






# Mental Wellbeing among Children with Cancer during COVID-19 Pandemic in Indonesia: A Cross-sectional Study

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Ind J Med Paediatr Oncol

## Abstract

**Introduction** Coronavirus disease 2019 (COVID-19) has affected both physical and mental aspect of people worldwide, especially the high-risk group such as pediatric cancer patients. Children with cancer were considered both clinically and mentally vulnerable during this pandemic. They were also affected by the self-isolation, quarantine, and social distancing policy taken as a respond to public threat.

**Objectives** To evaluate the impact of social distancing and health protocol during COVID-19 on the mental health profile of children with cancer in Indonesia.

**Methods** A cross-sectional study evaluating the mental health of children with cancer during COVID-19 pandemic was conducted in Cipto Mangunkusumo Hospital, Jakarta, Indonesia from June to September 2020. An online questionnaire was used to collect demographics of parents and children, children's Strength and Difficulties Questionnaire (SDQ) score, and parents' Self-Reporting Questionnaire (SRQ). SDQ score consists of five subscales, including the emotional symptoms, conduct problems, hyperactivity, peer relationships problems and prosocial behavior. Cancer types were grouped into retinoblastoma, nonretinoblastoma (other solid tumors), and leukemia.

**Results** There were 156 valid responses, consisting of 42 patients with retinoblastoma, 34 patients with nonretinoblastoma (other solid tumors), and 80 patients with leukemia. Pandemic-related lifestyle changes did not significantly impact emotional or behavioral problems. Children with normal total SDQ (odds ratio [OR]: 473,  $p = 0.001$ ) and emotional scores (OR: 3.19,  $p = 0.07$ ) had parents with normal SRQ scores ( $<6$ ). Leukemia patients with shorter diagnosis period had worse hyperactivity score ( $p = 0.01$ ). On the contrary, leukemia inpatients had better prosocial scores than outpatients ( $p = 0.03$ ). More bilateral retinoblastoma patients ( $p = 0.04$ ) with longer duration of cancer diagnosis ( $p = 0.03$ ) faced peer problems.

## Keywords

- ▶ mental health
- ▶ pediatric cancer patients
- ▶ COVID-19
- ▶ psychiatry
- ▶ hematology
- ▶ medical oncology
- ▶ ophthalmology

DOI <https://doi.org/10.1055/s-0043-1768053>.  
ISSN 0971-5851.

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**Conclusions** Our study revealed that lifestyle changes during early COVID-19 pandemic were not major factors impacting emotional and behavioral problems in children with cancer. However, disease-related factors pose great challenges; thus, a holistic mental health support system should be available to both children and parents.

## Introduction

The coronavirus disease 2019 (COVID-19) pandemic has posed a global threat since December 2019. It affected both physical and mental health of the public, leading to detrimental effects on quality of life. The World Health Organization expressed concern over the psychosocial consequences of COVID-19, as it stated that the new measures including quarantine and social distancing have disrupted people's routines, thus increasing the feeling of anxiety, depression, loneliness, insomnia, and self-harm.<sup>1-5</sup>

Following government responses to COVID-19 on schools, educational institutions, and closure of public places, ample evidence has revealed the psychological impact of COVID-19 pandemic toward children and adolescents manifesting as behavioral and emotional problems.<sup>6-10</sup> A study showed that children who have more highly educated parents, live in big cities, come from either high- or low-income households, and have parents with mental problems are the most vulnerable group during the pandemic. There is also evidence that extended period of parental stress during the pandemic is related to child behavioral problems.<sup>11</sup>

Children and adolescents faced emotional struggles while experiencing social isolation and disrupted education. Children encountered fear, uncertainties, and isolation, resulting in conditions such as poor appetite, physical discomfort, agitation and inattention, clinginess, separation problems, and poor sleep.<sup>6-10</sup> In published research on stress levels among students during the pandemic, the values ranged from 24.7 to 71.2%, mostly related to the adaptation of long-distance learning.<sup>12-14</sup> In addition, the increased use of digital devices during lockdown has also been used as indicator of developing the internet addiction, gaming disorder, anxiety, depression, irritability, sleep disturbance, and poor mental health in children during the pandemic.<sup>12-15</sup>

Pediatric cancer patients are not indifferent to the dramatic impact of COVID-19. The uncertainty regarding their condition is now worsened by the risk of contracting viral infection and disruption in cancer treatment protocol.<sup>16,17</sup> Even before the pandemic, children with cancer were already at risk of developing mental health disorders precipitated by the anxieties following diagnosis, treatment, and alteration of daily activities. The side effects of cancer treatments, including surgery, chemotherapy, and radiotherapy, may lead to cognitive problems, behavioral disorders, and poor coping skills. There are also increased levels of depression, anxiety, and concerns related to mortality.<sup>18-20</sup>

Children with cancer are considered as clinically vulnerable during this pandemic due to their immunocompromised status caused by cancer and anticancer treatments.<sup>17,20,21</sup>

Hence, they are recommended to undergo stricter rules to keep them safe by always remaining at home and avoiding contact with anyone beyond their household, except attending medical care in the hospital. There is an emerging concern regarding the damage of these measures on the mental wellbeing of pediatric cancer patients.<sup>16,22-25</sup> A study in Milan showed that majority of adolescent cancer patients were worried and felt personally at risk during this pandemic, as they encountered high levels of stress and anxiety, facing dilemmas regarding continuation of their treatment and access to health care facility under these threatening circumstances.<sup>17,22-26</sup>

Not only the patients but also the families of children with cancer experience challenges in balancing their life during the pandemic. A study in UK found that parents/caregivers were worried that their children would get infected by the virus and felt that hospital was not a safe place, thus increasing parents' anxiety and concerns about their child's care.<sup>26,27</sup> Another study also stated that hospital restriction increased parent's psychosocial distress during the pandemic, especially regarding the risk of suboptimal care received by their children.<sup>27-29</sup>

There are limited data on the mental health status of pediatric patients with cancer during the COVID-19 pandemic. Therefore, we conducted the first Indonesian study that aimed to evaluate the experience and psychological impact of COVID-19 toward children with cancer and their parents in Indonesia. These findings can provide comprehensive foundation for the development of mental health programs to support children with cancer during this pandemic.

## Materials and Methods

### Study Design and Data Collection

A cross-sectional survey study of parents and children with cancer diagnosed between 2015 and 2020 was conducted to assess their mental health and experience during the social isolation of COVID-19 pandemic. The data were collected by clinicians who are members of the research team (R. M., A. S. N., N. S.) from June to September 2020, 3 months after the start of social distancing and lockdown implementation in Indonesia.

The variables in our study are as follows: gender, age, education level, parent's marital status, time from diagnosis to data collection (TDD), treatment status, place of stay during self-isolation, duration of study from home per day, total duration of using gadget per day, cancer staging, treatment received, phase of treatment, number of eyes affected (retinoblastoma patients), children's Strength and

Difficulties Questionnaire (SDQ) score, emotional problems score, conduct problems score, hyperactivity score, peer problems score, prosocial score, and parents' Self-Reporting Questionnaire (SRQ) score. The primary outcomes of this study are the association between patient's clinical characteristics (cancer staging, types of treatment, and TDD) and their total SDQ score (and its domain) during the COVID-19 self-isolation period. The secondary outcomes are the patients' and their parents' demographic characteristics (gender, age, total screen time, treatment status, place of stay during pandemic, marital status, parents' marital status, and parent's SRQ score) and their association with the SDQ score (and its domain), in addition to the comparison between each cancer group.

The inclusion criteria of this study were parents and their children aged between 0 and 18 years, who were clinically diagnosed with cancer (either were still undergoing treatment or had completed their treatment) and were literate and able to respond to questions in Indonesian language. Patients were recruited from Pediatric Oncology and/or Pediatric Ophthalmology Department outpatient clinics, Ciptomangunkusumo Hospital. We exclude parents and children who refused to complete the questionnaire or are not able to comprehend and respond to questions.

### Instrument

We gathered information on parents' and children's demographics and then evaluated their experiences during the COVID-19 pandemic including the social distancing practice, work/study from home practice, problems, and hopes during this pandemic. A questionnaire was developed to address the lifestyle-related behavior changes during the pandemic including the duration of work from home and study from home, source of COVID-19 information, and problems experienced during the pandemic.

The main outcome, which is the mental condition of the pediatric cancer patients, was assessed using validated questionnaire. The survey was conducted via an online survey tool (Google Forms) in Indonesian language, available in the **Appendix 1**. Before we performed the statistical analyses, all patient-related medical information was validated through the medical record.

### SDQ for Children

The emotional and behavioral problems of the children were assessed using the SDQ.<sup>30,31</sup> The SDQ questionnaire was each categorized based on the age of the children, which consists of a parent-completed SDQ for ages 2 to 4 years old<sup>30</sup> and 4 to 11 years old,<sup>31</sup> and a self-completed SDQ for ages 11 to 18 years old. SDQ had been officially translated and validated into Indonesian language by one of our authors (T. W.). It is available as online assessment tool for children at [www.sdqinfo.com](http://www.sdqinfo.com). SDQ for ages 11 to 18 years was filled in by the children themselves, meanwhile SDQ for ages 2 to 11 years was filled in by their parents.<sup>30,31</sup>

The SDQ questionnaire consists of 25 questions on Likert scale (0 = not true; 1 = somewhat true; 2 = certainly true). It was divided into two major parts including the difficulties

domains, which consist of 20 questions (emotional problems, conduct problems, hyperactivity scale, and peer problems), and strength domain, which comprises 5 questions (prosocial scale). The total score for the difficulties domains ranged from 0 to 40. The newer four-band categorization was used as cutoff points for total SDQ score and its domain in our study. The initial three-band categorization divided SDQ scores as "normal," "borderline," and "abnormal," with cutoff points such that 80% of children population scored "normal," 10% "borderline," and 10% "abnormal." New four-band classification with cutoff points such that 80% of children population were "close to average," 10% "slightly raised," 5% "high," and 5% "very high" for all scales except prosocial, which is 80% "close to average," 10% "slightly lowered," 5% "low," and 5% "very low," was used.<sup>30,31</sup>

### SRQ for Parents

Parents also completed the SRQ consisting of 20 yes/no questions, which has been translated and validated in Indonesian language, with a cutoff score of 6 to be indicative of common mental disorder.<sup>32</sup>

### Definitions

TDD was defined as the duration of time since the patient was diagnosed with cancer until the data were obtained. We classified patients into three groups: retinoblastoma, leukemia, and nonretinoblastoma (other solid tumors) group. We defined combined therapy in both retinoblastoma and nonretinoblastoma (other solid tumors) groups as combination of surgical, chemotherapy, radiotherapy, and other modalities. Monotherapy in the nonretinoblastoma (other solid tumors) group was defined as surgical only or chemotherapy only. The retinoblastoma group was classified into early (stage 1 and 2) and advanced (stage 3 and 4). Cancer staging in nonretinoblastoma (other solid tumors) diagnosis was grouped into early to advanced (stages 1, 2, and 3) and late (stage 4). The treatment phase in leukemia group was categorized into two groups based on the treatment received, namely, inpatient, which consists of induction, consolidation, and intensification phase, and outpatient, which consists of maintenance and remission phase.

### Statistical Analyses

From questionnaire results, we excluded housewives and unemployed in the analysis of "work from home" variable. We also excluded patients who received chemotherapy only in the retinoblastoma group from the analysis of "treatment received for cancer" as they have not completed treatment regimen.

Statistical analysis was performed with SPSS version 24.0 for Mac (SPSS Inc., Chicago, IL, United States). Categorical data were reported in the form of frequency (percentage) and assessed using chi-square ( $\chi^2$ ) test or Fisher's exact test. Continuous variables were reported in the form of mean  $\pm$  standard deviation or median (range). Normality of the data was evaluated by using Shapiro-Wilk test. Normally distributed data were analyzed using one-way analysis of variance. Nonnormally distributed data were analyzed using Kruskal-Wallis test.

Analysis was conducted according to the cancer diagnosis, grouped as retinoblastoma, nonretinoblastoma (other solid tumors), and leukemia. Descriptive statistics were carried out to summarize all variables included based on the diagnosis groups. We performed a bivariate analysis and risk assessment on parents' and children's characteristics toward children's SDQ score. A  $p$ -value  $< 0.05$  was considered statistically significant.

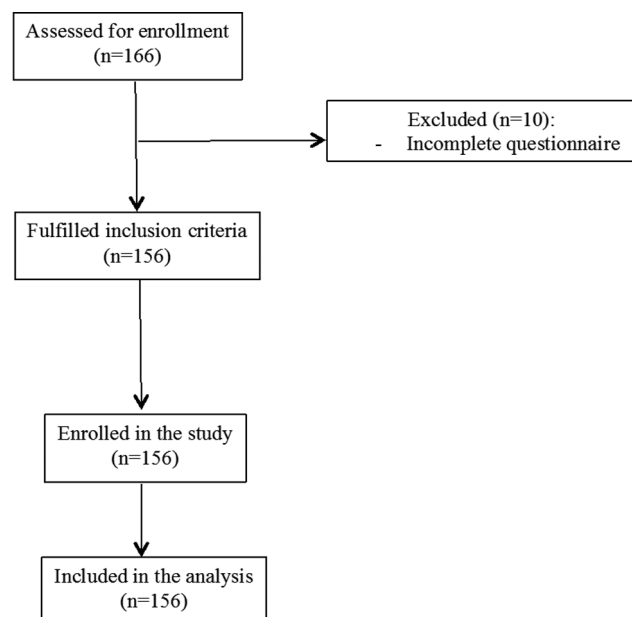
### Ethics

This study has been approved by the Research Ethic Committee in Cipto Mangunkusumo Hospital, Jakarta (KET-476/UN2.F1/ETIK/PPM.00.02/2020), as listed in ►Appendix 2 and conducted in accordance with the tenets of the Declaration of Helsinki. All participants were provided study information and completed electronic consent before completing the online survey.

## Results

### Patient's Clinical Characteristics

A total of 166 patients were assessed for enrollment. Ten patients were excluded and 156 patients who met the eligible criteria were included in the study, as seen in ►Fig. 1. Among them, 42 patients belonged to the retinoblastoma group, 34 patients were in the nonretinoblastoma (other solid tumors) group, and 80 patients were diagnosed with leukemia. Half of our retinoblastoma patients suffered from unilateral cases (50%,  $n = 21$ ). Approximately 85.7% ( $n = 36$ ) of the children were in the early stage (stages 1 and 2) of the disease. The combination of enucleation and chemotherapy was the most common treatment modality given in accordance with disease stage. Meanwhile, the diagnosis for the other (nonretinoblastoma) solid tumor group in our study included neuroblastoma (26.5%,  $n = 9$ ), lymphoma (23.53%,  $n = 8$ ), rhabdomyosarcoma (11.76%,  $n = 4$ ), osteosarcoma (11.76%,  $n = 4$ ), and others



**Fig. 1** Consort diagram showing participants enrollment.

(26.47%,  $n = 9$ ). Around 70.58% ( $n = 24$ ) came to the hospital during late stage of the disease (stages 3 and 4). The most common types of treatment given to these patients were chemotherapy only (41.2%,  $n = 14$ ) and combination of chemotherapy and surgery (23.5%,  $n = 8$ ). Lastly, 75.75% ( $n = 59$ ) of leukemia patients in our study were in maintenance phase of chemotherapy treatment. Patient's demographic characteristics are listed in ►Table 1. Patients' clinical information based on the cancer diagnosis is summarized in ►Table 2.

### Patients' Clinical Data and SDQ Score

►Appendix 3 displayed comparison between total SDQ score and its domains based on clinical characteristics in each cancer group. Our results showed significant differences in the scores of three domains, including hyperactivity, peer problems, and prosocial domains between cancer groups. Significantly shorter TDD in leukemia patients was found in group with at-risk hyperactivity score ( $p = 0.01$ ). Numbers of bilateral retinoblastoma patients ( $p = 0.04$ ) and patients who were diagnosed longer ( $p = 0.03$ ) were also significantly higher in group with at-risk peer problems score. Lastly, the prosocial score of the leukemia group was significantly different between those receiving inpatient and outpatient treatments ( $p = 0.03$ ).

### Parents'/Children's Demographic Characteristics and Children's SDQ Score

The comparison between total SDQ score and its domain based on parents' and children's demographic characteristics is detailed in ►Appendix 4. Several characteristics should be highlighted. Children with normal total SDQ (odds ratio [OR]: 4.73; 95% confidence interval [CI]: 45.04–4,975.42;  $p = 0.001$ ) and emotional problems (OR: 3.19; 95% CI: 0.91–11.18;  $p = 0.07$ ) scores had parents with normal SRQ score ( $< 6$ ) during this COVID-19 pandemic. A significant difference was also seen in the emotional problems, conduct problems, and prosocial scores among the children's age groups. Compared with children aged 10 to 17 years, preschool children aged between 0 and 5 were more likely to experience problems in emotional (OR: 4.83; 95% CI: 1.36–17.11;  $p = 0.02$ ) and prosocial scores (OR: 3.27; 95% CI: 1.31–8.19;  $p = 0.01$ ), while children aged 6 to 9 were more likely to face emotional (OR: 5.07; 95% CI: 1.21–21.23;  $p = 0.03$ ) and conduct problems (OR: 8.19; 95% CI: 2.02–33.19;  $p = 0.003$ ). In addition, most of the children with emotional problems also were still on their cancer treatment during the survey rather than being cancer survivors (OR: 2.11; 95% CI: 0.92–4.83;  $p = 0.07$ ).

### Comparison of Children's SDQ Score among the Cancer Diagnosis Groups

The comparison of children's SDQ score and its domain between the diagnosis groups showed no significant difference of children's SDQ score and its domain between the three diagnosis groups.

## Discussion

Children with cancer face stress not only from their medical condition but also from lifestyle changes brought about by

**Table 1** Children's demographic characteristics based on cancer diagnosis

	Retinoblastoma (n = 42)	Solid tumor (nonretinoblastoma) (n = 34)	Leukemia (n = 80)
Gender			
Male	26 (61.9%)	20 (58.8%)	47 (58.8%)
Female	16 (38.1%)	14 (41.2%)	33 (41.3%)
Age (y)			
0–5	33 (78.6%)	20 (58.8%)	34 (42.5%)
6–9	8 (19%)	3 (8.8%)	17 (21.3%)
10–17	1 (2.4%)	11 (32.4%)	29 (36.2%)
Education level			
Preschool	29 (69%)	19 (55.9%)	30 (37.5%)
Kindergarten	7 (16.7%)	2 (5.9%)	9 (11.3%)
Elementary school	6 (14.3%)	4 (11.8%)	25 (31.3%)
Junior high school	0 (0%)	8 (23.5%)	9 (11.3%)
Senior high school	0 (0%)	1 (2.9%)	6 (7.5%)
University	0 (0%)	0 (0%)	1 (1.3%)
Time from diagnosis to data collection (mo)	24 (1–96)	12 (3–48)	17.5 (1–72)
Treatment status			
On treatment	15 (35.7%)	30 (88.2%)	75 (93.8%)
Survivor	27 (64.3%)	4 (11.8%)	5 (6.3%)
Place of stay			
Private housing	16 (38.09%)	9 (26.47%)	40 (50%)
Temporary housing	26 (61.91%)	25 (73.53%)	40 (50%)
Duration of study from home per day (min)	0 (0–120)	0 (0–240)	45 (0–300)
Total duration of using gadget per day (min)	60 (0–540)	80 (0–540)	120 (0–780)

pandemic. Their ability to cope with additional stress is a cause of concern as psychological and social problems could affect the children's enthusiasm in continuing cancer treatment and their ability to adapt to new lifestyles. Recommendation regarding standard of care in children with cancer provides insight to balance the risk of COVID-19 and continuation of care for children, which caused burden and challenges toward parents, children, and health care providers.<sup>16</sup> A study in UK reported an increased worry experienced by parents of a child with cancer.<sup>26</sup> In addition, children with cancer and their families also expressed their concerns living in a life of uncertainty, which leads to fear of adaptation, loneliness, and confusion.<sup>17</sup> Our study showed that pandemic-related changes such as increased screen time, place of stay during lockdown, and duration of homeschooling did not significantly affect their psychosocial wellbeing. Disease-related factors such as TDD, being on treatment, and other factors such as gender, age, and parental SRQ scores had greater influence instead.

#### Lifestyle Changes during the Pandemic

To our surprise, in our study lifestyle changes during the COVID-19 pandemic were not significant factors in deter-

mining social and psychological problems in children with cancer. This was supported by other studies as well. A Dutch study<sup>26</sup> had also reported that there was no significant difference in psychosocial health of children with cancer before and during the pandemic. Children with chronic illness and cystic fibrosis who were thought to have risks of developing psychosocial problems during the pandemic were also not significantly affected.<sup>33,34</sup>

In addition, more than half of our patients (58.3%) undergoing treatment lived in temporary housing such as rentals and boarding home for childhood cancer patients. The boarding home for childhood cancer patients helped establish a community of patients and their guardians for mutual support. Hence, this could be a possible explanation why the place of stay did not have a significant impact on the psychosocial health of the patients.

#### The Impact of Increased Screen Time

School closures, homeschooling that utilized online learning, lockdown, and isolation resulted in a sharp increase of screen time for children. Children in our study experienced a median of 160 minutes of daily screen time. Our data revealed that total screen time per day did not significantly



**Table 2** Clinical characteristics of cancer patients based on the diagnosis

Retinoblastoma patients (n = 42)	
Number of eyes affected	
Unilateral	21 (50%)
Bilateral	21 (50%)
Cancer staging	
1	21 (50%)
2	15 (35.7%)
3	4 (9.5%)
4	1 (2.4%)
Treatment received for cancer	
Enucleation	10 (23.8%)
Enucleation, chemotherapy	22 (52.4%)
Enucleation, chemotherapy, laser	6 (14.3%)
Enucleation, chemotherapy, radiation	2 (4.8%)
Chemotherapy	2 (4.8%)
Other solid tumor (nonretinoblastoma) patients (n = 34)	
Diagnosis	
Neuroblastoma	9 (26.47%)
Lymphoma	8 (23.53%)
Rhabdomyosarcoma	4 (11.76%)
Osteosarcoma	4 (11.76%)
Others	9 (26.47%)
Cancer staging	
1	1 (2.94%)
2	9 (26.47%)
3	12 (35.29%)
4	12 (35.29%)
Treatment received for cancer	
Chemotherapy	14 (41.2%)
Chemotherapy, operation	8 (23.5%)
Chemotherapy, radiation	5 (14.7%)
Chemotherapy, operation, radiation	3 (8.82%)
Operation	4 (11.76%)
Leukemia patients (n = 80)	
Phase of treatment	
Induction	3 (3.75%)
Consolidation	11 (13.75%)
Intensification	2 (2.5%)
Maintenance	59 (73.75%)
Remission	5 (6.25%)
Treatment received for cancer	
Chemotherapy	80 (100%)

impact children's mental health during the pandemic. This was different from previous findings,<sup>32,35,36</sup> which showed that excessive screen time was related to poorer mental health. Another study<sup>29,37</sup> had also shown that these detrimental effects were related to social media and Internet use, but not gaming and watching television.

The necessity of gadget usage during the pandemic for schooling and entertainment activities for children staying at home could help them cope with stress instead. This solution may be helpful in the short term, but can turn out to be inappropriate or even bad in the long run. Recreational screen use may be good for children, to a certain extent, during this difficult pandemic. It is also important to inform parents about the importance of controlling their child's screen time and content. Therefore, parents should establish sufficient screen-free periods each day.<sup>32,36,37</sup>

### Mental Wellbeing in Retinoblastoma Patients

Disability brought about by pediatric cancer can be detrimental to children's mental wellbeing. Our study showed that children with bilateral retinoblastoma faced difficulties with peers, which could be linked to their loss of sight. Longer duration since cancer diagnosis also significantly raised the risk of peer problems. Retinoblastoma patients in developing countries such as Indonesia often exhibit symptoms long before seeking medical help; therefore, the duration is an underestimation of the actual TDD. Retinoblastoma patients often present with advanced stage at diagnosis. As most children with retinoblastoma had to undergo enucleation surgery, visual impairment could cause their peer problems. A recent study in China by Feng et al<sup>38</sup> revealed that retinoblastoma survivors who underwent enucleation were more self-conscious about their appearance resulting in low self-confidence. In our study, visual disability not only reduced self-confidence but also caused problems in socializing with their peers. A study conducted in the Netherlands by van Dijk et al<sup>39</sup> found that 88% of adult retinoblastoma survivors had experienced bullying related to their appearance, eye prosthesis, and their visual impairment and blindness, which consequently affected their mental health. Participants also mentioned that their peers had difficulty reading their facial expressions and emotions due to lack of eye contact. Unlike children with other forms of cancer, children with retinoblastoma face greater challenges as their sight and appearance are adversely affected. Children with cancer and resulting disabilities should receive guidance on dealing with peer problems and psychological counseling when necessary.

### Mental Wellbeing in Leukemia Patients

Our study showed that in children with leukemia, outpatients were at higher risk of prosocial problems than inpatients. Outpatient treatment can impose more problems for children with cancer, as they are required to socialize with other children and family members outside of the hospital environment. Lengthy period of previous hospitalization might have affected their prosocial abilities. A Turkish

study<sup>40</sup> of leukemia survivors found that children were unwilling to reattend school after treatment and their parents were more likely to restrict their social activities, as they feared that the children were more vulnerable of infections. Outside the hospital, children should be encouraged to socialize, and adequate guidance should be given to allow them to build friendships with other children.

Leukemia patients in our study with shorter period since diagnosis (median of 5 months) were associated with hyperactivity problems. Patients and parents alike were often in denial after initial diagnosis of leukemia. Furthermore, chemotherapy regimen would be in the induction stage for the initial 4 to 5 months when children would experience strong side effects from intense chemotherapy treatment. At the maintenance stage, however, chemotherapy regimen is less intense, and children are better adjusted to chemotherapy. Children initially diagnosed with cancer exhibit hyperactive behavior to gain more parental care as coping mechanism. In contrast, children with retinoblastoma who experienced peer problems had longer period of cancer diagnosis. Chemotherapy for retinoblastoma does not follow the induction-maintenance regimen but is administered in cycles. Longer period since diagnosis meant that children undergo intense chemotherapy in repetitive cycles and repeatedly affected by side effects.<sup>41,42</sup>

### The Psychological Impact of COVID-19 in Younger Children

Across the board, adolescents aged 10 to 17 were less likely to be at risk of emotional problems compared with younger children. A study by Bloom et al<sup>43</sup> also supported this finding, showing that younger children were more negatively affected by lockdown and had more mental health problems than adolescents, including emotional problems, misconduct, and hyperactivity.

Young children aged 0 to 5 showed highest risk of hyperactivity and prosocial score. This was in line with another study, which reported an increased inattention and hyperactivity/impulsivity were seen on young children aged 4 to 6 years during the pandemic.<sup>44</sup> In our study, children aged 6 to 9 were most likely to experience emotional problems and conduct problems. On the other hand, a study in UK reported those aged 7 to 12 years found depression symptoms worsened but reported no significant changes for anxiety symptoms and emotional problems.<sup>6,45,46</sup> A contradictive result was shown in study of pediatric patients with rheumatological diseases, in which female adolescents diagnosed with juvenile idiopathic arthritis experienced more anxiety and depressive symptoms during the pandemic.<sup>47</sup>

Children under 9 years were less able to cope and verbalize their discomfort of their experience; therefore, they express misbehavior and misconduct. It highlights the impact that the COVID-19 pandemic and consequent restrictions might have had on children who are perhaps too young to understand the meaning of the pandemic, compared with adolescents. Younger children are a lot more reliant on their parents throughout the day including support with education and monitoring, entertaining, and providing for them.

On the contrary, adolescents may have been more independent during lockdown with better access to their peers.<sup>6,42,46</sup>

### Impact of Parents' Mental Health Status toward Children

Parents have a large impact on the mental health of children with cancer. Our analysis showed that parents with SRQ score  $\geq 6$  who were more likely to face psychological problems might affect their children to be at greater risk of facing psychological difficulties. Studies also reported that during COVID-19 pandemic, parents of children with cancer have increased sense of isolation and loneliness, especially due to the lack of support from family, friends, relatives, and cancer support group<sup>17,27</sup> in addition to the high stress level and significant level of anxiety.<sup>48</sup> Several studies<sup>49,50</sup> had shown that parents of children with cancer were psychologically distressed due to mental and financial burden of caregiving. Parents with psychological problems were less able to build healthy parent-child relationships. In comparison to another study in highly vulnerable group of children with rare diseases, a study by Rihm et al also reported a high psychosocial burden in caregivers and reduced quality of life in children with rare diseases.<sup>51</sup> A similar trend was also observed in both caregivers and children with type 1 diabetes.<sup>52</sup>

A study by Kim et al<sup>53</sup> also reported an increased risk of children sleep and behavioral problems related to parents' stress and depression during the pandemic. Reciprocal relationship between parents' and children's mental health was also seen, especially associated with higher levels of depression, anxiety, and stress.<sup>43</sup> Hence, not only should children be provided with psychological support, but also parents should have access to mental health care and make effort to build healthy parent-child relationships.

Our study has several limitations. First, the study population was not enough to draw a generalized conclusion, which represents the whole diagnosis groups in pediatric cancer patients as the study only covered pediatric cancer patients in a single institution using a convenience sampling method. Second, the data collection was conducted through self-report surveys and online questionnaires. We recommended psychiatrists to perform clinical in-depth interview in follow-up studies in order to gain detail regarding factors affecting the mental health conditions of pediatric cancer patients during this pandemic. In addition, the self-report nature of the assessment tools used in our study also increases the chance of subjectivity of the answers. Third, several important factors that may affect the outcome such as friends and families support, information collection regarding COVID-19 and mental health during the pandemic, and coping strategies were not included in the analysis. Therefore, further studies with larger samples and more comprehensive assessment should be conducted in order to gain a better understanding of pediatric cancer patients' mental wellbeing during this COVID-19 pandemic.

### Conclusion

Our study has shown that although the pandemic has altered the routine and lifestyles of children with cancer, disease-

related factors had greater impact on their mental health. Children with cancer might even benefit from more time spent at home and increased interaction with parents working from home. The process of cancer treatment and having less developed emotional coping ability pose risks to their emotional and behavioral wellbeing. These findings highlight the ongoing need to target vulnerable groups. A holistic mental health support system is essential for both children and parents to help them promote self-management, enhance physical and psychological wellbeing, and raise their quality of life.

#### Authors' Contributions:

R. S. S., T. T. S., T. W., S. D. E., and I. S. W. designed and conceptualized the study. R. M., A. S. N., and N. S. carried out the survey. R. S. S., T. T. S., T. W., S. D. E., I. S. W., N. S., and S. T. analyzed the data and wrote and edited the manuscript. All authors have read and approved this manuscript.

#### Source of Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

#### Conflict of Interest

The authors declare that they have no competing interests.

#### Acknowledgements

The authors would like to acknowledge Mrs. Ira Soelistyo, Chairperson of Indonesia Care for Cancer Kids Foundation (Yayasan Kasih Anak Kanker Indonesia) for aiding us in distributing online questionnaire for this study.

#### References

- Amsalem D, Dixon L, Neria Y. The coronavirus disease 2019 (COVID-19) outbreak and mental health: current risks and recommended actions. *JAMA Psychiatry* 2021;78(01):9–10
- Golberstein E, Wen H, Miller BF. Coronavirus disease 2019 (COVID-19) and mental health for children and adolescents. *JAMA Pediatr* 2020;174(09):819–820
- Jiao WY, Wang LN, Liu J, et al. Behavioral and emotional disorders in children during the COVID-19 epidemic. *J Pediatr* 2020; 221:264–266.e1
- Kumar A, Nayar KR. COVID 19 and its mental health consequences. *J Ment Health* 2021;30(01):1–2
- Pfefferbaum B, North CS. Mental health and the Covid-19 pandemic. *N Engl J Med* 2020;383(06):510–512
- Wiguna T, Anindyajati G, Kaligis F, et al. Brief research report on adolescent mental well-being and school closures during the COVID-19 pandemic in Indonesia. *Front Psychiatry* 2020; 11:598756
- Garcia de Avila MA, Hamamoto Filho PT, Jacob FLDS, et al. Children's anxiety and factors related to the COVID-19 pandemic: an exploratory study using the children's anxiety questionnaire and the numerical rating scale. *Int J Environ Res Public Health* 2020;17 (16):5757
- Nearchou F, Flinn C, Niland R, Subramaniam SS, Hennessy E. Exploring the impact of COVID-19 on mental health outcomes in children and adolescents: a systematic review. *Int J Environ Res Public Health* 2020;17(22):8479
- Ramaswamy S, Seshadri S. Children on the brink: risks for child protection, sexual abuse, and related mental health problems in the COVID-19 pandemic. *Indian J Psychiatry* 2020;62(9, Suppl 3): S404–S413
- Yue J, Zang X, Le Y, An Y. Anxiety, depression and PTSD among children and their parent during 2019 novel coronavirus disease (COVID-19) outbreak in China. *Curr Psychol* 2022;41(08): 5723–5730
- Sifat RI, Ruponty MM, Rahim Shuvo MK, Chowdhury M, Suha SM. Impact of COVID-19 pandemic on the mental health of school-going adolescents: insights from Dhaka city, Bangladesh. *Heliyon* 2022;8(04):e09223
- Limone P, Toto GA. Psychological and emotional effects of digital technology on children in COVID-19 pandemic. *Brain Sci* 2021;11 (09):1126
- Rutkowska A, Cieřlik B, Tomaszczyk A, Szczepańska-Gieracha J. Mental health conditions among e-learning students during the COVID-19 pandemic. *Front Public Health* 2022;10:871934
- Kishida K, Tsuda M, Waite P, Creswell C, Ishikawa SI. Relationships between local school closures due to the COVID-19 and mental health problems of children, adolescents, and parents in Japan. *Psychiatry Res* 2021;306:114276
- Pandya A, Lodha P. Social connectedness, excessive screen time during COVID-19 and mental health: a review of current evidence. *Front Hum Dyn* 2021;3:684137
- Moreira DC, Millen GC, Sands S, Kearns PR, Hawkins DS. The care of children with cancer during the COVID-19 pandemic. *Am Soc Clin Oncol Educ Book* 2021;41:1–10
- Mirlashari J, Ebrahimpour F, Salisu WJ. War on two fronts: experience of children with cancer and their family during COVID-19 pandemic in Iran. *J Pediatr Nurs* 2021;57:25–31
- Mavrides N, Pao M. Updates in paediatric psycho-oncology. *Int Rev Psychiatry* 2014;26(01):63–73
- Young AM, Ashbury FD, Schapira L, Scott F, Ripamonti CI, Olver IN. Uncertainty upon uncertainty: supportive Care for Cancer and COVID-19. *Support Care Cancer* 2020;28(09):4001–4004
- Mertens A, Gilleland Marchak J. Mental health status of adolescent cancer survivors. *Clin Oncol Adolesc Young Adults* 2015; 5:87–95
- Amicucci M, Mastronuzzi A, Ciaralli I, et al. The management of children with cancer during the COVID-19 pandemic: a rapid review. *J Clin Med* 2020;9(11):3756
- Liu Y, Sundquist J, Sundquist K, Zheng D, Ji J. Mental health outcomes in parents of children with a cancer diagnosis in Sweden: A nationwide cohort study. *EClinicalMedicine* 2022;55:101734
- Garutti M, Cortiula F, Puglisi F. Seven shades of black thoughts: COVID-19 and its psychological consequences on cancer patients. *Front Oncol* 2020;10:1357
- Tsamakis K, Gavriatopoulou M, Schizas D, et al. Oncology during the COVID-19 pandemic: challenges, dilemmas and the psychosocial impact on cancer patients. *Oncol Lett* 2020;20(01): 441–447
- Wang Y, Duan Z, Ma Z, et al. Epidemiology of mental health problems among patients with cancer during COVID-19 pandemic. *Transl Psychiatry* 2020;10(01):263
- Darlington AE, Morgan JE, Wagland R, et al. COVID-19 and children with cancer: parents' experiences, anxieties and support needs. *Pediatr Blood Cancer* 2021;68(02):e28790
- Davies J, O'Connor M, Halkett GKB, Kelada L, Gottardo NG. Parents' experiences of childhood cancer during the COVID-19 pandemic: an Australian perspective. *J Pediatr Psychol* 2022;47(02):148–157
- Kotecha RS. Challenges posed by COVID-19 to children with cancer. *Lancet Oncol* 2020;21(05):e235
- van Gorp M, Maurice-Stam H, Teunissen LC, et al. No increase in psychosocial stress of Dutch children with cancer and their caregivers during the first months of the COVID-19 pandemic. *Pediatr Blood Cancer* 2021;68(02):e28827



- 30 Scoring the Strengths & Difficulties Questionnaire for 2–4 years old. Development and Well-Being Assessment (DAWBA). October 2015. Accessed March 3, 2021 at: <https://sdqinfo.org>
- 31 Scoring the Strengths & Difficulties Questionnaire for age 4–17 or 18+. Development and Well-Being Assessment (DAWBA). June 2016. Accessed March 3, 2021 at: <https://sdqinfo.org>
- 32 Domingues-Montanari S. Clinical and psychological effects of excessive screen time on children. *J Paediatr Child Health* 2017; 53(04):333–338
- 33 Bekar P, Erkul M, Efe E. Investigation of coronavirus anxiety and caregiving burden among the parents of children with cancer during the COVID-19 outbreak: a descriptive and cross-sectional study. *Eur J Cancer Care (Engl)* 2022;31(04):e13600
- 34 Zijlmans J, Teela L, van Ewijk H, et al. Mental and social health of children and adolescents with pre-existing mental or somatic problems during the COVID-19 pandemic lockdown. *Front Psychiatry* 2021;12:692853
- 35 Li X, Vanderloo LM, Maguire JL, et al; TARGet Kids! Collaboration. Public health preventive measures and child health behaviours during COVID-19: a cohort study. *Can J Public Health* 2021;112(05):831–842
- 36 Bergmann C, Dimitrova N, Alaslani K, et al. Young children's screen time during the first COVID-19 lockdown in 12 countries. *Sci Rep* 2022;12(01):2015
- 37 Twenge JM, Farley E. Not all screen time is created equal: associations with mental health vary by activity and gender. *Soc Psychiatry Psychiatr Epidemiol* 2021;56(02):207–217
- 38 Feng Y, Zhou C, Jia R, Wang Y, Fan X. Quality of life (QoL) and psychosocial outcomes in adult survivors of unilateral retinoblastoma (RB) in China. *J Ophthalmol* 2020;2020:4384251
- 39 van Dijk J, Imhof SM, Moll AC, et al. Quality of life of adult retinoblastoma survivors in the Netherlands. *Health Qual Life Outcomes* 2007;5:30
- 40 Baytan B, Aşut Ç, Çırpan Kantarcıoğlu A, Sezgin Evim M, Güneş AM. Health-related quality of life, depression, anxiety, and self-image in acute lymphocytic leukemia survivors. *Turk J Haematol* 2016;33(04):326–330
- 41 Hutchinson AD, Pfeiffer SM, Wilson C. Cancer-related cognitive impairment in children. *Curr Opin Support Palliat Care* 2017;11(01):70–75
- 42 Cheung YT, Sabin ND, Reddick WE, et al. Leukoencephalopathy and long-term neurobehavioural, neurocognitive, and brain imaging outcomes in survivors of childhood acute lymphoblastic leukaemia treated with chemotherapy: a longitudinal analysis. *Lancet Haematol* 2016;3(10):e456–e466
- 43 Bloom J, Lachman A, Gaxo E, Pillay J, Seedat S. Child, adolescent, and caregiver mental health difficulties and associated risk factors early in the COVID-19 pandemic in South Africa. *Child Adolesc Psychiatry Ment Health* 2022;16(01):65
- 44 Kauhanen L, Wan Mohd Yunus WMA, Lempinen L, et al. A systematic review of the mental health changes of children and young people before and during the COVID-19 pandemic. *Eur Child Adolesc Psychiatry* 2022 (e-pub ahead of print). Doi: 10.1007/s00787-022-02060-0
- 45 Bignardi G, Dalmaijer ES, Anwyll-Irvine AL, et al. Longitudinal increases in childhood depression symptoms during the COVID-19 lockdown. *Arch Dis Child* 2020;106(08):791–797
- 46 Sahril N, Ahmad NA, Idris IB, Sooryanarayana R, Abd Razak MA. Factors associated with mental health problems among Malaysian children: a large population-based study. *Children (Basel)* 2021;8(02):119
- 47 Cela L, Ardenti Morini F, Cortis E, et al. The psychophysical impact of COVID-19 lockdown on pediatric patients with rheumatological disease. *Minerva Pediatr (Torino)* 2022 (e-pub ahead of print). Doi: 10.23736/S2724-5276.22.06854-9
- 48 Guido CA, Amedeo I, Avenoso F, et al. Risk factors and mental health promotion strategies in children during COVID-19. *Front Public Health* 2020;8:580720
- 49 Isabel Tan XW, Mordiffi SZ, Lopez V, Leong K. Psychological distress in parents of children with cancer: a descriptive correlational study. *Asia Pac J Oncol Nurs* 2020;8(01):94–102
- 50 Aziza YDA, Wang ST, Huang MC. Unmet supportive care needs and psychological distress among parents of children with cancer in Indonesia. *Psychooncology* 2019;28(01):92–98
- 51 Rihm L, Dreier M, Rezvani F, Wiegand-Grefe S, Dirmaier J. The psychosocial situation of families caring for children with rare diseases during the COVID-19 pandemic: results of a cross-sectional online survey. *Orphanet J Rare Dis* 2022;17(01):449
- 52 Al-Abdulrazzaq D, Khalifa D, Alqaisi T, et al. Health-related quality of life of children and adolescents with type 1 diabetes during the COVID-19 pandemic in Kuwait. *Front Public Health* 2022; 10:1056967
- 53 Kim SJ, Lee S, Han H, Jung J, Yang SJ, Shin Y. Parental mental health and children's behaviors and media usage during COVID-19-related school closures. *J Korean Med Sci* 2021;36(25):e184