POLICY BRIEF

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School reintegration for children with cancer: insights from parents of child survivors

HIGHLIGHTS

In Malaysia, over 4,000 children (0-19 years old) were diagnosed with cancer between year 2007 and 2011\(^1\). Treatment for childhood cancers include surgery, radiotherapy, and chemotherapy, with the period varying from weeks to years.

Issue

Most childhood cancer patients have to miss school frequently. This applies especially to children who live far away from public paediatric oncology hospitals\(^2\), and thus have to travel interstate for their treatment. While the Ministry of Education has set up a ‘school-within hospital’ (sekolah dalam hospital) service for warded children to catch up on their studies, Malaysia still lacks a formal re-entry programme when child survivors who have completed treatment return to school.

*Current hospitals in Malaysia that contain a paediatric oncology unit include: HUKM, HKL, PPUM, Hospital Wanita & Kanak-Kanak Sabah, Hospital Raja Perempuan Bainun Ipoh, Hospital Sultan Ismail Johor, Hospital Pulau Pinang, Hospital University Sains Malaysia, Sultanah Nur Zahirah, Hospital Umum Sarawak.

Why does this matter?

Schools can be a respite – and provide a feeling of ‘returning to normalcy’ – for children who have survived a long illness from diseases such as cancer or other chronic illnesses and have been isolated from peers as well as social environments\(^2\). Children with positive relationships with their peers and teachers are reported to be more resilient than those who do not\(^3\).

In addition, by helping the child develop their intellect, social skills, and peer relationships, schools are also the best avenue for social, emotional, and cognitive development\(^4\). However, child survivors often face the following challenges upon re-entry:

Drop in academic performance

Absence from school and learning disabilities as a result of treatment could affect the child’s academic performance. Even after completion of treatment, residual effects such as fatigue or infections could also result in poor attendance\(^5\).

Affected Psychosocial development

Children with cancer and chronic illnesses are at risk of rejection from their peers due to physical and mental changes they have undergone due to the disease. Social isolation during treatment can also have a negative impact on the child’s academic and psychosocial development\(^6\).

References

BACKGROUND

Statistics¹

1. Slightly over 4,000 children were diagnosed with cancer between years 2007 and 2011. Cancer incidence was slightly higher in boys than in girls.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Sex</th>
<th>Number</th>
<th>Percentages</th>
<th>ASR Per 100,000</th>
<th>ASR Per million</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-19</td>
<td>Male</td>
<td>2260</td>
<td>55.3%</td>
<td>3.5</td>
<td>34.8</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>1829</td>
<td>44.7%</td>
<td>2.9</td>
<td>29.1</td>
</tr>
</tbody>
</table>

2. The most common types of childhood cancer include: leukaemia, lymphoma, brain/nervous system, and ovary.

3. Most childhood cancers occur at 0-4 years and 15-19 years of age

<table>
<thead>
<tr>
<th>Age group</th>
<th>Cancer incidence rate* (boys and girls)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4, 15-19</td>
<td>19</td>
</tr>
<tr>
<td>5-9</td>
<td>11</td>
</tr>
<tr>
<td>10-14</td>
<td>13</td>
</tr>
</tbody>
</table>

*incidence per 100,000 population

4. Survival rates

<table>
<thead>
<tr>
<th>Age group</th>
<th>Cancer type</th>
<th>5-year relative survival rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>Lymphoma, Leukaemia</td>
<td>66.3, 69.3</td>
</tr>
<tr>
<td>5-9</td>
<td>Lymphoma, Leukaemia</td>
<td>67.0, 62.1</td>
</tr>
<tr>
<td>10-14</td>
<td>Lymphoma, Leukaemia</td>
<td>60.0, 47.5</td>
</tr>
</tbody>
</table>
Focus Group Discussion with parents/caregivers of children with cancer

In order to determine the challenges of school reintegration of children with cancer, the National Cancer Society of Malaysia (NCSM) conducted two focus group discussions with caregivers of children with cancer.

Consisting of parents or older siblings, these caregivers and the children have previously stayed at NCSM’s Children’s Home of Hope, which provides free accommodation for families from out of Kuala Lumpur, and whose children/sibling are receiving treatment at Hospital Kuala Lumpur, the largest national treatment centre for pediatric cancer.

The table below describes the condition of the children, their education level upon diagnosis, as well as the period of school missed.

<table>
<thead>
<tr>
<th>Disease</th>
<th>Child</th>
<th>Education level at diagnosis</th>
<th>Period of school missed</th>
<th>Age of parent or caregiver interviewed</th>
<th>Occupation of parent/caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leukaemia (ALL)</td>
<td>Child 1</td>
<td>Kindergarten</td>
<td>8 months</td>
<td>36</td>
<td>Housewife</td>
</tr>
<tr>
<td></td>
<td>Child 2</td>
<td>Kindergarten</td>
<td>1 year</td>
<td>42</td>
<td>Housewife</td>
</tr>
<tr>
<td></td>
<td>Child 3</td>
<td>Kindergarten</td>
<td>1 year 6 months</td>
<td>42</td>
<td>Housewife</td>
</tr>
<tr>
<td></td>
<td>Child 4</td>
<td>Primary school</td>
<td>1 year 6 months</td>
<td>45</td>
<td>Clerk</td>
</tr>
<tr>
<td>Leukaemia (APML)</td>
<td>Child 5</td>
<td>Secondary school</td>
<td>3 months</td>
<td>39</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Yolk Sac Tumour (brain tumour)</td>
<td>Child 6</td>
<td>Primary school</td>
<td>6 months</td>
<td>53</td>
<td>Assistant mechanical engineer</td>
</tr>
<tr>
<td>Hodgkin’s Lymphoma</td>
<td>Child 7</td>
<td>Primary school</td>
<td>8 months</td>
<td>44</td>
<td>Small business owner</td>
</tr>
<tr>
<td>T-cell lymphoma</td>
<td>Child 8</td>
<td>Primary school</td>
<td>2 years</td>
<td>29</td>
<td>Clerk</td>
</tr>
</tbody>
</table>

Questions

Questions asked were framed around the following themes:

1. whether the school supported the child’s academic progress during treatment and prior to re-entry.
2. whether the child received any academic support after re-entry.
3. whether the child received any emotional support after re-entry.

From the answers, thematic qualitative analysis was performed to cluster challenges faced by these children as well as to formulate recommendations to key stakeholders including the Ministry of Education, Malaysia.
SCHOOL REINTEGRATION FOR CHILDREN WITH CANCER

Overall recommendation

A school re-integration model should be created and implemented for children with cancer and other chronic illnesses under aegis of the Ministry of Education, overseen by a steering committee consisting of parents of children with cancer, educators, relevant healthcare professionals and NGOs representing children with cancer.

CHALLENGE 1

Lack of a formal system that supports the child’s academic progress during treatment and prior to re-entry

1. When informed about the child’s diagnosis and impending absence, the school did not offer any academic assistance: any learning materials (textbooks) and homework provided by the teachers were on an ad-hoc and voluntary basis.

2. Despite there being the availability of ‘school-within-hospital’ service, there was no communication or connection between this entity and the child’s school about the child’s academic progression during treatment.

3. No formal assessments were carried out to determine the child’s academic ‘level’ upon re-entry. Any decision on re-entry point, including whether the child needed to be in ‘special needs’ classes, was arbitrary.

For instance, one child missed a year of classes right after completing primary school. At re-entry, the decision to enroll the child into Form 1 or Form 2 was left to the parent.

RECOMMENDATIONS

The creation of a school re-entry model which should include:

1. a navigation guideline for parents, as well as clinical and academic staff: with the process beginning from point of diagnosis, and ending after successful re-integration (when the child has caught up with their re-entry academically). 8

2. the appointment of a hospital-based officer in paediatric wards for children with cancer and other chronic diseases. This liaison will be responsible for coordinating communication on the child’s academic progress between the school, the hospital-based school teacher and parents upon diagnosis until successful re-integration 9.

3. the identification and development of suitable online programmes to help children, parents, and teachers manage academic requirements from the hospital or during convalescence at home 10.

4. An assessment process to determine the academic capabilities (and subsequently re-entry point) specifically for children with long absences from school due to chronic illness such as cancer 11.

8. Association of Pediatric Hematology Oncology Education Specialists. APHOES practice recommendations for managing the educational needs of pediatric hematology and oncology patients. Stony Brook, NY: Searles Graphics; 2011
**CHALLENGE 2**

**Lack of academic support for the child at public schools after re-entry post treatment.**

1. Some teachers were frustrated by a lack of progress by the child, and expressed it to the parents. Some eventually ‘gave up’ on teaching the child.

2. Some children who had concentration and fatigue issues, or who suffered from the side-effects of treatment, were pressured to ‘tough it out’ by the teachers.

3. No additional classes were held for children who had fallen behind in the syllabus in public schools. Children who had returned to school did not receive any coaching or tutoring at the school.

4. Parents have to inform and periodically update the school of their child’s past illness at the start of every school year. They also need to resubmit documents (in hardcopy) continuously as the information is not recorded in the system.

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**RECOMMENDATIONS**

The school re-entry model should include:

1. a designated staff-member within the school to coordinate the school re-entry programme. Possible candidates include the school counsellor\(^\text{11}\), who can aid in determining whether the school is meeting the child’s academic needs\(^\text{12}\), and whether any delays are normal (in line with other children without cancer or other chronic illnesses) or due to the side effects of the illness or treatment\(^\text{13,14}\).

2. guidance on developing individualised education plans for children upon re-entry\(^\text{7}\).

3. compulsory courses, workshops, or training programmes that aim to improve the educator's skills on supporting children diagnosed with chronic illnesses such as cancer\(^\text{15}\). Teachers are often unconfident and unable to manage these children due to a lack of knowledge about the disease, expectations, and the reactions of the child’s classmates\(^\text{2}\).

4. the adoption of Electronic Health Record (EHR) systems in all schools in Malaysia, as is increasingly used in other countries such as the US\(^\text{16}\).

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CHALLENGE 3
Children who return to school were not accepted by their peers, and even bullied. In addition, schools do not provide emotional support or assess the mental wellness of these children. Often, the children who were teased and bullied tried to hide it from their parents.

1. Some children were teased by their peers, such as being called ‘stupid’, for falling behind in their studies.

2. Some children were isolated as their peers thought that cancer was contagious. Some were teased and harassed for having to wear surgical masks.

3. A child was pushed down the staircase and had their hair was pulled. The parent of the aggressor, when confronted, questioned the sick child’s parents on their decision to keep their child in a public school. No action was taken by the school, and the parent of the child survivor eventually sent the child to a special needs school.

4. Some child survivors insisted on joining extra-curricular activities despite fatigue, for fear of being teased or left out.

5. While each school had counsellors, the parents felt that the counsellors focused more on children with disciplinary problems and did not assist children with cancer or other chronic illnesses who had returned to school.

RECOMMENDATIONS
The school re-entry model should include:

1. Workshops to improve knowledge about cancer for peers as well as parents: a better understanding of the disease can minimise their fear and promote more interaction with their chronically ill classmates:

   (a) Children of older ages should have guided discussions, whereas:

   (b) Children of younger ages could have the issue shared via other storytelling formats, such as puppet shows.

2. The designated staff-member coordinating the school re-entry programme (as outlined in Recommendation 1 for Challenge 2) should also determine whether the child’s emotional needs are met.
