



## Case Report

## Impact of COVID-19 containment measures on children with cancer in Indonesia

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## ABSTRACT

**Introduction:** Containment measures to limit COVID-19 spreading profoundly impact children around the globe, especially in low- and middle-income countries such as Indonesia. The aim of this case series study is to uncover the impact that COVID-19 measures have on Indonesian children with cancer and their families.

**Materials and Methods:** A case series study was conducted in July 2021. Investigators identified three children diagnosed with cancer at an Indonesian referral hospital and studied their medical records. Caretakers were interviewed inside the hospital by an independent interviewer using a semi-structured questionnaire.

**Results:** This study presents three children with cancer and their families. Access to proper healthcare was hindered during the COVID-19 pandemic due to mobility restrictions, medical staff shortage, limited chemotherapy and blood products availability, postponed medical procedures, and delayed or modified treatment administration. Financial hardships resulted because caretakers lost their jobs due to lockdowns and medication costs were no longer fully covered by health-insurance. Children and their relatives suffered from mental health issues. Anxiety, depression, stress, and loneliness were caused by the fear of receiving suboptimal cancer treatment, serious concerns about financial difficulties, and restricted social interactions. All families believed that COVID-19 measures worsened their children's survival chances.

**Conclusion:** COVID-19 measures adversely impact children with cancer and their families in Indonesia, and most likely in other low- and middle-income countries as well. Disruptions in timely and adequate childhood cancer treatment administration may importantly deteriorate survival chances. Governments and policymakers should take these indirect effects into account to protect vulnerable children and their families.

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## 1. Introduction

On the 11<sup>th</sup> of March 2020, the WHO announced that COVID-19 would be considered a pandemic and provided

recommendations for containment measures.<sup>1</sup> Governments of both high-income countries (HIC) and low- and middle-income countries (LMIC) implemented similar measures to limit virus spreading.<sup>2</sup>

The Indonesian government for instance imposed business closures, school closures, travel restrictions, and

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lockdowns. This had an adverse impact on the nation's level of poverty, education, mental health, and access to healthcare.<sup>3</sup> The nature of these indirect effects is not unique to Indonesia but has been reported all over the world. However, the extent of the indirect effects is more salient in LMIC such as Indonesia, aggravating pre-existing socioeconomic and medical inequalities between HIC and LMIC.<sup>4</sup>

These indirect socioeconomic effects of COVID containment measures all play a role in the access to healthcare that vulnerable populations such as children with cancer have. Hospital audits and questionnaires among healthcare workers illustrated that childhood cancer services have been hampered worldwide. Yet little is known about the experiences of children with cancer and their families after the pandemic outbreak, especially in LMIC.<sup>5</sup>

The aim of this case series study is to uncover the impact that the COVID-19 containment measures have on children with cancer living in a LMIC, being Indonesia.

## 2. Materials and Methods

### 2.1. Setting

Indonesia is a lower middle-income country with 273 million inhabitants. This study was conducted at a large academic hospital on the island of Java, where yearly 180 children are diagnosed with a malignancy. Five pediatric-oncologists and 28 nurses supervise the pediatric-oncology ward.<sup>6</sup> Four hospital classes are differentiated: VIP, first, second, and third class. With higher rank, ward conditions improve and number of patient beds per hospital room decreases. Most patients are from lower socio-economic backgrounds and are hospitalized at the third-class ward.<sup>7</sup>

Starting from 2014, the Indonesian government has initiated an obligatory national health-insurance system. It covers all inpatient and outpatient hospital care and medication. The system combines a government-paid health-insurance for citizens with low socio-economic backgrounds and a contributory-based health-insurance for citizens with higher socio-economic backgrounds. Citizens with government-paid health-insurance solely have access to third class healthcare services.<sup>7</sup>

### 2.2. Study design

A case series study was performed in July 2021. Investigators identified three children with cancer and studied their medical records. Caretakers were interviewed inside the hospital by an independent interviewer using a semi-structured questionnaire. The questionnaire was based on a literature review. It contained open-ended and closed-ended questions. The latter were evaluated on two

to five-point rating scales. The interviews took 90-120 minutes. Informed consent was obtained. Case reports were checked by the families concerned.

## 3. Results

### 3.1. First case

A nine-year old girl was diagnosed with acute lymphoblastic leukemia in November 2020. She was hospitalized at the third-class ward and put on chemotherapy according to standard-risk protocol. Her family obtained health-insurance during hospitalization (Table 1).

#### 3.1.1. Financial hardships

During the COVID-19 pandemic her father, working as truck driver, lost his job and the family's only source of income due to reduced economic activities during the lockdown. Consequently, the family experienced hardships to pay cancer treatment. They were forced to sell their jewelry to finance the daily costs-of-living, transportation, and certain medicines.

#### 3.1.2. Access to healthcare

COVID-19 containment measures have importantly hindered their access to cancer treatment. Less medical staff has been present at the pediatric oncology ward as they were taking care of COVID-19 patients. Import of various chemotherapeutic drugs by the government, for example 6-mercaptopurine, had been disrupted due to supply chain obstructions during the lockdown. Consequently, certain medicines were no longer available inside the hospital. The parents tried to purchase these medicines outside the hospital. Consequently, these drugs must then be paid out-of-pocket and are not covered by health-insurance. Also, the availability of blood products has been limited. This implies that adherence with prescribed treatment schedules is no longer possible. Parents mention that psychosocial services at the hospital have also been restricted, although mental health issues of families have increased during the pandemic.

#### 3.1.3. Fear

The family has been living in fear during the pandemic. Not only the direct virus threat, but also concerns that cancer treatment will be further hindered by containment measures scares them. The parents fear that 6-mercaptopurine, which has been out-of-stock inside the hospital, can also no longer be purchased outside the clinic in the near future. In addition, they are afraid that the shortage of pediatric oncology staff will worsen because COVID-19

care was prioritized. Childhood cancer treatment will then become more and more marginalized and less capable of curing cancer. The family had considered using traditional medicine due to these obstacles during the pandemic.

#### 3.1.4. Isolation at COVID-room

Although the girl had no symptoms of COVID-19 infection, she was quarantined at the COVID-19 ward prior to admission at the pediatric oncology ward because she had a medical history of allergy and bronchitis. This isolation from family was a traumatic experience. She started overthinking and suffered from stress, dyspnoea, and panicked when she heard other people cough as she feared she would be contaminated with COVID-19 and die. She knew her aunt had passed away due to COVID-19 and feared the same fate. Ever since this experience, the girl has become silent, and her facial expressions show constant sadness.

#### 3.1.5. School closure

School closure has harmed their daughter's wellbeing and future prospects. Online education has been ineffective, explanations by teachers insufficient, and the subsequent overuse of gadgets generated stress in children. When children ask their parents to explain school subjects, their low-educated parents often lack appropriate knowledge, which increases tensions among family members.

#### 3.1.6. Mental health issues

The girl has experienced stress, depression, and loneliness during the pandemic. Her family members have also suffered from stress and loneliness. Especially the uncertainty regarding how long these containment measures would last, made coping difficult. Her older sister is afraid to seek employment to financially support her family now that her father is unemployed, as she might get infected with COVID-19 at the workplace and believes that this could directly endanger her sister with cancer.

#### 3.1.7. Evaluation

Unfortunately, the girl had a bone marrow relapse with central nervous system involvement in July 2021 and her condition has worsened ever since. The family believes that their daughter would have received better cancer treatment and better survival chances if the pandemic had not occurred, as the government could then take better care of non-COVID-19 patients as well.

### 3.2. Second case

An eleven-year-old boy was diagnosed with acute lymphoblastic leukemia and meningeal involvement in February 2021. His family had health-insurance and the boy was hospitalized at the third-class ward.

#### 3.2.1. Financial hardships

Due to limited economic activities during the lockdown, the father lost his job as laborer which was the family's only source of income. Despite financial help from relatives to cover daily costs of living and transportation to the hospital, their financial difficulties resulted in debts.

#### 3.2.2. Access to healthcare

COVID-19 measures have hindered their healthcare access. Not only because of their loss of income, but also because treatment administration has importantly been delayed. Availability of life saving blood products has been limited during the pandemic. Travel restrictions further hinder or halt cancer treatment. Indonesian citizens are not allowed to leave their municipality without proof of vaccination or negative PCR-test. However, only a minority of the Indonesian population has been vaccinated and the costs of rapid antigen tests are unaffordable for most Indonesians.

#### 3.2.3. Fear

The parents are deeply worried that cancer treatment and survival chances are suboptimal during the pandemic due to delays. The parents are also concerned about the direct virus threat. Staying inside this hospital, which is a referral center for COVID-19 patients, increases their risk of getting infected. Consequently, the parents considered abandoning treatment or turning to traditional medicine.

#### 3.2.4. Face masking, physical distancing, travel restrictions, and lockdowns

Containment measures have negatively impacted their child's already confined quality-of-life. Wearing a face mask when you are seriously ill is uncomfortable. Physical distancing reduces the intensity and quality of encounters with close family. Travel restrictions and lockdowns make meetings with relatives impossible and increase loneliness.

#### 3.2.5. School closure

School closure has adversely affected their son's wellbeing and future prospects. Online education harms children by stimulating them to play video games or games on their mobile phones. It disturbs their socioemotional development and increases feelings of loneliness and tenseness. The boy misses physical contact with pupils and friends.

#### 3.2.6. Mental health issues

The mother emphasizes that her son's psychological state has worsened due to COVID-19 measures. The boy often

cries because of stress, sadness, and loneliness. Also, the parents experience stress, anxiety, and solitude during the pandemic. It saddens the mother to see her son suffer under these COVID-19 restrictions, which exacerbate an already difficult situation. Their family members cannot visit them in hospital, her husband lost his job, and they feel completely alone in their fight.

### 3.2.7. Evaluation

The physical condition of the boy is worsening. He has become weaker, suffers from seizures, and is unable to talk. The parents are convinced that their child would have received better cancer treatment and survival chances if the pandemic had not occurred. Consequences of containment measures are worse than the virus itself. So many strict rules and regulations have been implemented, that they are afraid of what restrictions will come next. And how this will further hinder their son's treatment and reduce his chances of cure.

## 3.3. Third case

A two-year old boy was diagnosed with histiocytosis in July 2020. He was hospitalized at the third-class ward and registered for health-insurance. Chemotherapy was started and completed in January 2021. His condition worsened in May 2021, and he had to be hospitalized again.

### 3.3.1. Financial hardships

His father is a daily laborer, who has received no work orders since the pandemic outbreak. Hereby the family's only source of income was lost. The grandfather owns some land where agricultural products are grown for sale. Since the pandemic, the profits from these products have dropped due to reduced buyers' interest and lower prices. The family has faced difficulties to pay cancer treatment and had to sell their jewelry and goats.

### 3.3.2. Access to healthcare

Due to COVID-19 measures healthcare access has been hindered. Travel restrictions, lockdowns, and loss of income have been important obstacles. Required blood products have been lacking. Because oxygen has been out of stock at the hospital, the family needs to travel far to buy it. Yet travel restrictions have become increasingly strict. Without evidence of vaccination or negative COVID-test citizens are not allowed to leave their municipality. These vaccines or tests are however inaccessible or unaffordable for most Indonesians. This forces families to find alternative ways to reach the hospital, causing more delays, worsening their children's condition or deterring families to come to the

hospital at all.

### 3.3.3. Fear

The parents are worried about the direct virus threat. They are afraid that their son will be tested for COVID-19 during hospital admission and put in isolation while waiting for the test results. He then might get infected by others inside the hospital, which will worsen his condition and complicates achieving cure. They are also afraid that cancer treatment is suboptimal due to the government measures. Particularly the low stock of blood products is of great concern as their son frequently needs blood transfusions and without these his condition further deteriorates. This all eventually harms their child's survival chances.

### 3.3.4. Face masking, physical distancing, travel restrictions, and lockdowns

The government obligation of face masking has negatively impacted their son as his lungs are already corroded and wearing a mask gives him more breathing difficulties. Physical distancing hinders social interaction. Travel restrictions and lockdowns have forced the family to seek alternative routes to reach the hospital which has prolonged their travel time and causes unnecessary delays which also harm their son's condition.

### 3.3.5. Mental health issues

The parents have suffered from stress, anxiety, and loneliness during the pandemic. They worry who might take care of their sick child if they are infected by the virus. The government policies about physical distancing, restricted travel and community activities have limited their social relationships aggravating their feelings of loneliness.

### 3.3.6. Evaluation

The parents conclude that their child would have better survival chances if the pandemic had not occurred. Particularly because the blood stock would then have not been limited. Consequences of COVID-19 measures are worse than the virus itself. Parents emphasize that COVID-19 policies are devastating for people with low incomes. Governments and policy-makers should help poor people during lockdowns through distribution of free groceries or cash money to fulfil daily costs of living.

**Table 1:** Patient and family characteristics and the impact of COVID-19 measures

<b>Patient and Family Characteristics:</b>			
	<b>First case</b>	<b>Second case</b>	<b>Third case</b>
<b>Patient:</b>			
Age at diagnosis	9 years	11 years	2 years
Gender	Girl	Boy	Boy
Diagnosis	ALL*	ALL*, meningeal involvement	Histiocytosis
Treatment modality	Chemotherapy	Chemotherapy	Chemotherapy
Hospital class at diagnosis	Third class	Third class	Third class
Health-insurance status	Insured during hospitalization	Insured prior to onset illness	Insured during hospitalization
<b>Family:</b>			
Education level father	High school	Primary school	High school
Occupation father	Truck driver	Laborer	Laborer
Education level mother	High school	Primary school	High school
Occupation mother	Housewife	Housewife	Housewife
Marital status	Married	Married	Married
Total number of children	3	1	3 (one child has deceased)
Distance home to hospital	230 kilometers	150 kilometers	60 kilometers
Mode of transport	Borrowing vehicle	Renting vehicle	Private motorbike
Travel to hospital	Expensive, difficult, takes long	Expensive, difficult, takes long	Expensive, difficult, takes long
<b>Impact of Covid-19 Measures</b>			
<b>Healthcare Access:</b>			
Medical staff	Shortage	Shortage	Shortage
Chemotherapy	Not or less available	Not or less available	Available
Blood products	Not or less available	Not or less available	Not or less available
Oxygen	Not applicable	Not applicable	Not or less available
Travel restrictions and lockdowns delay/ modify treatment	Yes	Yes	Yes
Protocol adherence	Not possible	Not possible	Not possible
Chance of survival	Worsened	Worsened	Worsened
Consideration of:			
- Treatment abandonment	No	Yes	No
- Traditional medicine	Yes	Yes	Yes

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*Table 1 continued*

<b>Financial Situation:</b>			
Loss of income	Father lost job	Father lost job	Father lost job
Health-insurance	Chemotherapy bought outside hospital is not covered	Chemotherapy bought outside hospital is not covered	Oxygen bought outside hospital is not covered
Financial hardships	Selling valuables to pay cancer treatment	Costs of cancer treatment resulted in debts	Selling valuables to pay cancer treatment
<b>Mental Health:</b>			
Mental health child	Anxiety, depression, stress, loneliness, taciturn	Sadness, stress, loneliness, tearful	Child is too young to report this
School closure	Harms cognitive and social development	Harms cognitive and social development	Child does not attend school yet
Mental health parents	Anxiety, stress, loneliness	Anxiety, stress, loneliness	Anxiety, stress, loneliness

#### 4. Discussion

The percentage of children being diagnosed with cancer in LMIC is expected to increase in the future.<sup>8</sup> Before the COVID-19 pandemic, it was already known that this rise in childhood cancer diagnoses in LMIC will exacerbate the existing challenges in the unavailability and unaffordability of childhood cancer care.<sup>9</sup> The COVID-19 pandemic further augments these challenges and deepens the gap between HIC and LMIC.<sup>5</sup> This study illustrates that children with cancer and their families in a resource-limited setting face financial hardships, hindered healthcare access, and mental health problems due to government containment measures and induced fear. Parents are not only afraid of the virus, but also of the adverse impact COVID measures have on their children's cancer treatment and chances of survival.

Families of all three children with cancer reported reduced healthcare access. Next to travel restrictions and financial challenges that families face, a reduction in medical staff, medicines, blood products, psychosocial services, and oxygen has been appraised by the families. Pediatric oncology departments in other LMIC face similar challenges. A study among 34 pediatric oncology centers in the Middle-East, North-Africa, and West-Asia region reported that patients were unable to keep appointed visits because of travel restrictions and the pandemic's economic impact.<sup>10</sup> A cross-sectional survey among 213 institutions in 79 countries concluded that although childhood cancer care was substantially impaired by the pandemic worldwide, the unavailability of chemotherapeutic agents, treatment abandonment, and interruptions in radiotherapy were more prominent in LMIC.<sup>5</sup>

Mental health issues have been reported in all three cases. Stress, depression, anxiety, and loneliness of both children and family members were caused by financial difficulties, restricted social interactions, and the fear of receiving suboptimal cancer treatment and consequent lower survival chances. Literature regarding the effects of the COVID-19 pandemic on the mental health of children living in LMIC is present. Aggression, fear, clinginess, distractions, adjustment problems, depression, stress, substance abuse, risky behaviors, self-harm, suicidal ideation or attempt are mentioned, especially among vulnerable children.<sup>11,12</sup>

The main limitation of this study is the small sample size of the three participating families. These children were all treated at the same hospital. The results are therefore challenging to generalize to children with cancer and their families in other LMIC.

#### 5. Conclusion

This case series study accentuates that COVID-19 measures adversely impact children with cancer and their families

in Indonesia. Disruptions in timely and adequate childhood cancer treatment administration may importantly deteriorate chances of cure and survival. Dedicated focus and research on a wider scale is needed. Governments and policymakers should take the indirect effects of COVID-19 containment measures into account to protect vulnerable children and their families.

#### 6. Author Contributions

1. *I El Salih*: conceptualized and designed study, analyzed and interpreted data, drafted initial manuscript, approved final manuscript as submitted.
2. *PH Widjajanto*: conceptualized and designed study, collected data, critically revised the manuscript, approved final manuscript as submitted.
3. *SWA Sutrisni*: collected data, critically revised the manuscript, approved final manuscript as submitted
4. *IO Hoogland*: analyzed and interpreted data, drafted initial manuscript, approved final manuscript as submitted
5. *GJL Kaspers*: conceptualized and designed study, critically revised the manuscript, approved final manuscript as submitted.
6. *S Mostert*: conceptualized and designed study, analyzed and interpreted data, critically revised the manuscript, approved final manuscript as submitted.

#### 7. Data Availability Statement

Data available on request from the authors.

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#### 9. Conflict of Interests

The authors have no conflict of interest to declare.


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