

# Knowledge and Perception on Chemotherapy among Parents of Children Undergoing Chemotherapy in a Cancer Hospital, Guwahati, Assam

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## **Abstract**

Cancer is a group of diseases characterized by abnormal cell proliferation. Childhood cancer is thought to have unknown causes. The most prevalent forms of the childhood disease are leukemia, lymphomas, malignancies of the brain and other central nervous systems, neuroblastoma, Wilms tumor, retinoblastoma, and bone cancer (including osteosarcoma and Ewing sarcoma). Chemotherapy is frequently administered in conjunction with other treatments, such as radiation therapy and surgery, although it might be the only course of treatment. Chemotherapy can be distressful to both the children and the parents as it can bring about various side effects. Being aware of possible side effects allows parents to monitor their child's condition closely and seek prompt medical attention if necessary. Also, Understanding the treatment process helps parents set realistic expectations about the course of treatment and the potential outcomes. The purpose of the present study is to increase our understanding of parents' knowledge and perception that they are having regarding chemotherapy which will ultimately allow health workers to respond to their needs. It is very important to quickly identify and respond to the negative perception of families to minimize the negative effects of the stressor, allowing families to focus on patient care.

## **BACKGROUND:**

Cancers are a group of diseases associated with abnormal growth of cells. Without any check, the disease may keep on progressing ultimately leading to pre-mature death. They can arise anywhere in the body and can affect people from all age groups, socioeconomic strata and race. Childhood cancer is usually defined as a malignant disease that is diagnosed up to 16years of age and results when the body fails to regulate cell production, and occurs a proliferation and spread of abnormal cells (Michel et al. 2010).

Childhood cancers rank ninth as a leading cause of childhood diseases at the global level, accounting for 11.5 million of the Disability Adjusted Life Years (DALYs').<sup>[1]</sup>

Based on the Global Burden of Disease Study 2019, 91,319 new cases and 98,834 (86,124 to 113,581) deaths from childhood cancer were documented globally<sup>[2]</sup>. In India, according to a recent report of the National Cancer Registry Programme, the proportion of childhood cancers (0-19 years) relative to cancers in all age groups was found to range from 1% to 4.9%. As per Hospital based cancer registry (HBCR) report 2018-2019 of Dr B Borooah Cancer Institute, Guwahati Assam, a total of 274 numbers of new childhood cancer were registered out of which 53.4% were boys and 46.6% were girls.

Chemotherapy is a cancer treatment where medicine is used to kill cancer cells. The causes of childhood cancer are unknown and the most common types of childhood cancer are leukemia, lymphoma (including both Hodgkin and non-Hodgkin), brain and other central nervous system tumors, neuroblastoma, Wilms tumor, retinoblastoma, bone cancer (including osteosarcoma and Ewing sarcoma (Hockenberry and Wilson, 2011; Pillitteri and Funk, 2007) <sup>[3]</sup>

The mothers play important roles where children with cancer are often limited in their opportunities to develop independence and autonomy, the limitation come from restrictions placed by treatment regimens and therapy related complications; therefore, mothers can promote their children to be more comfortable through prevention of infection, regular activity, skincare, emotional support. So that mothers should be informed in a manner that can understand the nature of the disease, its causes, treatment, complication and prognosis (Elsayed and Mahmoud, 2012) <sup>[4]</sup>

Cancer is a life-threatening illness that involves emotional distress, fear of the unknown and changes in life priorities for the child and family. It is at a significant risk of depression for parents because of the lack of knowledge, wrong perception, frequent stressful diagnostic tests, treatments and side effects of treatments. Therefore, this study is aimed at assessing the knowledge and perception of chemotherapy among parents of children undergoing chemotherapy in a cancer hospital of Guwahati, Assam.

### **NEED OF THE STUDY**

Parents can handle their reactions of having a child with cancer by seeking information and gaining knowledge about the diagnosis and its treatment. It has been suggested that this is a way for parents to restore order in a chaotic existence. The purpose of the present study is to increase our understanding of parents' knowledge and perception that they are having regarding chemotherapy which will ultimately allow health workers to respond to their needs. It is very important to quickly identify and respond to the negative perception of families to minimize the negative effects of the stressor, allowing families to focus on patient care. Parents will always play a decisive role in child care; they directly interact with sick children and deal with related problems and challenges. Therefore, we need to know what knowledge and perception they have about chemotherapy in order to provide them, together with the healthcare institution, with full support and help the child.

The assessment of knowledge and perception of families, is of great importance as it enables the prediction of psychosocial risk and potential stress.

As I went through various review of literatures, I found no such comprehensive work which was dedicated to my objectives in the north eastern region of India. General research on assessing knowledge and perception of parents whose child is undergoing chemotherapy is still at its infancy.

So, I believe my study will help in conducting a systematic view to buildup new evidence on the current title.

### **STATEMENT OF THE RESEARCH STUDY:**

A Study to assess the Knowledge and Perception on chemotherapy among parents of children undergoing chemotherapy in a cancer hospital, Guwahati, Assam.

### **OBJECTIVES**

#### **Primary objective:**

1. To assess the knowledge on chemotherapy among parents of children undergoing chemotherapy.

2. To assess the perception on chemotherapy among parents of children undergoing chemotherapy

**Secondary Objective:**

1. To find out the association between the knowledge on chemotherapy among parents of children undergoing chemotherapy with the demographic variables.
2. To find out the association between perception on chemotherapy among parents of children undergoing chemotherapy with the demographic variables.
3. To find out the correlation between knowledge and perception on chemotherapy among parents of children undergoing chemotherapy

**OPERATIONAL DEFINITIONS:**

**ASSESS -**

- According to oxford dictionary “it means to evaluate the nature or quality”.
- In this study, it means to evaluate the knowledge and perception of chemotherapy among parents.

**CANCER -**

- According to WHO, cancer means a large group of diseases that can start in almost any organ or tissue of the body when abnormal cells grow uncontrollably, go beyond their usual boundaries to invade adjoining parts of the body and/or spread to other organs.
- In this study, cancer refers to the disease that the children are having for which they are taking chemotherapy treatment.

**CHEMOTHERAPY -**

- According to medical dictionary, chemotherapy is the treatment of disease by the use of chemical substances, especially the treatment of cancer by cytotoxic and other drugs.
- In this study, chemotherapy refers to the treatment that the children are getting as a treatment for cancer.

**PARENTS -**

- According to oxford dictionary, parent means “a person’s father or mother.”
- In this study parents refer to either mother and father of the children undergoing chemotherapy irrespective of age in a cancer hospital of Guwahati, Assam.

**CHILDREN-**

- According to UNESCO, child is every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.
- In my study, children refer to patients with age group 1- 18 years who are receiving chemotherapy in IPD and OPD in BBCI, Guwahati, Assam

**KNOWLEDGE -**

- According to oxford dictionary, knowledge refers to “the information, understanding and skills that you gain through education or experience.”
- In this study, knowledge refers to the information and understanding of parents about chemotherapy which will be assessed by section B.

**PERCEPTION-**

- According to oxford dictionary, perception means “an idea, a belief or an image you have as a result of how you see or understand something.”

- In this study, perception refers to the idea that the parents carry about chemotherapy which will be assessed by section C

**ASSUMPTION OF THE STUDY:**

In conducting this study, the following assumptions are made. It is assumed that

- The parents in the study may have some knowledge regarding chemotherapy.
- The parents in the study may have some idea and perception of effectiveness of chemotherapy.

**HYPOTHESIS**

**H1** -There is significant association between knowledge about chemotherapy among parents with children undergoing chemotherapy and selected demographic variable.

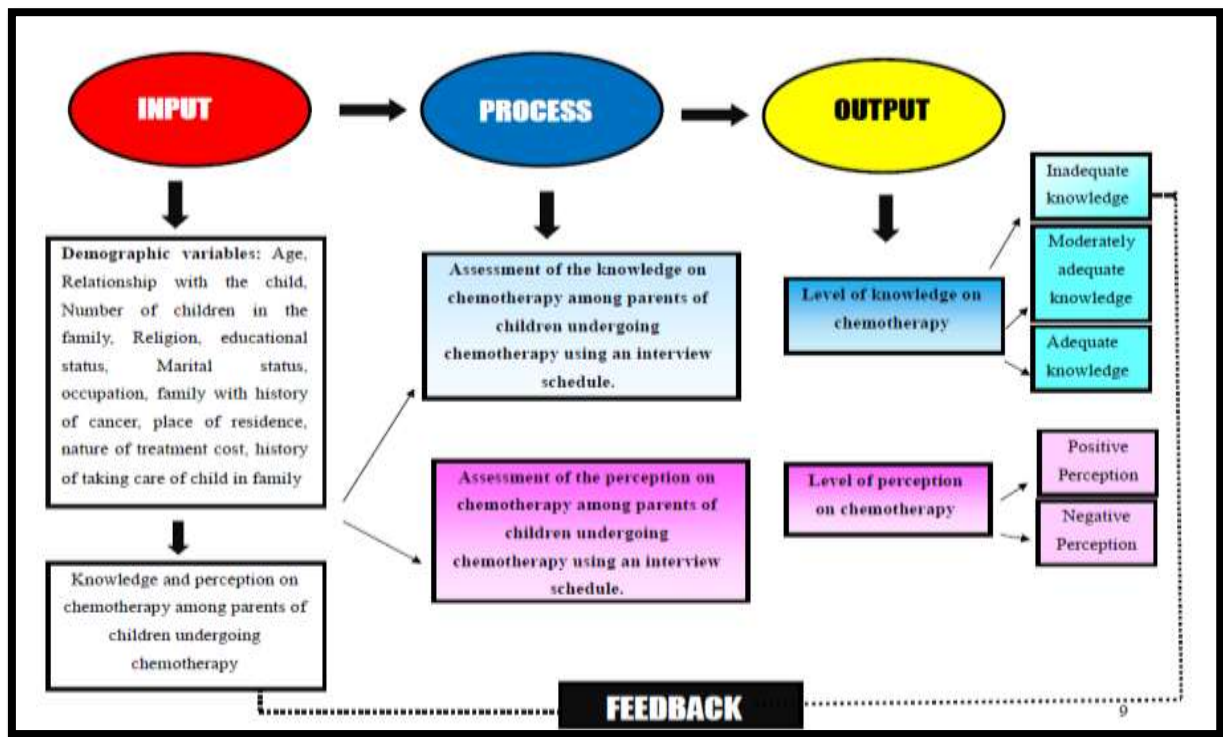
**H2** – There is significant association between perception about chemotherapy among parents with children undergoing chemotherapy and selected demographic variable.

**H3** - There is significant association between knowledge and perception among parents with children undergoing chemotherapy and selected demographic variable.

**VARIABLES:**

- **Research variables:** Knowledge and Perception of parents of children undergoing chemotherapy.
- **Demographic variables:** Age, Gender, Religion, educational status, Socio- Economical status, Marital status, occupation, family with history of cancer, place of residence.

**CONCEPTUAL FRAMEWORK**



**DELIMITATION**

The study is delimited to the parents whose child is receiving chemotherapy at cancer hospital, Guwahati and who are between the age group of 1 to 18 years of age.

## **REVIEW OF LITERATURE**

1. Roug LI, Jarden M, Wahlberg A, Hialgrim LL, Hansson H (2023) conducted a study using Ethnographic fieldwork comprising participant observation and semi-structured interviewing analysed using qualitative thematic analysis. This study contributes to a deeper understanding of the varying experiences of children and adolescents and their parents in managing different care tasks for a child or adolescent with cancer. It underscores the need to establish clear expectations of parents as caregivers throughout the cancer treatment trajectory.<sup>[5]</sup>
2. Natalie T, Anja K, Sue Z, Araby S, Rikesh P, Priya Pet.el (2021) conducted a study to describe the experiences and perspectives of parents of pediatric patients with acute lymphoblastic leukemia (ALL) regarding oral chemotherapy administration during maintenance therapy. And it was found that Oral chemotherapy administration during ALL maintenance therapy was hard for some parents. Identification of these parents and discussion of strategies to facilitate adherence to oral chemotherapy regimens may optimize patient outcomes.<sup>[6]</sup>
3. Wiebke Stritter, et al (Jan, 2021) conducted a study to assess the Perception of integrative care in pediatrics oncology—perspectives of parents and patients in Germa University Hospital. Its results were as Parents and families intuitively developed strategies for dealing with crisis situations such as childhood cancer. In addition, many of the families brought with them a wealth of experience in complementary medicine. Parents perceived the integrative care treatments as soothing, relaxing and pain-relieving for their child. Patients could relax and side effects of chemotherapy were alleviated. However, children, who were undergoing chemotherapy were not always open for physical touch and thus sometimes also rejected the treatments.<sup>[7]</sup>
4. El Shaima Gamal Hasan, et al (dec,2020) conducted a study to assess the knowledge and performance of mothers having children with cancer undergoing chemotherapy at the paediatric oncology unit at Minia Oncology Centre that is located in Minia city. The current study results concluded that there was an obvious lacking in knowledge and performance of the mothers having children with cancer undergoing chemotherapy. The overall level of mothers' knowledge and performance was unsatisfactory. There were no statistically significant relationships between the total mean scores of mothers' knowledge and performance regarding childhood cancer and chemotherapy and their age, level of education, social status, place of residence, occupation, children's age, gender, and child's rank in the family.<sup>[8]</sup>
5. Nomfundo F Moroe and Kirstie Hughes (Feb, 2017) conducted a non-experimental quantitative study to collect data through questionnaires, one for pediatric oncologists and the other for parents. This study aimed at exploring whether the parents of children undergoing chemotherapy are aware of ototoxic effects of chemotherapy. A convenience sampling strategy was employed to recruit 11 pediatric oncologists and 7 parents from two public hospitals in Gauteng. The questionnaires were analyzed quantitatively, using descriptive statistics. About 55% of paediatric oncologists indicated informing parents about the ototoxic effects of chemotherapy. On the contrary, 71% of parents reported having been informed by paediatric oncologists about the possible hearing loss because of chemotherapy; however, 57% of the children are receiving a combination of cisplatin and cyclophosphamide despite being aware of their ototoxic nature.<sup>[9]</sup>
6. Rajvinder Kaur, Sanjenbam Emon Chanu and Dipti Yashwantrao Sorte (2017) conducted a study to Assess the Effectiveness of Structured Teaching Program on Knowledge Regarding “ Home Management of Side Effects of Chemotherapy” among Parents at cancer research institute, Himalayan hospital, SRHU. It is concluded that structured teaching programme on knowledge regarding

- home management of side effects of chemotherapy was found effective in increasing knowledge of parents of children receiving chemotherapy. <sup>[10]</sup>
7. Doaa Bahig Anwr Akl. Et al ( Dec, 2016) conducted a study to Assess the knowledge and reported practice of mothers having children with cancer and undergoing chemotherapy at inpatient and out-patient departments at Oncology Institute in Mansoura City. Results revealed that, only 14% of mothers had satisfactory knowledge related childhood cancer and chemotherapy .In relation to total reported practice, only 34.0% of the studied mothers had total reported practice related to side effects management of chemotherapy. The study recommended: developing frequent educational training programs for mothers of children with cancer about care of their children who undergoing chemotherapy through updated posters, booklets and brochures and a repeat of this research on a large sample and in various places in Egypt for improving mother's knowledge and practice. <sup>[11]</sup>
  8. Manjusha Nair, Lidiya T Paul and Kusumakumary Parukkutty (Oct 2017- Dec 2017) conducted a study to assess mothers' knowledge of their child's cancer and treatment after initial disease counselling, to examine their attitude and psychosocial responses after a brief period, and thereby assess the effectiveness of the initial counselling. This study indicates that child's disease-related stress and anxiety persist in many parents even after acute period of adjustment to stress is over. A good amount of relevant information about cancer and its treatment can be imparted in simple language even to parents with school-level education, and this may help their psychosocial response in a positive manner. Pain related to injections and procedures is a major concern in parents. Even if prognosis of cancer is good, parents remain vulnerable to psychological distress despite child's stable clinical condition. This reveals the unmet areas of psychological needs of parents for which involvement of counsellor as part of treating team may be beneficial. <sup>[12]</sup>
  9. P Chitra<sup>2</sup> and Vishnu Priya M B (2014) conducted a study to assess the awareness regarding adverse effects of chemotherapy among parents of children attending oncology units of AIMS and the result were as follow regarding the CAE, 4 (6.7%) of the subjects had very poor knowledge, 41(68.3%) had inadequate knowledge and 15 (25%) had adequate knowledge. The highest occurrence of adverse effects was vomiting and the next was alopecia. The other adverse effects reported were fatigue 10(16.7%), diarrhoea 6(10%), colour change in nails 5(8.3%), fever 3(5%), constipation 2(3.3%) respectively. Regarding awareness of cancer and its treatment 27(45%) had inadequate knowledge. <sup>[13]</sup>
  10. Hwaida Moawad Ahmed Ali (2008) conducted a study to assess mothers' knowledge and attitude regarding care of their children undergoing chemotherapy. The study conducted at the paediatric oncology unit in specialized paediatric hospital in Benha, which is the only established known place in Kalubia that provides care to such children. In conclusion, the mothers have good knowledge regarding care of their children undergoing chemotherapy at home, while their knowledge was poor regarding complications, causes/predisposing factors and clinical manifestations of childhood cancer, also care of physical problem that may occur after chemotherapy administration, care during and after chemotherapy administration. The study recommends continuous educational program for mothers to develop their knowledge and attitude regarding care of their children undergoing chemotherapy. <sup>[14]</sup>

## **RESEARCH METHODOLOGY:**

### **STUDY DESIGN:**

Research design is the plan, structure and strategy of investigation to answer the research questions. It is the overall plan or blueprint the researcher selects to carry out their study.

In this study, Research design will be Descriptive co relation Research design.

### **RESEARCH APPROACH:**

Research Approach will be quantitative descriptive approach.

### **SETTING OF THE STUDY:**

The study will be conducted in Dr. B Borooah Cancer Institute, Guwahati, Assam

### **POPULATION:**

In this study, population is the parents of any children with the age group 1 year to 18 years undergoing chemotherapy.

- **Target population** - In this study, target population are all the parents whose children are undergoing chemotherapy.
- **Accessible population** - In this study, the accessible population includes all the parents whose children are undergoing chemotherapy in IPD and OPD in Dr B Borooah Cancer Institute, Guwahati, Assam.

### **SAMPLE AND SAMPLING TECHNIQUE:**

#### **SAMPLE**

In this study, the sample will be all the parents whose children are undergoing chemotherapy

#### **SAMPLE SIZE**

Since my population is known which is 274 childhood cancer as per Hospital Based Cancer Registry 2018-2019, my sample size is 72.

Formula used is  $n = N \times \frac{z^2 \times p(1-p)}{(N-1) + \frac{z^2 \times p(1-p)}{\epsilon^2}}$ , where N= Population = 274, Z= z score = 1.96

P=population proportion=50%

$\epsilon$  = Margin of error= 10%

### **SAMPLING TECHNIQUE:**

Sampling is the process of selecting a representative segment of the population under study.

In this study, the sample technique that will be used is Purposive sampling.

### **SAMPLING CRITERIA:**

#### **Inclusion Criteria:**

- Parents who are available during the time of data collection.
- Parents who are willing to participate in the study.
- Parents who understand and communicate Assamese and English.

#### **Exclusion criteria:**

- Parents whose child is too sick.
- Parents of children receiving chemotherapy who are health care providers or health personnel by profession.

### **SELECTION AND DEVELOPMENT OF THE TOOL:**

Tools were constructed by the researchers after reviewing of the relevant literature and were tested for content validity by 10 experts which include Doctors, nursing faculties and statistician, modification were done accordingly to ascertain relevance and completeness.

The tool consists of 3 sections:

- **Section A:** Demographic Performa
- **Section B:** Knowledge interview schedule
- **Section C:** Perception interview schedule.

### **DESCRIPTION OF THE TOOL:**

The tools were made in English and Assamese language.

**Section A** This section has 10 demographic elements which includes Age, Gender, Religion, educational status, Socio- Economical status, Marital status, occupation, family with history of cancer, place of residence.

**Section B** This section has 20 self-structured questionnaires regarding knowledge on chemotherapy.

**Section C** This section has 24 self-structured questionnaires regarding perception on chemotherapy

### **SCORING:**

**Section A** The scoring for self-structured knowledge questionnaire regarding chemotherapy will be done by the total score obtained in the questionnaire. For each correct answer, a score of 1 will be given to the participants. In case the participants pick the wrong answer or double tick the answer, it will be considered invalid and the scoring will be 0.

Total no of knowledge questionnaire = 20

The maximum score is 20 and the minimum score is 0.

Scoring will be interpreted as follows:

- Inadequate knowledge (Mean - standard deviation)
- Moderately Adequate Knowledge (Mean + Standard deviation) \* (Mean - Standard deviation)
- Adequate Knowledge (Mean + Standard Deviation)

**Section B** The scoring for perception will be done using 5-point Likert Scale. A sum of 24 questions is listed down which are either positive or negative statement and scoring will be done based on it.

### **ETHICAL CONSIDERATION:**

The study has been approved by the Institutional Ethics Committee of BBCI, Guwahati.

Consent forms were given to each participant stating their willingness to participate and that the information in the study records were kept confidential and the clinical charts were housed in Dr. B. Borooah Cancer Institute. Data to be stored securely for a period of 5 years and will made available only to persons conducting the study and to the regulatory authorities. The data will not be made available to another individual unless specific permission is given in writing. No reference will be made in oral or written reports which could link you to the study. Result of the study will not be communicated to the participant unless deemed necessary.

### **PLAN FOR DATA COLLECTION:**

1. A formal approval has been taken from scientific and ethical committee of Dr. B. Borooah Cancer Institute, Guwahati, Assam.
2. Pilot study was conducted prior to the main study after Ethical approval.
3. The participants of the study were selected based on voluntary basis. The participants were identified using participants ID and will be assured that their response will be purely confidential.
4. Participants were selected on the basis of inclusion and exclusion criteria.
5. Verbal and written consent were obtained from all the participants of the study after explaining the purpose and other details of the study.
6. The data collection was administered by using a self-structured questionnaire.
7. Results were analysed and interpreted.

### **PLAN FOR DATA ANALYSIS:**

Data analysis is the systematic organization of the research data and their testing of research hypothesis by using the data.

The data collected through interview schedule were analysed by both descriptive and inferential statistics, which are important to provide substantial summary of results. The analysed data were organized and presented in the forms of tables, bar diagram and pie diagrams. The analysis were made by using the important parameters like percentage, mean, standard deviation, chi-square test.

The plan for data analysis are as follows:

- Frequency and Percentage were used to compute and describe the demographic characteristics of the sample.
- Chi-square test ( $\chi^2$ ) was used to find out the significance of association between knowledge on chemotherapy with demographic variable and perception on chemotherapy with the demographic variables.
- Karl Pearson's coefficient correlation was used to find out the significance correlation between knowledge and perception on chemotherapy among parents of children undergoing chemotherapy
- SPSS Software was used for data analysis.

### **RESULT**

Based on data analysis, the investigator concluded that among 72 parents, majority 55(76.4%) of parents had moderately adequate knowledge, 12(16.7%) had adequate knowledge and 5(6.9%) had inadequate knowledge. Majority 66 (91.7%) had positive perception and 6 (8.3%) had negative perception on chemotherapy. The result of the study revealed that **age** had significant association at  $p < 0.05$  level with knowledge on chemotherapy among parents of children undergoing chemotherapy. The study also revealed that **religion and nature of the treatment cost** had significant association at  $p < 0.05$  with perception on chemotherapy among parents of children undergoing chemotherapy. The Correlation between knowledge and perception indicated weak positive correlation and is statistically non-significant. The study enables the investigator to conclude that there is a room for further improvement of knowledge and perception among the parents. Therefore, it is necessary to stress the importance and collaborate with

other health care team in conducting teaching or training to improve the knowledge and perception of chemotherapy among parents to improve the quality of life of the patients.

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