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Original Article

The impact of the COVID-19 pandemic on the psychological distress of parents and children cancer care: A cross-sectional study

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ABSTRACT

Introduction: The current situation of the COVID-19 pandemic has an impact on stress among parents of children with cancer. This uncertain situation can cause psychological distress experienced by parents and can reduce the level of care for children with cancer, it can reduce the cure rate and increase the morbidity rate of children with cancer. The study aimed to analyses the impact of the COVID-19 pandemic on the psychological distress of parents and the treatment of children with cancer.

Methods: The research design used was descriptive analytics with a cross-sectional approach. The population in this study were parents of children with cancer living in the Surabaya and East Java areas who lived in a halfway house. Respondents were 78 parents of children with cancer. The children were aged between 2 and 15 years. Selected using the convenience sampling technique for three months (June to August 2022). The independent variable in this study was the level of psychological distress, while the dependent variable was the treatment of children with cancer. The data was obtained using the DASS-21 questionnaire and analyzed using the Spearman Rank Correlation test with $\alpha = .05$.

Results: The results of the study showed that there was an impact of the COVID-19 pandemic on psychological distress [(stress *P*-value = .002; r = .341); (anxiety *P*-value = .013; r = .281), and depression *P*-value = .026; r = .252)] and cancer care for children.

Conclusion: The COVID-19 pandemic has an impact on the psychological distress of parents and the care of children with cancer. The level of stress experienced by parents should be given further treatment immediately.

Keywords: cancer; chronic diseases; COVID-19; pandemic; psychological distress

INTRODUCTION

According to World Health Organization (WHO), the rate of The world's nations must face the COVID-19 pandemic because it impacts all aspects, including the health sector. One aspect of health that the COVID-19 pandemic has impacted is changes in care for cancer patients and children with cancer (Jazieh et al., 2020; Moreira, 2021). The COVID-19 pandemic can lead to decreased patient attendance in chemotherapy and radiotherapy and fewer patient visits (Ranganathan et al., 2021). Chemotherapy is one of the treatments for children that children with cancer must carry out to control the number of cancer cells (Majorana et al., 2016). Delay and termination of chemotherapy can increase the severity of cancer. However, because of the pandemic situation, cancer patients and parents of children with cancer are afraid to come to the hospital (Indonesia Cancer Care Community, 2021).

Cancer care in Indonesia was greatly affected during the COVID-19 pandemic, making complex healthcare access even more complex. As an archipelagic nation, distance made specialized treatment more difficult, especially in remote areas (Harapan et al., 2023). Resources reallocated to facilitate COVID-19 management further restricted cancer services, while economic downturns left many families unable to afford treatment (Jumadi et al., 2024; Kong et al., 2020). With these and other factors, patients may delay cancer diagnosis or present with advanced-stage diseases (Dabkeviciene et al., 2021; Jazieh et al., 2020). While high-income countries adapted with telemedicine and home-based care, Indonesia's infrastructure limitations compounded treatment disruption and parental distress (Gatellier et al., 2021; Ray & Mukherjee, 2023).

Every parent will feel worried, fearful, anxious, and stressed when a child is sick, especially with a serious illness such as cancer (Krisnana, 2019; Krisnana et al., 2021). Parents who have children with cancer show increased symptoms of psychological distress (Patiño-fernández et al., 2008). Parents' stress levels can increase when parents feel a threat to their children's condition. Parents hope they can carry out therapeutic procedures for their children well in order to increase the cure rate. However, some things can change in a pandemic that affects child care. These changes include the possibility of parental difficulties due to limited public transportation facilities and the increase in transportation costs, especially coupled with a decrease in family income due to the termination of employment experienced by the head of the family.

Some treatments for cancer children include monitoring the child's response to chemotherapy treatment, preventing

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secondary infection or controlling signs of infection in children, preventing injuries that can cause bleeding, providing nutrition, overcoming pain with non-pharmacological techniques, and preventing and treating oral mucositis (Palestin, 2012). Parents must apply these various types of care as the main caregivers for children (Arabiat et al., 2018). Some treatments require patience and parental discipline; for example, for the prevention of oral mucositis due to chemotherapy, parents must be diligent in implementing oral care protocols, including brushing teeth, gargling, and mouth-rinsing using chlorhexidine (Allen et al., 2014; Qutob et al., 2013). However, this treatment can be interrupted if the parents experience psychological distress. This study aimed to analyze the impact of the COVID-19 pandemic on the psychological stresses and the treatment of children with cancer. This research is fundamental to do because the pandemic situation has an impact on various aspects including health. This uncertain situation can cause stress for parents. Psychological stresses experienced by parents can reduce the level of care for children with cancer to reduce the cure rate and increase the morbidity rate of children with cancer. The level of stress experienced must be identified immediately so that further management can be given.

METHODS

Study Design

This research's design was cross-sectional with correlation analysis without assessing causality or change over time between psychological distress and pediatric cancer care among parents of children with cancer.

Sample

The population in this research were parents of children with cancer living in the Surabaya and East Java areas who lived in shelters or at the Indonesian Children's Cancer Care Foundation (YPKAI). The sample was selected based on inclusion criteria, including 1) parents of children with cancer who had media to access online questionnaires through Android mobile phones or computers, 2) parents of cancer children who can speak Indonesian, 3) parents of children with cancer who underwent cancer treatment and care during the COVID-19 pandemic, 4) parents who were willing to do research.

The YPKAI administrators actively assisted in coordinating the supply of information about the study to eligible parents for recruiting participants. The researchers informed parents of the study objectives and procedures, thereby obtaining informed consent prior to questionnaire distribution. Parents considered to meet inclusion criteria were invited to voluntarily take part. In order to minimize selection bias, efforts were made to ensure the participants had a wide variety of socioeconomic status and geographical locations within the region of East Java.

Furthermore, including both shelters and YPKAI in recruitment gave access to parents with varying levels of healthcare service access. The researchers distributed online questionnaires for three months (June-August 2022) and obtained 78 respondents in East Java. The sampling method used was convenience sampling. The independent variable in this research was the level of psychological distress, while the dependent variable was pediatric cancer care.

Instruments

The instrument used in this research was the Depression Anxiety Stress Scale-21 (DASS-21) questionnaire to assess the level of psychological distress. Psychological distress was measured using the DASS-21 questionnaire (Lovibond & Lovibond, 1995). DASS-21 consisted of 21 statements with a Likert scale; never = 0; sometimes = 1; often = 2, almost always = 3. DASS-21 was designed to measure the psychological states of depression, anxiety and stress self-administered by respondents. Scores on the DASS-21 were multiplied by 2 to calculate the final score. The DASS-21 questionnaire has been translated into Indonesian by Damanik (Damanik, 2011) and tested for validity and reliability by Krisnana (Krisnana, 2012; Krisnana et al., 2019) with Cronbach Alpha = .97. The questionnaire was declared reliable to measure anxiety because it was more than .70 (Heale & Twycross, 2015).

A pediatric cancer care questionnaire was developed by research team has undergone validity and reliability testing to ensure its accuracy in measuring parental caregiving practices for children undergoing cancer treatment consist of the monitoring the children's response to chemotherapy treatment (Palestin, 2012). The cancer child care questionnaire consists of 20 questions with seven subscales, namely 1) care when children have diarrhea, 2) dry mouth, 3) nausea and vomiting, 4) fever, 5) oral mucositis, 6) hair loss, and 7) infection prevention efforts. The response is a Likert scale consisting of never = 0; sometimes = 1; often = 2, and almost always = 3.

Data Collection

Concerning the COVID-19 Pandemic, the data was collected through the spread of online questionnaires and offline questionnaires for parents who registered on YPKAI in Surabaya. Before filling out the questionnaire, respondents got a detailed explanation of the research. Then, if they agreed, the respondents gave their signatures directly through the online media as proof of approval. Respondents who agreed then continued to fill out the questionnaire completely.

Data Analysis

The data analysis used by the researchers in this study was descriptive and inferential. Measures of descriptive analysis included the mean, standard deviation, and minimum and maximum values. Meanwhile, the researchers used bivariate data analysis for the inferential analysis. The statistical tests used were Spearman Rank Correlation with the level of significance $\alpha = .05$.

Ethical Clearance

Ethics statement: The research was conducted with respect for human rights by applying ethical principles to human subjects. This research has obtained ethical clearance from the Health Research Ethics Commission of the Faculty of Nursing Universitas Airlangga, with certificate number 2532-KEPK. Informed consent was obtained from all participants.

RESULTS

The research proved that the age of mothers who had children with cancer was 63 people (80.8%) and 15 people (19.2%) who had cancer children aged 20-40 years. Parents have an equally important role in carrying out care for children with cancer. Mothers' education had a high level of variation, almost half of the mothers had the last education, namely high

school or equivalent (43.6%), and the other mothers' education was junior high school (32.1%). There were still mothers who had an education equivalent to elementary school, as many as 12 people (15.4%), and a small proportion of mothers who had the last education of diploma/bachelor as many as nine people (9%). Most of the mothers became housewives or did not work as many as 59 people (75.6%), and a small portion had jobs as private employees, civil servants, farmers, and entrepreneurs.

Providing care for children with cancer requires quite a lot of costs for treatment, transportation, and other additional costs. It can be interpreted that family income is very influential on the continuity of care in children with cancer. Most of the income of families who have children with cancer was Rp. 3.500,000 (lower middle class), as many as 64 families (82.1%) and the upper middle class (17.9%). Most parents had two children, with an average of the first order of children experiencing cancer (50%). The children were aged between 2 and 15 years. The length of time that children experienced cancer had a high level of variation, ranging from less than one year to more than four years (Table 1).

Table 2 shows that parents' care for children with cancer when children have diarrhea, including giving drinks through their mouths more often (44.9%), giving small portions of food but often (46.2%), and never avoiding giving vegetables and fruits when children have diarrhea (43.6%). However, there were still parents who never gave frequent drinks when children had diarrhea (9.0%). Statements about the treatment of dry mouth in children with cancer varied widely. Table 2 showed that parental care for children's mouths (oral hygiene) was still relatively lacking, as evidenced by most parents who never encouraged their children to chew gum, which was the most significant percentage compared to other statements (70.5%). The most significant percentage was that parents never gave cold water to drink when the child's mouth was dry (43.6%). Furthermore, parental statements regarding oral care when their child had canker sores were that most parents sometimes brushed their child's teeth twice daily (46.2%) and some parents often did it (38.5%). However, some parents still encouraged their children to rinse their mouths after eating every meal (46.2%) and gave a normal saline solution every time their child had thrush (26.9%).

Parents' statements about taking care when their child felt nauseous and vomiting also varied. The percentage of parents who sometimes avoided giving fatty foods was the most significant percentage compared to other statements (43.6%). However, some parents still always avoided pungent-smelling foods (25.6%). Then the statement of parents in caring for children when experiencing hair loss, namely preventing the use of chemicals on hair, was the most significant percentage compared to other statements (57.7%). Table 2 also showed that most parents had good attention to treating their children with leukemia. The highest percentage was concerning always preventing infection by washing their hands before and after having contact with children (71.8%). However, some parents still never washed their hands to prevent infection in children (2.6%). Prevention of other infections by limiting contact with other people was rarely done by most parents (33.3%).

Based on the Spearman Rank Correlation statistical test, if significance value is .05, it is stated that there is an influence between the independent and dependent variable. In addition, the degree of strength of influence can be determined from the value of the correlation coefficient (r). The results of hypothesis testing using Spearman Rank Correlation showed that there was an effect of psychological distress on stress conditions

Table 1. Demographic Characteristics of Respondents (n=78)

Respondents' Characteristics	n	%
Mother's Age (Years Old)		
20 – 40	63	80.8
> 40	15	19.2
Mother's Education		
Elementary School	12	15.4
Junior High School	25	32.1
Senior High School	34	43.6
Bachelor	7	9.0
Mother's Job		
Housewife	59	75.6
Private employees	5	6.4
Government employees	2	2.6
Farmer	4	5.1
Entrepreneur	8	10.3
Family Income		
≤ IDR 3.500.000	64	82.1
≥ IDR 3.500.000	14	17.9
Number of Children		
One	9	11.5
Two	39	50.0
Three	19	24.4
>Three	11	14.2
Children with Cancer		
1st	39	50.0
2nd	26	33.3
3rd	9	11.5
4th	4	5.1
Cancer Duration		
≤ 1 year	18	23.1
> 1 years	12	15.4
> 2 years	13	16.7
> 3 years	6	7.7
> 4 years	29	37.2

(*P*-value = .002; r = .341), anxiety conditions (*P*-value = .013; r = .281), and depression conditions (*P*-value = .026; r = .252) for the pediatric cancer care (Y1) with a weak degree of strength indicate that other factors may influence in shaping caregiving behaviors. These results indicated that the hypothesis was accepted, which means that the COVID-19 pandemic has an impact on the psychological distress of parents in treating children with cancer in East Java.

DISCUSSION

Treatment for children with leukemia requires special attention from parents because children receiving chemotherapy can experience side effects such as nausea, vomiting, oral mucositis, and chapped lips (Majorana et al., 2016; Permono et al., 2006). In this condition, parents can play a role in providing oral hygiene for children (Potter & Perry, 2010). The greater the parental attention to the care of children with cancer, the lower the severity of cancer in children. However, due to the COVID-19 pandemic situation, patients and parents

Table 2. Frequency Distribution Children Cancer Care (n=78)

Indicators	Always (%)	Often (%)	Sometimes (%)	Never (%)
When the child has diarrhea				
Giving more drinks through the mouth	33.3	44.9	12.8	9.0
Feeding a little but often	26.9	46.2	19.2	7.7
Avoiding giving vegetables and fruit	19.2	10.3	26.9	43.6
When the child's mouth is dry				
Giving cold drink	5.1	17.9	33.3	43.6
Giving liquid food	12.8	34.6	42.3	10.3
Encouraging children to chew gum	5.1	7.7	16.7	70.5
When the child has nausea and vomiting				
Delivering dry food	16.7	16.7	39.7	26.9
Avoiding pungent smelling foods	25.6	10.3	33.3	30.8
Avoiding fatty foods	20.5	15.4	43.6	20.5
When the child has a fever and chills				
Wiping the child's body	52.6	28.2	14.1	5.1
Give a lot to drink	48.7	47.4	3.8	.0
Give a thick blanket	33.3	16.7	32.1	17.9
When a child has thrush				
Brushing children's teeth 2 times a day	38.5	12.8	46.2	2.6
Caring for children by gargling normal saline solution	26.9	26.9	25.6	20.5
Encourage children to rinse their mouths after every meal	46.2	28.2	17.9	7.7
When a child experiences hair loss				
Giving a hat or scarf to cover the child's baldness	24.4	28.2	26.9	20.5
Caring for children by shampooing as often as possible	29.5	21.8	34.6	14.1
Preventing the use of chemicals on hair	57.7	7.7	16.7	17.9
Infection prevention				
Washing hands before and after touching children	71.8	16.7	9.0	2.6
Preventing children from frequent contact with other people	28.2	24.4	33.3	14.1

Table 3. Psychological Distress Level of Parents with Cancer Children (n= 78)

Psychological Distress Level	%
Stress	
Normal	87.2
Mild stress	10.3
Moderate stress	2.6
Anxiety	
Normal	59
Mild anxiety	6.4
Moderate anxiety	24.4
Severe anxiety	10.3
Depression	
Normal	16.7
Mild depression	25.6
Moderate depression	20.5

Table 4. The relationship between parental psychological stress levels with children cancer care (n = 78)

Variables	*P*-value	r
The correlation between level of stress on parent and children cancer care	.002	.341
The correlation between level of anxiety on parent and children cancer care	.013	.281
The correlation between level of depression on parent and children cancer care	.026	.252

of children with cancer are afraid to come to the hospital, resulting in delays and termination of chemotherapy actions which can eventually increase the severity of the cancer itself (Indonesia Cancer Care Community, 2021).

Parents who have children with cancer show increased symptoms of psychological distress (Patiño-fernández et al., 2008). Parents' stress levels can increase when parents feel a threat to their child's condition. However, some things can change in a pandemic that affects child care. These changes include the possibility of parental difficulties due to limited public transportation facilities and the increase in transportation costs, especially coupled with a decrease in family income due to the termination of employment experienced by the head of the family. The results of this study indicated that during the last 7 days, there were parents who experienced increased psychological distress, both in conditions of anxiety, stress, and depression, while undergoing treatment for children with cancer during this pandemic. The level of anxiety experienced by parents also varied greatly, ranging from mild anxiety to severe anxiety. In these conditions, parents still have to carry out treatment for children with cancer. Treatment is primarily directed at the prevention of infection (Wong, Donna L, 2009). The results of this study indicated that the infection prevention efforts carried out by parents were quite reasonable. The statement item with a high value was that parents often applied hand washing before and after having contact with children. Washing hands before and after having contact with children is very important in preventing infection in children with cancer so that it can reduce the severity of children with cancer (Arabiat et al., 2018).

However, the prevention of other infections was still not maximally carried out by parents, namely by restricting visitors and limiting contact with children with cancer. In this pandemic situation, contact restrictions need to be considered because contact can increase the risk of exposure to infection in children, especially exposure to the COVID-19 virus, which can aggravate the condition of children with cancer. However, some parents felt that the support of others or the participation of others could help relieve the psychological distress experienced by parents in caring for their children with cancer during this pandemic.

Oral care in children with cancer is necessary to prevent chapped lips, canker sores, and dry mouth (Potter & Perry, 2010). This results indicated that children's oral care was relatively lacking, as evidenced by most parents never recommending their children chew gum or giving them cold water to drink. Overcoming the lack of saliva production can be done by chewing gum containing xylitol and with cold therapy. Both therapies were effective in increasing saliva production, thereby increasing oral humidity (Sholikhah et al., 2020).

Not only oral care, but when feeling nausea and vomiting is also an important thing that every parent must pay attention to their children with cancer. The results of this study indicated that there were still parents who still gave fatty foods when their children felt nauseous and vomiting and had not avoided pungent-smelling foods. In contrast, fatty foods can trigger nausea and vomiting in patients with cancer, especially patients with a history of chemotherapy (Zhou et al., 2021).

Treatment by parents for children with cancer is essential to increase the child's recovery rate and reduce morbidity in children with cancer, especially patients with post-chemotherapy who experience various side effects. The results of this study indicate that the COVID-19 pandemic has an impact on the psychological distress of parents and the care of children with cancer. The impact of the pandemic affects the psychological distress of parents, which then mostly has an impact on poor care. Cancer care for children, which includes many aspects, is still ignored by some parents. This is due to the condition of parents who have pressure on the treatment that must be carried out, coupled with the pandemic conditions that hinder the treatment of children with cancer (Indonesia Cancer Care Community, 2021). Specific interventions should be put in place to support parents and improve the quality of care for children with cancer to meet these challenges.

It's been proven by studies that psychosocial interventions, particularly cognitive behavioral therapy and problem-solving skills training, reduce distress and develop parents' coping strategies so that adjustment outcomes become better for both parents and children (Fair et al., 2021; Koumarianou et al., 2021). Establishing empowerment-based interventions can significantly improve parents' knowledge and caregiving behavior while reducing psychological distress, so they give very favorable health outcome improvements for their children, such as lessening oral mucositis or gastrointestinal complications (Nurhidayah et al., 2023). In addition, structured educational programs equipping parents with medical and nursing skills are essential to empower them so that they can manage their child's care effectively; however, such programs are still underused and need to be implemented broadly in facilities (Odom et al., 2023). It is also very important to address the issues of emotional and financial burden among parents. Regular psychosocial screening as well as tailored interventions can give emotional relief, while financial aid from medical institutions, charity, and public services can help to relieve the burden of stressed income (Hancock et al., 2022; Reshetnikov et al., 2024). These key areas of concern can contribute to strengthening the support systems that health providers administer to parents and at the same time foster effective healing and recovery operations for children with cancer.

Nonetheless, there are other limitations that must be noted, particularly concerning sample representation. Mostly mothers participated in the study, while fathers and other caregivers were scarcely involved. This particular gender disparity might limit the generalizability of the findings since fathers would have a different experience of psychological distress, or extended family members might add differing perspectives to caregiving responsibility. There must be future initiatives that target a more diverse caregiver sample to capture a more holistic perspective.

CONCLUSION

Based on the results of the research that has been done, it can be concluded that the COVID-19 pandemic has an impact on the psychological stresses of parents and the care of children with cancer. When viewed from their psychosocial problems, some parents experience mild to severe anxiety, some experience mild and moderate stress, and some experience mild and moderate depression. The condition of spiritual distress can affect the care parents should take for children with cancer. This study emphasizes the urgency of a strong response to provide interventions to reduce psychological stress in parents.

In the future, it would be beneficial to develop longitudinal studies to understand the long-term consequences of the pandemic on such areas as parental well-being and caregiving. It is also necessary to validate psychological evaluation

instruments in this particular population so as to improve the accurate assessment of mental health. Independence in the study of effective interventions, including telehealth-based psychological support, peer support programs, and culturally attuned mental health strategies, will inform the provision of care during similar crises.

Declaration of Interest

There is no potential conflict of interest.

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Data Availability

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

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