

A Qualitative Study to Assess the Stressful Factors and the Coping Strategies of Parents of Children Living with Cancer Admitted in a Selected Hospital in New Delhi

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Abstract: *A qualitative study to assess the stressful factors and the coping strategies of parents of children living with cancer admitted in a selected hospital in New Delhi. Phenomenological research design was used in the study. Unstructured interview guide with trigger questions were developed. Sampling technique employed was Purposive sampling. Samples were parents who were taking care of their children with cancer for a period of 6-12 months. Sample size was based on the saturation of data which was achieved after interviewing 9 parents of children with cancer. Data was collected using in-depth interviews which was a kind of self-reporting method. The in-depth individual interviews were recorded in an audio-recorder and transcribed and translated from Hindi to English. Data was analyzed using thematic analysis and there was emergence of themes, sub-themes and categories. It can be concluded that Parents of children with cancer have the daunting task of both parenting and caring for their child with cancer. The diagnosis and treatment services need to be more accessible to families all over the country as these further compounds to the distress and anxiety among the parents of children with cancer.*

1. Introduction

Cancer is the Latin word for crab. The ancients used the word to mean a malignancy, doubtless because of the crab like tenacity a malignant tumor sometimes seems to show grasping the tissues it invades. Cancer, a life threatening illness, is an abnormal growth of cells which tends to proliferate in an uncontrolled way and in some cases, to metastasize (spread) [1].

Cancer biology is extremely complex. Cancer is initiated when genetic material DNA within a body cell is damaged and mutates. The next stage, 'promotion', involves expression of these damaged genes, leading to uncontrolled proliferation of abnormal cells. A variety of biological factors, including genetic makeup, diet, smoking, virus, infection, exposure to certain chemicals, hormones, etc. are all known to contribute to some form of cancer. Whether psychological variables can directly contribute to some form of cancer remains unclear. Most cancer start off in a localized 'primary site' and then, unless controlled either by host defenses or medical treatment, spread to produce 'secondary's' or 'metastases' in other parts of the body. As well as being classified as primary site, cancers are divided into different 'histological' types on the basis of their cell composition [1].

According to WHO Report (2016) [2], worldwide, approximately, 215,000 cancers are diagnosed per year in those younger than 15 years with an estimated 80,000 cancer related deaths in these annually.

In India, 1.6–4.8% of all cancers are seen in children below 15 years of age, and incidence rate for India ranges from 38

to 124 per million children per year [3]. The Indian Council of Medical Research started National Cancer Registry Programme with a network of cancer registries across India in December 1981. Currently, there are 29 PBCRs in India under National Cancer Registry Programme (NCRP) [4].

Chronic illness of childhood affects the parent's quality of life [5]. The family is required to adapt to a new situation that involves long hospitalizations, aggressive therapy, many losses, and changes in family relationships and routines that may hinder the child and the family in performing tasks inherent to the developmental process [6]. Even with advancements achieved to prolong life, childhood cancer is still associated with death, incurability, loss, and suffering [7].

Parents have their role extended in the context of pediatric care: they need to provide the emotional responses of the patient and siblings, moderate their own emotions, establish satisfactory communication within the medical-hospital context, adapt to family routines, deal with potential relapses, deal with expectations, care for the child's wellbeing, and pay attention to medication, handle interferences and side effects, establish protective care, and accompany the child on medical consultations, hospitalizations and for invasive exams [8].

2. Material and Method

To explore the stressful factors and the coping strategies of parents of children living with cancer, the research approach used for the study was Qualitative Approach. Unstructured interview guide with trigger questions were developed. Sampling technique employed was Purposive sampling.

Volume 9 Issue 2, February 2020

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Samples were parents who were taking care of their children with cancer for a period of 6-12 months. Sample size was based on the saturation of data. The study was conducted in inpatient oncology unit of Selected Hospital of New Delhi. Participation in the research study was entirely on a voluntary basis. Data was collected using in-depth interviews which was a kind of self-reporting method. The tool had been developed under three sections: Subject data-sheet, In –depth interview guide, Record of interviews. The in-depth individual interviews were recorded in an audio-recorder and transcribed and translated from Hindi to English. Data was analyzed using thematic analysis and there was emergence of themes, sub-themes and categories.

Data collection procedure

Data was collected from the parents of children living with cancer admitted in Selected Hospital of New Delhi for a period of 1 month. The parents were selected using purposive sampling technique. The researcher introduced herself to the participants and intimated them about the purpose of the study along with the proper channel of permission to do so. The type of interview employed for the current study was unstructured interview. The unstructured interview consisted of five broad questions which were guided by trigger questions. Each interview was approximately of 30 minutes each. After conducting interview through in–depth unstructured interview schedule and written description of specific experiences in diaries, audio-recordings of the data and making transcripts of the audio recordings, the researcher planned to do data analysis through thematic analysis.

3. Result and Discussion

In the present study 9 parents of children with cancer were interviewed. The findings showed that out of the 9 parents of children living with cancer, 7 were females and two were males with a mean age of 32yrs. It showed that out of 9 children, 1 was female and the remaining 8 were male. The mean age was 6yrs.

The analysis of the data procured from the in-depth interviews with the parents of children living with cancer led to the emergence of various themes, sub-themes and categories developed on the basis of five broad research questions.

In the present research study it was found that there was lack of acceptance of the illness among the parents of children living with cancer. For the parents being told their child is diagnosed with cancer came as shock and was hard to believe. This is in congruence with the finding of Karine A et al [9] which showed lack of acceptance among the parents of children living with cancer.

Lack of knowledge about cancer in a child, its treatment, and its complications among the parents of children living with cancer derived as an important theme in the present study.

This finding is consistent to one of the findings of a study conducted by ReisiDehkordi et al [10] in Iran which showed inadequate knowledge regarding cancer among mothers of a child with cancer, and it was concluded that the parents who know about the disease and its complications, faced fewer conflicts in overcoming the problems encountered and managing the circumstance.

Financial costs for treating childhood cancer care are not only the diagnostic cost and that of the hospitalization but also the costs for travel, accommodation, for food, phone bills, and loss of income due to reduction or termination of parental employment. Similar study conducted by Singh G et al [11] in Chandigarh revealed in the area of financial burden that half of the parents were having severe burden, 80 (43%) had moderate and others 12 (7%) low financial burden.

It was important to note there was a sense of strength and comfort when the mothers spoke of the support from their family members, even though it was only telephonic contact. This is undeviating with the findings of Fletcher et al [12] who found that social support provided by the family members is a strong pillar to coping with the illness among the parents having a child diagnosed with cancer.

Table 1: Themes, Sub-themes and Categories Emerged in the Study, n=9

| S.No. | Themes | Sub-themes | Categories |
|-------|--|---|---|
| 1. | What are your experiences as a parent having a child diagnosed with cancer? | | |
| | 1.1 Perception towards Cancer | 1.1.1 Lack of Awareness 1.1.2 Delay in Diagnosis inspite of seeking Doctor's advise | 1.1.1.1 Misconceptions about cancer 1.1.1.2 Knowledge regarding treatment modalities |
| | 1.2 Lack of Acceptance of illness | 1.2.1 Disbelief over occurrence of illness | |
| 2. | How has life changed while living with, and caring for your child with cancer? | | |
| | 2.1 Problems Encountered | 2.1.1 Detrimental effects of Oncology treatment 2.1.2 Desertion by significant others 2.1.3 Disrupted family Dynamics 2.1.4 Stigmatization about the illness | |
| | 2.2 Feeling of Despair | 2.2.1 Initial Response to the Diagnosis 2.2.2 Apprehension about the future 2.2.3 Fear of the unknown | |
| | 2.3 Responding to challenges | | |
| 3. | How has the stress (psychological and physiological) associated with cancer interfered with your personal, | | |

| | | | |
|----|---|---|--|
| | social and occupational life? | | |
| | 3.1 Disrupted Personal Life | 3.1.1 Self-sacrifice | |
| | 3.2 Disordered Occupational Life | | |
| | 3.3 Disturbed Social Life | | |
| 4. | How has it affected your financial aspects? | | |
| | 4.1 Financial Burden | | |
| 5. | What coping resources you have used and still using to cope with the current situation? | | |
| | 5.1 Coping with the illness | 5.1.1 Faith in God 5.1.2 Adaptation 5.1.3 Social support 5.1.4 Relaxation can help | |

4. Conclusion

All the parents stated that having a child with cancer is a bitter experience on account of the varied experiences related to the initial diagnosis, disruption in the personal and social factors and the added financial burden. Even today in spite of the tremendous efforts on awareness programmes there still is a strong stigma attached to cancer. All the parents had strong faith in God in spite the burden encountered by them. Parental knowledge about childhood cancer and its treatment may help in allaying disease-related threat and make them more confident.

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