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Problems Faced by Children with Cancer in Sarawak, Malaysia

Parveen Kaur[1*]
[1]Faculty of Social Sciences, University Malaysia Sarawak, Jalan Datuk Mohamad Musa, 94300 Kota Samarahan, Malaysia
sspkaur@unimas.my

Arif Jawaid[2]
[2]Lahore Garrison University, Street 6, Sector C DHA Phase 6, Lahore, Punjab, Pakistan
a.jawaid@lgu.pk

Khalil ur Rehman Muhammad Gul Sher [3]
[3]Umm AlQura University, 21955 Makkah, Saudi Arabia
k.sher@uau.ac.sa

Abdul Khaliq Alvi[4]
[4]Lahore Garrison University, Street 6, Sector C DHA Phase 6, Lahore, Punjab, Pakistan
a.alvi@lgu.pk

Mazhar Farid Chishti[5]
[5]Lahore Garrison University, Street 6, Sector C DHA Phase 6, Lahore, Punjab, Pakistan
m.chishti@lgu.pk

Abstract

This study aims to examine the demographic profile of children with cancer, mode of transportation to the hospital, financial aid, knowledge and sources of knowledge of parents and coping strategies by the parents of children with cancer via comparative qualitative research methods. It is found that social support is the fundamental base that every family should have. In conclusion, parents must know how to handle difficult situations wisely because they are the main

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pillars of a family and they need to be positive in order to help their ill child.

Keywords: cancer, children, Sarawak, problems, childhood.

Problemas enfrentados por niños con cáncer en Sarawak, Malasia

Resumen

Este estudio tiene como objetivo examinar el perfil demográfico de los niños con cáncer, el modo de transporte al hospital, la ayuda financiera, el conocimiento y las fuentes de conocimiento de los padres y las estrategias de afrontamiento de los padres de niños con cáncer a través de métodos comparativos de investigación cualitativa. Se encuentra que el apoyo social es la base fundamental que toda familia debería tener. En conclusión, los padres deben saber cómo manejar las situaciones difíciles con prudencia porque son los pilares principales de una familia y deben ser positivos para ayudar a su hijo enfermo.

Palabras clave: cáncer, niños, Sarawak, problemas, infancia.

1. INTRODUCTION

Sarawak is the largest state in Malaysia with a land area of 124.5 thousand square kilometres. Despite the abundance of natural resources, the large area causes hardship in accessing issues. Based on the National Statistics of 2012, Sarawak has one of the highest poverty incidences in Malaysia. This shows that the people of Sarawak do have financial and accessibility problems in seeking medical services. Since independence, the government has been the main provider of health care. Inefficiency in health care in Sarawak is due to two main factors: 1) large states with many rural areas that need to be covered and 2) irregular or low monetary income (KHOO, 2009). Thus, medical access in Sarawak is rather limited compared to other states. According to KHOO (2009), in order to provide access to health care in a large state, the challenges faced include how to deliver health care in a non-communicable, vast area, relatively low income and remote area successfully.

Childhood cancer is an increasing and prevalent type of chronic illness worldwide. In Malaysia, for example, National Cancer Registry Report indicated that approximately 37 in every 100,000 Malaysian children aged 0 to 15 years are at the risk of developing cancer with a slightly higher incidence in males compared to females. About 37,000 new cancer cases and 22,000 cancer deaths were reported annually nationwide. Among the total population of 29.7 million as of 2013, 3 700 children are expected to be diagnosed with cancer every year. Whilst childhood cancer makes up only less than 10% of the total number of newly reported cancer cases every year. It is a significant cause of child mortality in the country and the incidence is increasing.

According to WOODS, YOUNG & HENEY (2005), experiencing childhood cancer is a traumatic experience. Childhood cancer would affect the child in various ways such as social relationship, lack of peer support, identity and biography, and uncertainty and fear. Social relationship refers to how cancer negatively affects the child’s friendships and normal social activities.

They will find it difficult to maintain a normal social life with the illness. Normal children without illness go to school but children with cancer are often forced to postpone or drop out of school for treatment. According to WILLIAM, CARROLL, & JESSICA (2003) lack of peer support is also experienced by those who have problems making friends, as the friends do not thoroughly understand what cancer is, they might alienate or even bully the child with cancer.

Various studies show numerous psychological distresses arise among the family when a child has cancer. According to WOODS ET AL. (2005), stress increases due to the problems such as parental employment problems, lower level of social support, child behaviour problems, increased the perception of illness strains, perceived life threat and treatment intensity and avoidant/passive thought of coping styles. Majority of studies suggest that, at some point of time, the parents display a range of emotional challenges especially anxiety and stress symptoms and these two were found to be significantly correlated (OW, 2003).

When faced with difficulties, most people tend to adapt to the problem and try to cope. The skill to cope is a human ability to adapt mentally and behaviourally when faced with a shocking situation (DRENCH, M., NOONAN, A., SHARBY, N., & VENTURA, 2012). However, the process of accepting a difficult situation might be different for each person. A person might be adaptive to the problem and will be more positive when looking at the problem (FERNANDEZ, 2017; AHMAD & AHMAD, 2018). However, there are individuals who become maladaptive which leads to more negative reasoning. There are three classic models for constructive coping which are:

1. Appraisal-Focused coping

An individual will seek for the meaning behind their problem. They justify the problem by seeking its meaning. An adaptive person will logically reason with themselves by comparing their lives with others who are in worse conditions than them like "It could be worse for other people; I better be grateful". A maladaptive person might blame God or others for their suffering.

2. Problem-Focused coping

An individual will focus on solving the problem. They will cope well if they managed to solve the problem. Thus, their aim would be focused on looking for a cure, almost to the point of being obsessive. Alternately, in others, they might develop other measures of satisfaction. If the patient is severely ill, their recovery will not be as successful as other healthy people. Thus, they will shift their aim to other achievable successes like helping others with the same disease.

3. Emotion-Focused coping

Others might cope with the problem by dealing with the emotional aspects that are related to the problem. Managing emotional aspects will reduce stress and negative feelings through counselling, sharing emotion and social support. However, maladaptive persons might try drugs or injure themselves in order to forget their suffering.

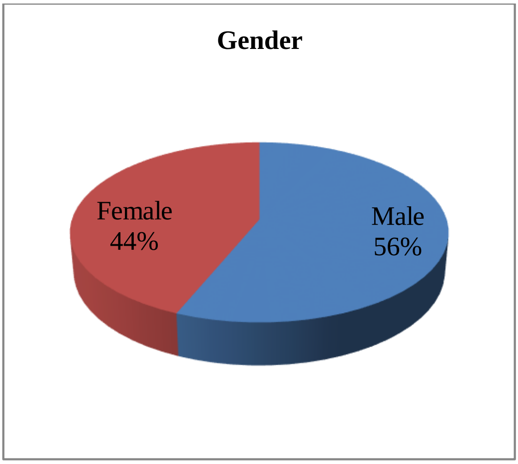
This study intends to examine demographic profile of children with cancer and their parents, mode of transportation to the hospital, financial aid, knowledge and sources of knowledge of parents and coping strategies by the parents of children with cancer.

2. METHODOLOGY

Ethical approval was granted by Sarawak Children's Cancer Society (SCCS), a local organization providing shelter and aid for the cancer children and their families and Sarawak General Hospital (SGH). A total sample of 16 parents of children with cancer was interviewed. These parents were invited to participate in this research while they were visiting the hospital or staying in the accommodation provided by the Sarawak Children's Cancer Society (SCCS). Parents of terminally ill children diagnosed during the study period were excluded. Sixteen parents out of twenty (80%) agreed to participate – all consists of Sarawak natives, Malays and also Chinese. (62.5%) were mothers and most of them claimed to receive family support. The interview was conducted with the 16 parents by using simple English language in order for them to understand the questions well. Malay language was used for those who were unable to understand well in English language. An interview schedule was used to interview the parents face to face.

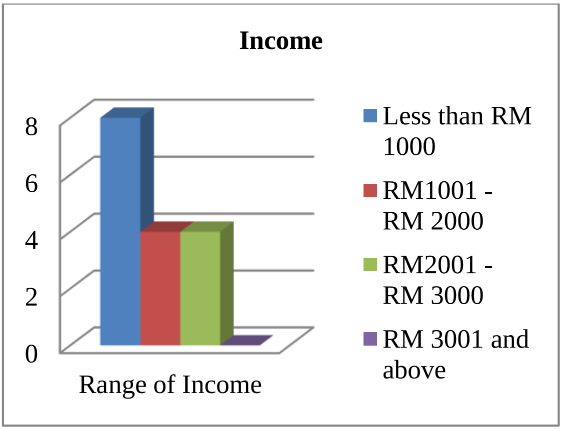
3. RESULTS

3.1. Demographic profile of children with cancer and their parents



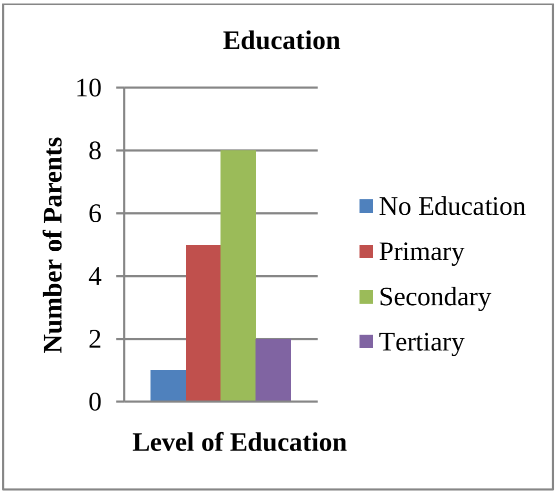
Pie Chart 1: Gender division of paediatric patients

Based on the Pie Chart 1, the male paediatric patients (55%) outnumbered the female paediatric patients (45%) by 10%. These gave a clear outline that the number of male paediatric has a higher risk of getting cancer compared to the female paediatric cancer in Sarawak. This statistic went well with the number of males (1,380,900) surpasses the number of females (1,202,100) in Sarawak.



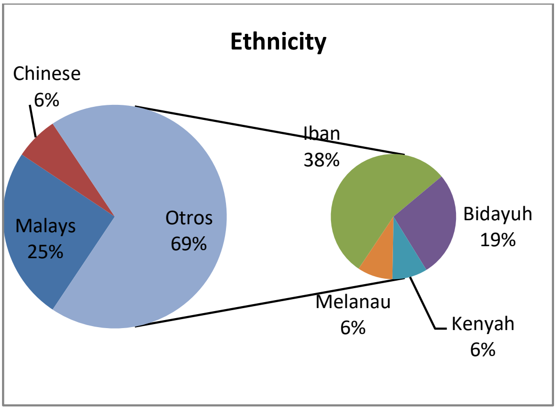
Graph 1: Income of parents

Based on Graph 1, the highest number of parents (50%) having children cancer have the range of income less than RM 1000, whilst none of the parents have an income more than RM 3000. There is an average number of parents (67%) who have an income range between RM 1001 – RM 2000 and RM 2001 – RM 3000, respectively. Parents who have income lesser than RM 1000 are due to the inability for both parents to continue their careers in order to take turn in caring for their sick child. Parents who have an income range between RM1000 up to RM 3000 have careers. In this case the fathers earned money to support their children's cost of treatment and other living expenses while the mother took care of the sick child.



Graph 2: Level of education of parents

Based on Graph 2, it is clearly showed that most parents (50%) only managed to finish secondary school. This also shows their lack of knowledge of cancer. There was one case that the parent did not receive any proper education and is considered as an illiterate as he did not know alphabets and only knows digit and numbers. Parents who completed their tertiary study (12.5%), show they have a wider knowledge of cancer. They are well aware of the treatment, the proper way of handling the sick child and the symptoms. The number of parents who only managed to finish their primary or did not even finish their primary school (31.25%) has a very low understanding of this chronic illness.



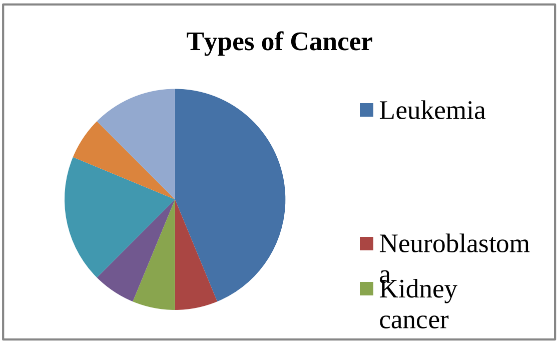
Pie chart 2: The ethnicity of children with cancer.

The pie chart above is on the various types of the ethnicity of children with cancer in Sarawak. This pie chart clearly shows that the majority native in Sarawak, the Iban, has the highest percentage of childhood cancer (6%), followed by Malays (4%). Although the Bidayuh is in 4th place in terms of their population in Sarawak with 205,900 people, they surpass the Chinese, who has the population of 596,100 people, in terms of the children contracted with cancer with the ratio of 1:3. As for the other Sarawak natives such as Melanau and Kenyah, the rate of childhood cancer is considered low compared to other ethnics.

Table 1: Types of cancer and duration

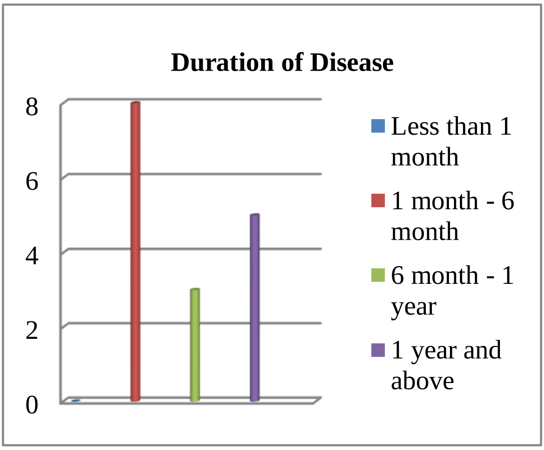
Types of paediatric cancer	**Number of cases**
Leukaemia	7 (43.75%)
Neuroblastoma	1 (6.25%)

Kidney cancer (Wilms's cancer)	1 (6.25%)
Lymphoma	1 (6.25%)
Brain tumour	3 (18.75%)
Nasopharyngeal Cancer	1 (6.25%)
Colorectal cancer	2 (12.5%)



Pie chart 3: Types of children's cancer

Table 1 and Pie chart 3 clearly show the types of paediatric cancer and also the number of children that suffer from the illness. Through the observation over the statistics, leukaemia can be said as the most common childhood cancer which made up to 7 out of 16 children or 43.75% which is almost half. This finding truly proves that leukaemia, the cancer of bone marrow and blood cancer are the most common cancer among children which account for about 31% of all childhood cancers in the world. The second type of cancer which the children suffer is brain tumour. The number of cases of this illness is 3 out of 16 children or equivalent to 18.75%. Our findings do support the fact that brain tumour recorded the second most common cancer in children, making up about 21% of the total number of children with cancer in the world. Next, the result shows that there are only 2 children which are 12.5% who suffer from colorectal cancer. Lastly, Neuroblastoma, Wilms'cancer, Lymphoma and Nasopharyngeal show 1 child out of 16 which is only 6.25% who have these.



Bar chart 1: Duration of the disease

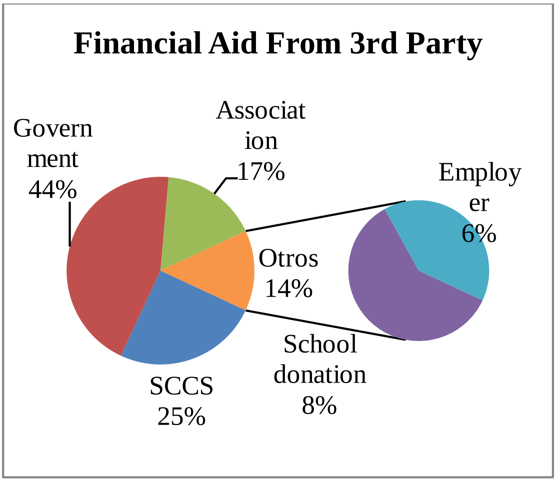
As shown in the bar chart above, the highest number of children having cancer between 1 month to 6 months is 8 out of 16, occupying half of the sample (50%). Next, 5 children suffer from cancer with the duration of 1 year and above and there are 3 of them having this illness for 6 months to a year. In a sample of 16 patients, there are no children who had cancer recently. By using the questionnaire, based on the parents' response, most of the children receive chemotherapy and radiotherapy which are the two most common treatments for cancer. According to the parents, most of their children easily fall sick and develop very high fever. The children will easily get tired, pale face, weight loss, headache, vomiting and high fever.

3.2. Mode of transportation to the hospital and financial aid

Table 2: Modes of transportation to the hospital

Transport used from home to hospital	Frequency
Bus	2
Personal vehicle	8
Express boat	0
Aeroplane	5
Bus and aeroplane	1

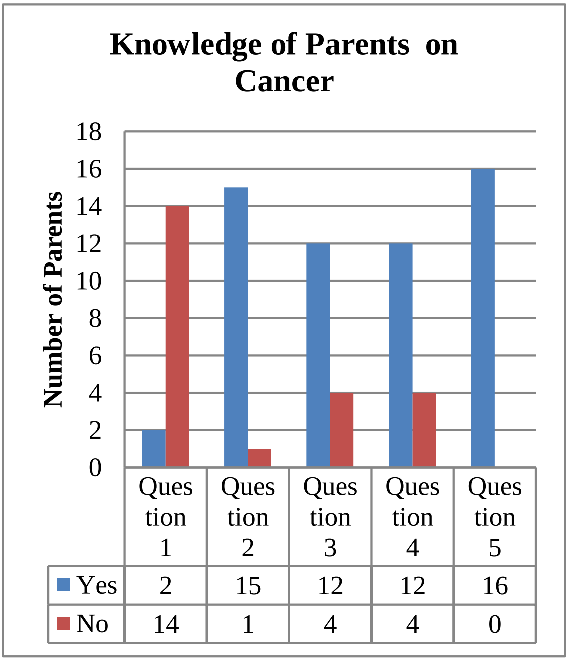
Table 2 shows the frequency and how the parents travel all the way from their home to the hospital in the city area, Kuching to seek treatment for their child. As we can see, 8 parents, which is half of them travel to the hospital by their personal vehicles. After further investigation, out of the 8 parents, 5 of them choose to travel by their personal vehicles because their homes are near to the hospital. The range of the distance of their home and the hospital is between 5km – 60km and the travel period is around 2 hours' drive. Parents have to sacrifice their strength and energy to travel to and fro from the hospital every day in order to visit their children who are admitted in the paediatric oncology ward at Sarawak General Hospital (SGH). On the other hand, the remaining 3 parents used personal vehicle although their home is far away from the hospital which is between 200km – 600km. The journey takes at least 2 hours and at most 12 hours of driving.



Pie chart 4: Financial aid from the third party

Referring to the pie chart 4, most parents receive financial aids from the Sarawak Children Cancer Society (SCCS) since they also provide the basic necessities for both parent and child. These parents come from rural areas or far places within Sarawak such as Tubau, Betong, Oya, Simunjan, Tatau, Belaga, Miri, Sibu and Mukah. Besides, the government also plays a role in subsidizing the cost of treatment to patients who cannot afford to receive treatment from private hospitals. Most of the treatments for cancer are very costly and expensive usually costing up to half a million Ringgit Malaysia for the whole process of curing the child depending on the type of cancer of the child and his/her stage of cancer. The government provides affordable price for treatment of cancer for children which costs less than 100 thousand Ringgit Malaysia including the cost of surgery, chemotherapy, radiotherapy and prescription of medicine and other supplements. This lessens the burden of the parents who cannot afford to pay for the child's medical fees. There is one parent who received financial support from Tabung Baitumal *Sarawak* which is one of the organizations set up by the Government of Sarawak. Besides, with the support of some associations and non-profit organizations such as National Council Cancer (MAKNA), parent from lower-income level are able to afford on paying the child's medical fees. Other than that, parents also received financial aids from other sources such as the school donation (collected from parents, teachers, school authority and students of the child's school) and the parents' company where the employer pays for the child medical fees.

3.3. Knowledge and sources of knowledge of parents on cancer



	Question 1	Question 2	Question 3	Question 4	Question 5
🟦 Yes	2	15	12	12	16
🟥 No	14	1	4	4	0

Graph 3: Knowledge of parents on cancer

Based on the graph 3, dichotomous questions (Yes/No) were answered to the parents to identify their knowledge about cancer. Those 5 questions were:

1. Do parents have any knowledge about cancer previously?
2. Do parents seek medical assistance immediately when their children show the symptoms of the disease?
3. Do they seek for any traditional treatment for cancer?
4. Do the parents have any superstitious belief?

5. Do parents have any knowledge about cancer after their child confronted with the disease?

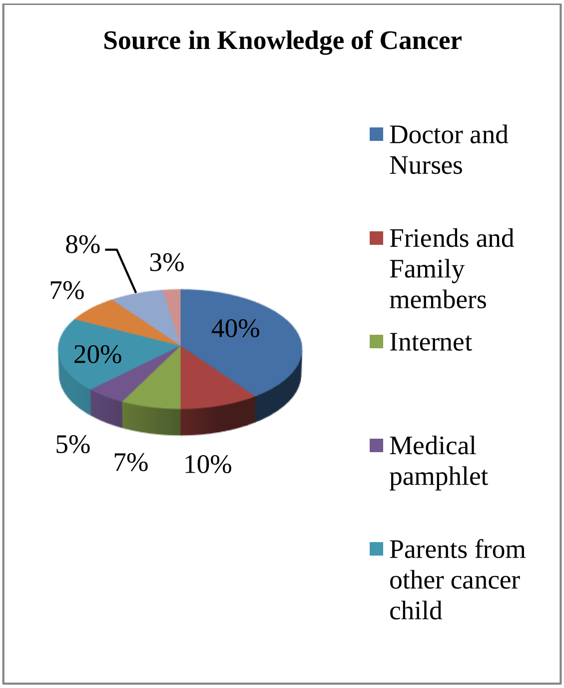
Based on our findings, most parents answered “Yes” to the questions asked. For question 1, most of the parents did not have any previous knowledge about cancer. When the symptom of cancer appeared, they assume their child only had typical sickness. They did seek medical assistance immediately after their child showed the symptoms of sickness (Question 2). In some significant symptoms, the doctor identified immediately that the child contracted cancer. The children were hospitalised immediately right after the doctor detected the disease. Whilst there are some with ordinary symptoms like fever, headache, felt easily tired and etc. where the doctor assumed the child contracted ordinary sickness. The doctor gave some prescription to the children, but it did not work on them. Only after the whole process of check-up, then the doctor found the children have cancer.

In Question 3 and 4, most of the parents have a superficial belief. They seek traditional medical assistance when their children showed symptoms before they saw the doctors. In some cases, the parents held believe in their ancestors’ culture (especially the Ibans) that the child was assumed to be possessed by some kind of bad spirit or evil aura around them. But when there is not any progress in treating the child traditionally, they decided to consult doctors. In some other cases, the parents seek traditional medical assistance while the children were seeking treatment from doctors. They tried to find another alternative way to cure their child, but the hope seems to be gone when the child was incurable by traditional medical assistance.

There are parents who stand by their religious and do not believe any other medical treatment besides than the one from the medical doctors. These parents do not believe in superstitions and highly dependable on the help of doctors. They keep put faith and hope with prayers.

For Question 5, after the children contracted cancer, the parents then began to have a general knowledge about what cancer is. The parents then knew better the conditions of their children. Although overall all the parents have knowledge on cancer, there are some of the parents still in questions of why and how their children contracted the disease even after they have been explained by the doctor-in-charge or any other sources on cancer that they can get.

Although the parents have knowledge of cancer, they are still in doubt about their children's health conditions and what will the disease lead their children in the future. They know how chronic the disease is, but they can only highly dependent on two sources, the capability of the doctor in treating their children and miracle.



Pie chart 5: Source of knowledge of cancer

According to the pie chart 5, the parents depend on information from the doctors and nurses regarding their child's disease. They consult the doctors to know their children's condition in detail. Besides doctors and nurses, some parents seek other sources to know more about their children's conditions such as through friends and family members, internet, medical pamphlets, journals, articles, TV shows, advertisement, workshop and seminar. The parents who received tertiary education or manage to complete their secondary education (refer to Graph 2 on level of education) will find other sources of knowledge regarding cancer in order to know better about their child's conditions (in terms of their symptoms, treatment, way of handling their children). As for the parents who only manage to complete their primary education or did not receive any proper education before highly depend on the doctors' and nurses' information. Due to that, their grasp of knowledge regarding their children's illness is very limited.

Overall from this research, we have found a few important points. Social support is the fundamental base that every family should have. Despite the social stigma of having cancer, society needs to be more understanding when it comes to who are dealing with health issues. Society needs to be educated on prevalent health issues, especially the issues in Malaysia. Other than that, parents must know how to handle the difficult situation wisely because they are the main pillars of a family and they need to be positive in order to help their ill child. In other words, they need to help themselves first before helping others.

4. CONCLUSION

This study looks at the perspective of parents living in the state of Sarawak who has for a child with cancer. Both mothers and fathers with a child diagnosed with cancer reported have very less education and knowledge towards their children with cancer thus reported a higher stress an emotional level. Parents of children with cancer reported almost the same level of stress during the interview sessions.

A small part of the parents had experienced a high level of stress when their child was first contracted with cancer. With the help of the counsellors from the Sarawak Children's Cancer Society (SCCS), through the counselling sessions with the parents, this contributes to a more stable emotion and richer knowledge about paediatric cancer. The findings provide evidence about the parents' perspective towards childhood cancer and able to give us suggestions of the need for psychological and physical support to be developed for families caring for a child with cancer in Sarawak.

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