

Volume: 12  
Issue: 01  
Years: 2022

Research Article

## **Factors Influencing Parental Adherence To Bring Their Child Undergoing Chemotherapy at Dr. Cipto Mangunkusumo Hospital**

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Editor: KS

Received: 17/01/2022

Accepted: 10/03/2022

Published: 25/03/2022

Available Article :

10.33221/jiiki.v12i01.1742

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Conflict of interest statement: There is no conflict of interest in the preparation of this research.

Funding: Personal Funding.

### **Abstract**

**Background:** Cancer is a disease that can be treated with several therapies, including chemotherapy. Chemotherapy is a type of anti-cancer drug treatment that works by killing cancer cells. Currently, this medical treatment has been covered by the national health insurance which is managed by the government that aimed at providing assurance of social protection and welfare. Adherence to chemotherapy is one of the treatments that can improve the quality of life of children with cancer.

**Objectives:** The aim of this study is to identify the factors influencing parental adherence to bring their child undergoing chemotherapy.

**Methods:** The research method was quantitative, employing a descriptive correlation approach and a cross-sectional design. The data was collected using a questionnaire. The sample was 96 parents of children who underwent chemotherapy, which taken by accidental sampling. Chi-square, Kendall's Tau B, and Kendall's Tau C were used in the analysis.

**Results:** There was a significant relationship between education level (p value = 0.006), knowledge (p value = 0.003), and no relationship with work (p value = 0.291), economic status (p value = 0.269), distance (p value = 0.389), side effect (p value = 0.624), and support system (p value = 0.309) with the adherence of parents in bringing their children to chemotherapy.

**Conclusion:** Health professionals can monitor and encourage parents to always bring their children to chemotherapy.

**Keywords:** children with cancer, chemotherapy, parenteral adherence

## Introduction

Cancer in children is a condition in which cells lose control of their normal processes, resulting in abnormal, rapid, and uncontrolled growth.<sup>1</sup> Cancer recognizes no age or education level, and most cancer patients are late in detecting the problem, causing cancer cells to spread more widely. According to data from the International Agency for Research on Cancer/IARC<sup>2</sup> as many as 137,419 children in Asia were diagnosed with cancer, with India having the greatest number with a total of 38,840 children and Indonesia having a relatively large number, with 11,278 children diagnosed with cancer. In 2015, one of the Banjarmasin hospitals treated 1611 pediatric cancer patients, and 1414 children were treated between January and November of this year.<sup>3</sup>

In the early days of a child being diagnosed with a chronic condition, parents frequently feel emotional upheaval, distrust, and rejection; the existence of cancer is an incredible disappointment and grief that makes them unwilling to accept reality.<sup>4</sup> The length of treatment and the side effects of therapy that arise make the child uncomfortable, and the restriction of the child's activity during therapy adds to the parents' stress. In developed countries, individuals with cancer can get a variety of therapies, including gene therapy, surgery, transplantation, immunotherapy, radiotherapy, and chemotherapy.

Chemotherapy is a type of cancer medication treatment that kills cancer cells.<sup>5</sup> The timing of chemotherapy in cancer treatment is a choice that must be taken before beginning treatment. Chemotherapy treatment might take a long period, depending on the stage of the patient's condition and the chemotherapy limitations set by professional disciplines. Data on children undergoing chemotherapy were collected from the Dr. Cipto Mangunkusumo National Central General Hospital (RSUPN)<sup>6</sup> which revealed 69 children awaiting chemotherapy treatments. The expected outcome of chemotherapy aimed at curing depends on several factors at diagnosis as well as other factors throughout planned treatment, including the extent to which the disease is diagnosed, the patient's functional status, the physiological presentation at diagnosis, and socioeconomic influences.<sup>7</sup> One of the keys to a child's success in undergoing chemotherapy treatments is impacted by a variety of factors, including the parents' age, level of knowledge, and economic status.<sup>8</sup>

According to the preliminary study of chemotherapy nurses at RSUPN Dr. Cipto Mangunkusumo in Central Jakarta, the reaction of parents to cancer treatment varies. Some parents immediately follow the treatment according to the advice of health workers, but some parents refuse to undergo the treatment. Parents who refuse chemotherapy will seek other treatments such as herbal remedies, traditional herbs, and other therapies, and if there is no change and the child's condition worsens, they will return to health services. Parents who have children undergoing chemotherapy will constantly attempt to heal them; they have great expectations for their children's recovery.<sup>9</sup> Adherence to chemotherapy is one of the treatments that can improve the quality of life of children with cancer. The purpose of this study is to investigate the factors that influence parental compliance in taking their children to chemotherapy.

## Methods

This study employed a quantitative approach and a cross-sectional method, and it was conducted between February and March of 2020. With a sample of 96 parents, the sampling approach utilized was accidental sampling. The determination of the sample size in this study used the Slovin formula with 5% precision. Parents whose children were or will be having chemotherapy, parents whose chemotherapy schedule was postponed owing to improvement in their overall condition, and parents who could read and write and were willing to engage in

the study comprised the samples in this study. The measuring instrument employed in this study was a questionnaire divided into three sections, the first of which contained the respondents' demographic data, the second of which contained statements about knowledge, and the third of which contained adherence statements. The valid test of this research was carried out in November 2019 and December 2019 at the Rumah Sakit Anak Bunda Harapan Kita, West Jakarta, on 35 respondents with similar characteristics and using a prepared questionnaire. The results of the reliability of the knowledge questionnaire with Cronbach's alpha 0.702, the compliance questionnaire with Cronbach's alpha 0.784.

Statistical tests were performed using chi-square, Kendall's Tau B, and Kendall's Tau C. This study received research ethics permission from the Faculty of Medicine, University of Indonesia, with the number KET-126D/UN2/F1/ETIK/PPM.00.02/2019.

## Results

According to Table 1, the majority of respondents (78,1%) are between the ages of 26 and 45. According to gender, (82,3%) of respondents are female, and (100%) of respondents utilize BPJS. According to the age of the majority of children aged 13-18 years, the amount reaches 29.2 percent. The most common type of cancer in children who had chemotherapy was retinoblastoma (27.1%). Most respondents (50%) had a secondary education level.

**Table 1.** Parent and Child characteristics

Parent characteristic	Frequency	Percentage (%)
<b>Age (years)</b>		
< 25	9	9,4
26 - 45	75	78,1
> 45	12	12,5
Child characteristics	Frequency	Percentage (%)
<b>Gender</b>		
Male	17	17,7
Female	79	82,3
<b>Health Insurance</b>		
BPJS	96	100
<b>Child's Age (years old)</b>		
1-3	21	21,9
4-6	26	27,1
7-12	21	21,9
13-18	28	29,2
<b>Type of cancer</b>		
ALL	22	22,9
AML	15	15,6
Retinoblastoma	26	27,1
Osteosarcoma	20	20,8
The other type	13	13,5
<b>Education Level</b>		
Primary Education	33	34,4
Secondary Education	48	50
Tertiary Education	15	15,6
Total	96	100

ALL: Acute Leukosit Leukimia

AML: Acute Myeloid Leukimia

Table 2 shows that most respondents had a degree of knowledge with (37,5%) falling into the adequate knowledge group. According to occupation, the majority of respondents (63,5%) were not working, and the majority of respondents (51%) had a family income of Rp.1,000,000 – 3,000,000. Most respondents (32,3%) traveled more than 30 kilometers, (76%) of children had treatment side effects, and (84,4%) had a support system.

**Table 2.** Characteristics of Respondent according to the level of knowledge, occupation, economic status, distance, side effects, and support system

Characteristics of Respondent	Frequency	Percentage (%)
<b>Knowledge</b>		
Less	35	36,5
Adequate	36	37,5
Good	25	26,0
<b>Occupation</b>		
Not working	61	63,5
Merchant	25	26
Civil Servant	1	1
Private employee	7	7,3
Farmer	2	2,1
<b>Economic status</b>		
< Rp 1.000.000	17	17,7
Rp 1.000.000 – 3.000.000	49	51
> Rp 3.000.000	30	31,3
<b>Distance</b>		
< 10 KM	26	27,1
10 – 20 KM	21	21,9
20 – 30 KM	18	18,8
> 30 KM	31	32,3
<b>Side effect</b>		
No	23	24
Yes	73	76
<b>Support system</b>		
No	15	15,6
Yes	81	84,4
Total	96	100

Table 3 shows that There was a significant relationship between education level (p-value = 0,006), knowledge (p-value = 0,003) with the compliance of parents in bringing their children to chemotherapy.

**Table 3.** The relationship between education level, level of knowledge, occupation, economic status, distance, side effects, and support system with compliance to taking children to chemotherapy

Variable	Compliance				Total	p-value	
	Not complying		Complying				
	f	%	f	%			
Education level	Primary	23	24	10	10,4	33	0,006*
	Secondary	22	22,9	26	27,1		

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	Tertiary	5	5,2	10	10,4	15	
Knowledge	Less	24	25	11	11,5	33	0,003*
	Adequate	18	18,8	18	18,8	48	
	Good	8	8,3	17	17,7	15	
Occupation	Working	21	21,9	14	14,6	35	0,291
	Not working	29	30,2	31	33,3	61	
Economy status	< Rp 1.000.000	11	11,5	6	6,3	33	0,269
	Rp 1.000.000 – 3.000.000	25	26	24	25	48	
	> Rp 3.000.000	14	14,6	16	16,7	15	
Distance	< 10 KM	14	14,6	12	12,5	26	0,389
	10 – 20 KM	9	9,4	12	12,5	21	
	20 – 30 KM	7	7,3	11	11,5	18	
	> 30 KM	20	20,8	11	11,5	31	
Side effect	No	13	13,5	10	10,4	23	0,624
	Yes	37	38,5	36	37,5	73	
Support system	No	6	6,3	9	9,4	15	0,309
	Yes	44	45,8	37	38,5	81	

\* p value <0.05

## Discussion

Compliance refers to an individual's capacity to adhere to prescribed health measures such as treatment, diet, or lifestyle changes. This study enlisted the participation of parents whose children were or will be undergoing chemotherapy. As many as 27,1% of respondents with secondary education and who were obedient took their children to chemotherapy. The findings of the statistical analysis using Kendall's Tau C showed a p-value of 0.006 ( $\alpha < 0,05$ ), implying that there is a relationship between education level and parental compliance with having their children undergo chemotherapy. A person's level of knowledge will differ from others due to a variety of aspects. For example, someone with a higher education level has broad insight and great curiosity, so that person learns a variety of health-related things that can be accessed via the internet, social media, and e-books.<sup>10</sup> This statement is consistent which found that the higher one's education, the greater the demand for health.<sup>11</sup> The degree of education a person has influences how well they grasp the information they receive. A person's compliance while undergoing therapy is produced by good understanding. Some parents claim that they consistently bring their child for chemotherapy on time in the hopes that it would cure their child's illness.

The knowledge of respondents' compliance to chemotherapy obtained data that most of the respondents had adequate information and were obedient as much as 18,8%, Kendall's tau c test resulted in a p-value of 0.003 ( $< 0,05$ ). The degree of education influences a person's knowledge, but knowledge may also be gained from experience, informal education, and information media accessible in health services. The more information gathered about chemotherapy; the more willing parents are to bring their children to endure chemotherapy. Knowledge is divided into six levels: knowing, understanding, application, analysis, synthesis, and evaluation.<sup>12</sup> Own experience, relatives, books, and mass media may all be used to gain knowledge about anything. Previous research results discovered that persons with a high degree of knowledge are impacted by exposure to proper and appropriate information.<sup>13</sup> According to data obtained from the respondent's work on compliance to chemotherapy, 33,3% of respondents did not work and were obedient. The chi-square test with a p-value of 0,291 ( $> 0,05$ ), indicates that there is no relationship between occupation and respondents' willingness to bring their children to chemotherapy. Working individuals have less time to attend health facilities, which limits the chance and time for treatment.<sup>12</sup> Work is something that must be

done to sustain one's life and family.<sup>14</sup> Work, according to the findings of the researcher's analysis, is a daily routine activity. In this study, most respondents work in the non-formal sector, with merchants to farmers being the most frequent type of occupation. The amount of time spent on non-formal work is uncertain. Because most respondents do not work, they have more time to spend with their families. One aspect of caring for a family is taking children through chemotherapy.

Based on the respondents' economic status in terms of compliance to chemotherapy, the data collected by the majority of respondents with the economic status of Rp. 1,000,000-3,000,000 and non-compliant as much as 26%. The Kendall's tau c test resulted in a p-value of 0,269 ( $>0,05$ ), indicating that there is no relationship between economic status and compliance with undergoing chemotherapy for their child. Obedient behavior is connected to the financial and family's economic levels in fulfilling life's demands, both fundamental necessities for development and health fulfillment.<sup>8</sup> The majority of those respondents in this study were insured by BPJS health insurance. Parents' income is utilized to fulfill daily necessities and to cover transportation fees to healthcare facilities. The availability of this health insurance is also one of the reasons why dutiful parents accompany their children to chemotherapy. Based on the distance traveled by respondents with chemotherapeutic compliance, it was discovered that most respondents traveled a distance of  $> 30\text{KM}$  and those who did not comply were 20,8%, followed by respondents who went a distance of 10-20KM and obeyed as much as 12,5%. With a p-value of 0,389 ( $> 0,05$ ), Kendall's tau c statistical test revealed that there was no relationship between distance and adherence to taking their children to chemotherapy. According to Niven (2012), one of the factors that influence medication compliance is the availability of health services, infrastructure, and accessibility, as well as socioeconomic conditions. The physical and social distance between health facilities and the community may contribute to the low utilization of health facilities.<sup>15</sup> Many patients are sent to this hospital from outside of Jakarta and Java. Respondents who lived outside of Java decided to stay in halfway homes near the hospital, which made it easier for them to go to the hospital. Respondents who live far away and use public transportation to change vehicles several times are motivated to undergo chemotherapy regularly, but some do not comply because they are wary of traveling and must carry children and children's equipment during chemotherapy.

Based on the side effects and parental compliance with chemotherapy, 37,5% of respondents suffered side effects and compliance to chemotherapy. Kendall's tau b test yielded a p-value of 0,624 ( $> 0,05$ ). The side effects that frequently occur and occur very quickly within 24-48 hours after chemotherapy are nausea and vomiting, as well as varying reaction times where these side effects may coincide with chemotherapy and may be delayed up to several times in therapy.<sup>16</sup> Cancer patients getting treatment are certain to have side effects.<sup>17</sup> Depending on the type of cancer, chemotherapy can have a variety of adverse effects. The immune system of each child influences how the body reacts to chemotherapy side effects. Most children having retinoblastoma chemotherapy have minimal side effects such as nausea, vomiting, and constipation. Children undergoing ALL chemotherapy suffer from significant hematological side effects such as anemia, leukopenia, and thrombopenia. Therefore, parents sometimes put off taking their children to chemotherapy. Based on data obtained on the support system of respondents with compliance to chemotherapy, 38,5% of respondents have a support system and adhere to chemotherapy. The Kendall's tau b statistical test revealed no relationship between the support system and compliance, with a p-value of 0,309 ( $> 0,05$ ). The family has several levels, one of which is the family as a system. The family's role in health care also ensures that family members' health is maintained so that they may remain productive.<sup>18</sup> The support system may be observed in the assistance provided to children receiving chemotherapy by their parents, siblings, and extended relatives. Family interaction reflects the dominant



culture as a reference in a relationship.<sup>19</sup> Whether or not there is a support system in place, respondents will continue to bring their children to undergo chemotherapy since the respondents' overall focus is on their child's recovery.

### **Conclusion**

Chemotherapy is a set of treatments that must be followed religiously. Parental adherence to bringing their child undergoing chemotherapy is significantly related to their level of education and knowledge. Knowledge is essential and can affect a person's decision to receive chemotherapy. Health workers can motivate parents to always take their children to undergo chemotherapy regularly. Further research is needed to determine other factors related to parental adherence such as the length of time the child undergoes chemotherapy, parental trust, motivation, experience, and support from health workers.

### **Conflict of Interest Declaration**

There is no conflict of interest in the preparation of this research.

### **Acknowledge**

The researcher would like to thank Dr. Cipto Mangunkusumo General Hospital and Sint Carolus School of Health Sciences for their important contributions to this research.

### **Funding**

Personal Funding.

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