


Parental Factors Contribute to Childhood Cancer Abandonment Treatment During COVID-19

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Abstract

Factors influence a person's health seeking behavior related to abandonment rate on pediatric oncology treatment during this pandemic is unknown. The aim is to identify factors influencing abandonment rates in early pandemic. This was a cross-sectional studies during early pandemic and analyze factors in parents whose children had treatment for malignancy contribute to their children's abandonment treatment rate through guided interview using questionnaire. The characteristic related significantly with treatment abandonment is maternal education. It is found that patients whose mother had education less than secondary school was 1.315 (CI 1.013-1.707) having risk experience abandonment treatment. Parental perception related to impact of COVID-19 was significantly related to treatment abandonment rate with RR 0.202 (CI 0.86-0.471). Patients whose parents have positive perception how abandonment treatment affect their child outcome, believe that doctor has taken step to prevent COVID-19 transmission during treatment, and receive information about COVID-19, having less risk being abandonment treatment.

Keywords

COVID-19, abandonment, pediatric cancer, parental factors, maternal education

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Introduction

COVID-19 was declared as global pandemic since 11 March 2020, a week elapse from the first confirmed positive COVID-19 case in Indonesia.¹ At the time this article was written, there had been 2 waves of Covid in Indonesia and various variants of the COVID 19 virus had been found. After 2 years of the pandemic, developed countries have handled the spread of COVID-19 quite well, starting from conducting screening tests, tracing, testing and extensive vaccination programs. Unfortunately, in low-middle income countries, such as in Indonesia, COVID-19 is still a threat to society, including pediatric cancer patients.

In this COVID-19 pandemic children with cancer were designated as clinically extremely vulnerable if they were contact with SARS-CoV-2 fear that there will be fatality once they got infected.² Children with cancer who undergoing treatment face ongoing compromises to their immune system.² The children and their parents were struggling to manage infection risks regularly even

without pandemic. Hence parents has to be more careful in taking care of their children during this pandemic.

One of the biggest obstacles during the COVID-19 pandemic for parents is if and how they can best protect their children.³ Having children with cancer who require special treatment to the hospital puts them at increased risk of infection. Therefore, parents' health seeking behavior in this pandemic will greatly determine the continuity of their child's treatment.⁴

Even before the pandemic abandonment rate of pediatric cancer patients in developing countries has become

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a big problem and become a bigger problem during a pandemic. Treatment abandonment is the most common cause of treatment failure for children with cancer in low-middle income countries accounting for up to 50% to 60% of cases or and 1 in 7 children globally.⁵ Abandonment not only contributes to failure of therapy, but also exposes children to potentially toxic therapies with little chance of cure, with concomitant unnecessary suffering and wasted healthcare resources.⁶ The abandonment treatment rate in Indonesia across several hospital were 25% to 41.7% which is in accordance with experience of other childhood cancer developing country.⁷⁻¹⁰ In our previous study we examined abandonment rates at the start of the COVID-19 pandemic, we found there was a significantly increased rate of treatment abandonment from 1.1% before to 17% during COVID-19 pandemic.¹

Factors influence a person's health seeking behavior related to abandonment rate on oncology treatment during this pandemic is still unknown. This study aims to identify factors influencing abandonment rates in an early pandemic. Our hope is that after these factors are identified we can overcome them to reduce the abandonment rate because it can be predicted that burden of COVID-19 in developing countries will still last for a long time.

Methods

Study Design

This was a cross sectional studies during pandemic COVID-19. This study will analyze whether knowledge, perspective, and behavior in parents whose children had treatment for malignancy contribute to their children's abandonment treatment rate. The treatment pattern then observed and followed in this period of time. Exclusion criteria were palliative care treatment, death, completed treatment schedule during observation, unavailability of contact number and enrollment refusal. The treatment pattern was classified as abandonment and non abandonment.

Primary data was taken from parents of childhood cancer treated in Dr. Hasan Sadikin from 1 November 2019 to 31 May 2020 with guided interview using questionnaire. The Questionnaire was consist of 6 parts and was pilot-tested on a separate group of parents for its content, clarity of language and cultural sensitivities. A few minor adjustments were made on basis of pilot-test. The questionnaire consist of 6 parts which include parents' socio demographic, adherence to treatment, the reasons for choosing to comply or not to comply with treatment, social support, level of knowledge, attitude, and behavior of parents having children with cancer

regarding COVID-19, exposure to COVID-19, the socioeconomic impact of COVID-19, and parental perceptions on impact of COVID 19 to their children's treatment.

The determination of good and poor the results of this questionnaire is determined by the median, if a value is obtained above the median it will be categorized as good and vice versa if a value is obtained below the median it will be categorized as poor.

Anonymity and confidentiality were guaranteed. The questionnaire was conducted as supplementary the reason of parental decision on their childhood cancer related abandonment treatment or continued the treatment. The 6 part of questionnaire was divided into social demographic data, knowledge attitude behavior related COVID-19 transmission.

Study Variable

We collected the following variables from the questionnaire, hospital information system and IP CAR (Indonesian Pediatric Cancer Registry) application including:

- Medical history name and registration number of childhood cancer patient, type of cancer, gender, age at first presentation, year of first presentation, assigned hospital class at diagnosis, health-insurance. Childhood malignancy was categorize to hematology malignancy and non-hematology.
- Socio economy background of parents (age, education, mode of transportation, address, number of family member).
- Parental knowledge, attitude, behavior, and perception related to COVID-19
- Social support and socioeconomic impact during COVID-19
- Treatment outcome (abandonment and non-abandonment treatment) Abandonment of treatment was defined as failure to start or continue scheduled curative treatment during 4 or more consecutive weeks.
- Reasons of parental decisions whether to abandonment or non-abandonment

Data Analysis

Frequency distribution, median, mean and SD were assessed for each variable. Differences in socio demographic and clinical characteristics between abandonment and non-abandonment were compared using χ^2 , Fisher's exact and *t* tests. To verify factors that affected

treatment abandonment, a binary logistic regression analysis was done. Two tailed *P*-values less than .05 were considered statistically significant at 95% confidence.

Results

From November 2019 to May 2020, there were total 263 patient treated for pediatric malignancy in Dr. Hasan Sadikin hospital. Of these 263, 20 intended to do palliative care, 6 had completed treatment during observation and 89 patients were died, leaving 164 patients for observation. Twenty-six patients were untraceable due to lack of contact available and 16 families refused to be interviewed, there were total of 122 participant interviewed for this study (see Figure 1).

Characteristic related significantly with abandonment of treatment is the degree of maternal education. It is found in this study that patients whose mother had education less than secondary school was 1.315 (CI 1.013-1.707) having risk experience abandonment treatment (Table 1). Parental age, number of family members, insurance provider, homestay location, distance to hospital, mode of transportation, and type of cancer were not significantly related with abandonment of treatment (Table 2).

Parental perception related to impact of COVID-19 was significantly related to abandonment of treatment rate. Patients whose parents have positive perception how abandonment treatment will affect their child outcome, believe that hospital and doctor has taken various step to prevent COVID-19 treatment during treatment, and they receive sufficient information about COVID-19, having less risk being abandonment treatment group RR 0.202: CI 0.86 to 0.471.

Although insignificant, it was also found that patients whose parents have poor attitudes and behavior related to COVID-19 infection also has an increased rate of abandonment. Previous research among childhood cancer reported that financial burden is the major cause of treatment abandonment,¹²⁻¹⁴ however our study shows the correlation between socioeconomic impact with abandonment rate of treatment is insignificant. In addition, the difference in COVID-19 knowledge and social support were not significantly related (Table 3).

The reasons were varied in abandonment treatment group, meanwhile in non-abandon group, following the doctor instruction to comply with schedule was the majority answer (60/98) (Table 4). Elaboration related social issues such as social support and also social impact of COVID-19 were not significantly different between 2 groups.

Discussion

This study found there were 2 factors that caused an increase of abandonment rate during the COVID-19 pandemic in our setting, namely maternal education and parents' poor perception of COVID-19. Treatment abandonment is certainly influenced by a person's health seeking behavior, in this case the parents' health seeking behavior is closely related to their child's treatment compliance.¹¹ Parents' with a good health seeking behavior is very important in children who have chronic diseases such as cancer since cancer need a long term treatment and it requires commitment from their parents to constantly seeking treatment and finally affect their health outcomes.^{6,11}

There are many factors that influence a person's health seeking behavior, one study about health seeking behavior of mothers in India found that determination of healthcare-seeking behavior is governed by the combination of many factors, such as mother's ages, education, religion, ethnicity, culture, decision-making power, place of residence, and socio-economic status, as well as the cost, quality, and location of healthcare services.^{12,13} In this study, we try to explore these factors that influence health seeking behavior in parents' whose children has cancer and associate it with their treatment abandonment during COVID-19 pandemic.

The level of education is a very important thing for parents to have in relation to their children's health.¹⁴ The mother's education has a strong and positive influence on the utilization of child healthcare services.^{12,15,16} Higher levels of parental education significantly contributed to seek appropriate care for children.¹⁷ A good maternal's education have positive effect to a better health outcomes of their children.¹²

Another study about mother's health seeking behavior in Surabaya, Indonesia, it concluded that if the level of parental education is high hence the level of understanding will be high and certainly include more knowledge about how to care when the child is in an unhealthy condition.^{14,18} This is in accordance with our study where higher education in mothers shows a better understanding when their children need cancer treatment that they keep bring their children for treatment so their children do not abandon the treatment.

Our study categorized maternal education as less than secondary school and high school or more, this indicate the number of years of schooling attend by the mothers. The longer the mother attend school the greater commitment they will take care of the child including seek help when a child is ill.¹⁵ This is why mothers who go to high school rather than elementary school in our study keep seeking treatment for their children amidst pandemic COVID-19 to avoid treatment abandonment.

Table 1. Parents' Socioeconomic Background.

Characteristic (n)	Abandonment	Non-abandonment	RR	Confidence interval	P
	n: 24	n: 98			
Mother age (year)					
Less than 39	13	59	0.831	0.401-1.682	>.05
39 or more	11	39	1.051	0.875-1.261	
Father age (year)					
Less than 36	11	51	0.819	0.398-1.683	>.05
36 or more	13	47	1.05	0.880-1.253	
Father education					
Less than secondary school	9	53	0.581	0.275-1.225	>.05
More than secondary school	15	45	1.14	0.953-1.363	
Mother education					
Less than secondary school	18	57	1.315	1.013-1.707	<.05
High school and more	6	41	0.524	0.231-1.18	
Family member					
Less than 4	16	68	0.905	0.424-1.929	>.05
4 or more	8	30	1.025	0.844-1.245	
Insurance (%)					
Government support	2	21	0.391	0.099-1.547	>.05
Private	22	77	1.174	0.996-1.384	
Homestay (%)					
Bandung area	8	44	0.673	0.312-1.452	>.05
Outside Bandung	16	54	1.923	0.923-1.303	
Distance (km)					
Less than 50 km	11	62	0.568	0.277-1.163	>.05
50 km or more	13	36	1.156	0.952-1.404	
Transportation before COVID-19					
Public	19	71	1.351	0.550-3.319	>.05
Private	5	27	0.935	0.778-1.123	
Transportation after COVID-19					
Public	19	71	1.351	0.550-3.319	>.05
Private	5	27	0.935	0.778-1.123	
Diagnosis					
Hematologic malignancy	12	56	0.794	0.388-1.625	>.05
Non hematology malignancy	12	42	1.059	0.884-1.268	

Table 2. Parental Knowledge, Attitude, Behavior Related COVID-19 Infection.

Characteristic (n)	Abandonment	Non-abandonment	RR	Confidence interval	P
	n: 24	n: 98			
Covid-19 knowledge					
Good	13	59	0.821	0.401-1.682	>.05
Poor	11	39	1.051	0.875-1.261	
Attitude related COVID-19 prevention					
Good	11	56	0.695	0.338-1.426	>.05
Poor	13	42	1.095	0.913-1.12	
Behavior of COVID-19 prevention					
Good	16	69	0.871	0.409-1.854	>.05
Poor	15	29	1.036	0.850-1.262	
Parental perception related impact of COVID-19					
Good	6	70	0.202	0.186-0.471	<.05
Poor	18	28	1.513	1.189-1.95	

Table 3. Social Support and Socioeconomic Impact During COVID-19 Pandemic.

Social support and socioeconomic impact (n)	Abandonment	Non-abandonment	RR	Confidence interval	P
	n: 24	n: 98			
Social support					
Good	11	41	1.139	0.555-2.336	>.05
Poor	13	57	0.968	0.809-1.159	
Socioeconomic impact losing job					
Yes	18	62	1.575	0.676-3.667	>.05
No	6	36	0.94	0.762-1.073	
Decrease of salary					
Yes	21	81	1.373	0.452-4.168	>.05
No	3	17	0.932	0.369-4.454	

Table 4. Reasons of Parental Decision.

Abandonment n: 24	Non-abandonment n: 98
Afraid of COVID-19 transmission from hospital (n: 5)	Delayed treatment will affect outcome (n: 33)
Travel restriction (n: 4)	Difficult to reschedule for next appointment (n: 5)
Withhold evaluation (n: 2)	Follow doctor instruction (n: 60)
Transportation difficulties (n: 5)	
Inactivation insurance (n: 1)	
Alternative Medicine (n: 1)	
Insufficient Life Cost (n: 6)	

Mothers have an important role in making decisions about the treatment of their children, especially for mothers who have children with cancer. Hence mothers are an ideal and potential targets to increase awareness about the importance of compliance with treatment in pediatric cancer patients during COVID-19 pandemic and its impact on their children's health outcomes.

This study also found that the parents' perceptions of the impact of COVID-19 on their child's treatment also significantly related to their children's treatment abandonment. Children with parents who have positive perceptions tend to have a lower risk of experiencing treatment abandonment compared to children with parents who have bad perceptions. Positive perception means that parents think that delaying their children's treatment due to COVID-19 will affect their child's health outcomes and parents believe that medical personnel have taken adequate steps to prevent transmission while their child is given therapy in the hospital.

This positive perception is concordance with the study in Australia about parent perceptions of pediatric oncology care during the COVID-19 pandemic which found that parents were confident that COVID-19 did not impact their medical decision-making and in this study they stick to their children's treatment as per scheduled.¹⁵ Although in this study the parents were feeling knowledgeable about COVID-19, obtaining

information from multiple trusted sources including government sources and health care providers, while in our study, good knowledge about COVID-19 did not show a significant relationship to abandonment treatment rate. This could be due to the fulfilling the questionnaire was done at the beginning of the pandemic so that parents may have not been exposed to much education about COVID-19.

Positive perceptions of COVID-19 are not always easy to find in the midst of this pandemic. One study on the Psychological Impact of COVID-19 on Parents of Pediatric Cancer Patients stated that there was an increase in stress levels for parents who have children with cancer during the COVID-19 pandemic due to fear and worry about the possibility that their child might be infected, especially if the child has a pre-existing condition such as cancer where infection with COVID-19 might aggravate symptoms and poses an additional risk to the child's health.¹⁹ Another study in the UK on experiences, anxieties and support needs during COVID-19 in parents with children with cancer reported that the majority of parents were worried about SARS-CoV-2 and transmitting the virus to their child and hospital was no longer perceived to be a safe place, and parents were worried about suboptimal cancer care.²

Poor attitudes and behavior related to COVID-19 infection has an increased rate of abandonment but not

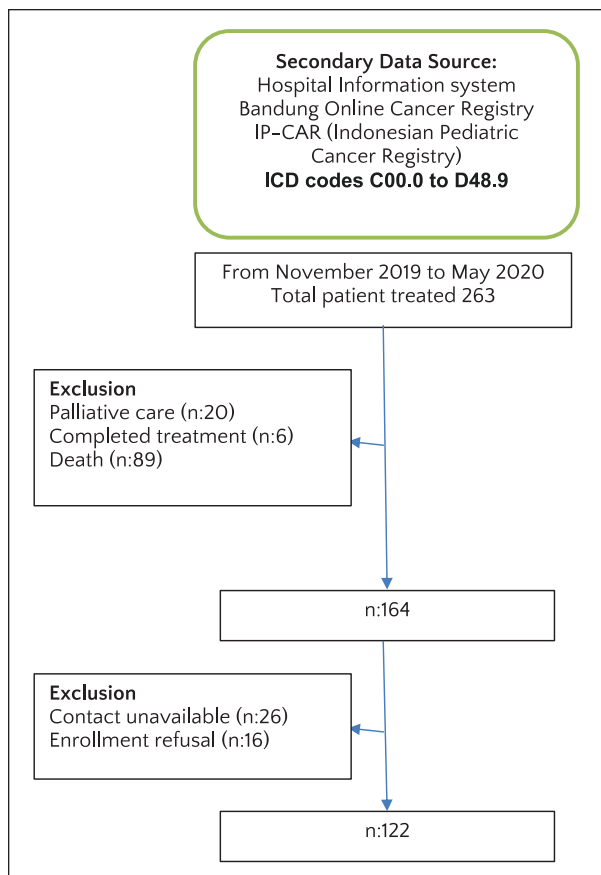


Figure 1. Patient enrollment.

significantly related. These 2 factors affect a person's health seeking behavior during COVID-19 pandemic. The behavior and attitudes in question are carrying out health protocols such as washing hands regularly, wearing face masks, and keep physical distancing. If someone carry out the health protocol well, then the health seeking behavior during the COVID-19 pandemic will be good.²⁰ Health seeking behavior in this case is seeking medical help if you experience an illness.

Previous research among childhood cancer reported that financial burden is the major cause of treatment abandonment.⁸ One study also mentions that the amount of one's income will affect one's health seeking behavior, the higher one's income, the better one's health seeking behavior will be,²¹ however our study shows the correlation between socioeconomic impact with abandonment rate of treatment is insignificantly related. this can be caused because most patients use health insurance to pay for treatment and none uses financial burden as a reason for their treatment abandonment.

One study in Australia stated there is an increasing need for social support during a pandemic due to the increasing psychological burden on parents and pediatric cancer patients such as fear of infection and disruption to

their treatment,²² however in our study found that social support in this study also did not show a significant relationship to treatment abandonment. this can be caused because most patients use health insurance to pay for treatment. Social support services in Indonesia are not generally provided to patients. In our setting, which is a level 3 referral hospital, social support services are not routinely provided to patients.

Limitations

The limitation of our study was the small study population due to the large number of patients who could not be contacted or parents whose children already had died then refused to fill out the questionnaire.

Conclusion

Low maternal education and parents' poor perception about COVID-19 are 2 factors that significantly contribute to parents' poor health seeking behavior during COVID-19 pandemic hence increase of treatment abandonment rate during the COVID-19 in our setting. Perceptions about COVID-19 can be improved by providing adequate information to parents, especially to mothers, about COVID-19 itself and the disadvantages of treatment abandonment on children's health outcomes. Mothers are ideal and potential targets for raising awareness about the dangers of their children's abandon treatment.

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Author Contributions

Authors testify that all persons designated as authors qualify for authorship and have checked the article for plagiarism. If plagiarism is detected, all authors will be held equally responsible and will bear the resulting sanctions imposed by the journal thereafter. Susi Susanah formulated and designed the study, conducted research, compelled, reviewed the original draft, data curation, analyzed and interpreted data and doubled check the results. Ismiana Fatimah collected the data, wrote the original draft, helped analyzed and interpreted the data. Nur Melani Sari also helped in data curation, analyzed and interpreted the data and doubled check the results. Nur Suryawan contributed in formulated and designed the study and doubled check the results. All authors have critically reviewed and approved the final draft and are responsible for the manuscript's content and similarity index.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Data Availability Statement

The data analyzed in this study are subject to the licenses/restrictions. Requests to access these datasets should be directed to the corresponding authors.

Ethic Statement

The studies were reviewed and approved by Dr. Hasan Sadikin ethical committee with document number LB.02.01/X.6.6/163/2020. Informed consent from the participants' legal guardian/next of kin were taken to participate in this study in accordance with the national legislation and the institutional requirements.

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