			1	10%

“Baby next to my child’s bed keeps on crying at night”. “I am eating properly”. “Hospital food is not good”. “I feel tired”.

Psychological dimension

The subthemes are fear and anxiety.

Majority of parents 6(60%) have fear about their child’s future, 3(30%) of them about the education of their child and 1(10%) of them have fear of losing the child. 4(40%) of the parents were anxious about the illness, 4(40%) of them expressed anxiety by seeing their child in pain and 2(20%) of them were anxious about the prolonged treatment of the child. The common statements described by parents were, “I don’t know how my child’s future will be” “He is missing his classes, he may have to repeat”.

Behavioural dimension

The sub themes are anger and irritability.

Majority 6(60%) of the parents showed anger out of which 5(50%) of parents showed anger on family members whereas 1(10%) showed on hospital members. 4(40%) of them didn’t show any anger. Majority 7(70%) of parents showed irritability, and irritability was absent in 3(30%) of the parents. The common statements described by parents were, “I shout at my wife”. “I get irritated when people continuously ask about my child’s condition. “My behaviour is fine”

Spiritual dimension

The sub themes are faith in god and conduction of prayer.

All the parents 10(100%) had faith in god. Majority of the parents 9(90%) conducted prayer whereas 1(10%) of them didn’t conduct the prayer. The most common statements described by parents were “I have total faith in him”. “I pray for my child everyday”. “I believe in God”

Social dimension

The sub themes are social relationship and relative’s support. 5(50%) of the parents had good relationship with society, 2(20%) of them had normal relationship and 3(30%) of them had poor social relationship. 2(20%) of the parents received financial support from relatives, 6(60%) of them got emotional support from relatives and 2(20%) of them were not supported by relatives at all. The most common statements described by parents were, “I have good relationship with people”. “My relationship with relatives is not that good”

Economical dimension

The sub themes are financial difficulty, debts and monetary loss. Majority 7(70%) of the parents had financial difficulty, 3(30%) of them didn’t have any financial difficulties. 3(30%) parents had sold their valuables and the remaining 7(70%) hadn’t. 5(50%) of parents have debts for the treatment and 5(50%) of them had no debts. The most common statements described by parents were, “ We’re managing it somehow”. “I’ve mortgaged my jewellery for money”.

Dimension of health care service

The sub theme is parental satisfaction. Majority 8(80%) of the parents are satisfied with the health service provided, 1(10%) of them are somewhat satisfied and 1(10%) of them are not satisfied. The most common statements described by parents were, "They take care of my child properly. "Doctors are good". "I am happy with the service". Shields et al (2008) suggested that parents could serve as a link between their children and the staff; in addition it can assist in relieving the children's anxiety and providing a sense of security.

Limitations

The investigator felt difficulty in finding the literatures related to lived in experience of parents of children with chronic illness.

The investigator felt difficulty in finding national statistics related to chronic illness in children

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