

The Financial Burden Model Experienced by Parents of Paediatric Cancer Patients in Malaysia

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To Link this Article: <http://dx.doi.org/10.6007/IJARBSS/v14-i7/22118>

DOI:10.6007/IJARBSS/v14 i7/22118

Published Date: 30 July 2024

Abstract

Parents particularly those who are low-income or single, are significantly impacted by the financial burden of cancer-related expenditures. The financial challenges associated with having a child with cancer may place a significant burden on parents (Santacroce et al., 2018). This research focused on the financial conditions of parents in Malaysia who had cancer. The use of Design and Developmental Research (DDR), as described by Richey and Klein in 2007, was implemented. This approach comprises the requirements assessment, development and execution, and usability evaluation stages. Purposive sampling is a method used to choose respondents based on certain features or attributes relevant to the inquiry. The participants consisted of parents whose children were afflicted with cancer. This research included a limited sample size of just nine parents. Each participant had a semi-structured interview, and the research was analyzed using Litchman's (2006) 3Cs analytical framework, which consists of Codes, Categories, and Concepts. The results of this study indicate that the elements depicting the financial situation of parents of cancer patients include fulfill the child's needs while in the hospital, monthly income being affected due to managing and caring for a sick child, making financial plans after quitting a job or taking unpaid leave, savings are impacted, family members helping financially, financial aid and support from external parties, and selling assets to cover insufficient finances.

Introduction

Informal carers are family, spouses, and friends who provide unpaid intense care to patients (Counoundouros et al., 2020). Parents assist child cancer patients with daily duties, medical care, social support, and advocacy (Counoundouros et al., 2020). Cancer parents may gain and suffer (Nightingale et al., 2022). Due to fear, worry, and despair during patient treatment, many parents develop Post-Traumatic Stress Disorder (PTSD) once their child is diagnosed with cancer (Neugebauer & Mastergeorge, 2021). Child cancer parents research is sparse. Most research has examined carers of elderly patients Slusarska et al (2019), parents of adult cancer patients Jones et al (2020), and parents of children with chronic conditions. Job

disruptions like frequent leave or rest breaks and patient care costs stress 25% of cancer patients' parents, according to several research (Nightingale et al., 2021).

Most cancer parents have high financial needs and little outside options (Bradley, 2019). Financial stress reduces cancer patient quality of life and treatment adherence (Sadigh et al., 2022). In high-income countries, cancer diagnosis and treatment may strain families financially and mentally (Salsman et al., 2019; Santacroce & Kneipp, 2020). Single parents and low-income households stress more (Santacroce & Kneipp, 2020). Even in wealthier nations where the government pays children's treatment expenses and offers sick leave for carers, parents struggle to pay for travel, accommodation, and other non-medical expenditures not covered by insurance (Santacroce & Kneipp, 2020).

Many studies have indicated that cancer-related financial limitations hurt parents (Neugebauer & Mastergeorge, 2021). This includes poverty, food, energy, and housing shortages, and a decline in family monthly income (Neugebauer & Mastergeorge, 2021). A paediatric oncology conceptual framework from the National Cancer Institute (2019), explains how chronic illness impacts health and finances (Santacroce & Kneipp, 2020). This revised model reveals that financial difficulties may promote concern, irrational thinking, and sleeplessness since the child's cancer diagnosis (Santacroce & Kneipp, 2020). Financial stress from cancer patient care affects parents well-being and quality of life, impacting palliative care (Gardiner et al., 2020). Malaysia has little qualitative research on cancer parents' financial stress. Malaysia-based Chan et al (2022), explored how cancer caring affects parents. Tan et al (2022), evaluated Malaysian cancer parents' information needs. This qualitative study comprised 14 child cancer parents and 8 healthcare workers.

Northouse et al (2012), found that cancer diagnosis harms parents' physical and emotional wellbeing. Financial costs, physical health, bad sleep, incorrect cancer patient care beliefs, and parents psychological and emotional shifts affect this. The parents' finances are damaged and monthly income is insufficient to cover cancer patient fees and medical charges (Kang et al., 2021). Cancer parents face greater costs due to the need for costly, advanced treatments (Counoundouros et al., 2020). Cancer parents worry about prescription costs, hospital fees, and delaying or forgoing medical treatment due to cost (Yabroff et al., 2020). Parents suffer financially when their children are hospitalised with cancer (Darlington et al., 2021). Child cancer patients' medical and treatment expenditures are the highest financial burden on parents, regardless of monthly income (Iragorri et al., 2021). Research shows that child cancer parents' well-being depends on financial difficulties. Similar to earlier studies, this study investigates the financial burden cancer parents endure. Nightingale et al (2022), identified seven financial hardship conceptual models for adolescent and young adult cancer parents. The study also found seven themes: direct and indirect cancer costs, socio-economic status's impact on financial burden, carers' desire to protect patients from financial stress, cancer cost management strategies, patients' financial anxiety about the future, financial support and assistance, and healthcare systems.

Malaysian parents of paediatric cancer sufferers' financial hardship needs urgent attention. A child's cancer diagnosis has significant psychological, social, and economic effects on the family, according to previous research (Lewandowska, 2021). Many studies have examined the physical and psychological implications of paediatric cancer, but few have

examined Malaysian families' financial struggles. Understanding the financial burden is crucial since it may affect the child and parents wellbeing and treatment outcomes (Liu et al., 2020). Previous study in other countries has indicated that factors including the child's age, parents' education, and the disease kind may affect parents' psychological distress (Isabel Tan et al., 2020). Diagnostics, treatments, and other child care costs may increase financial hardship (Chae et al., 2020). The economic hardship suffered by Malaysian parents of children with paediatric cancer may help shape targeted aid programs and regulations. This research might help counsellors and healthcare professionals understand this group's unique challenges and devise more effective ways to decrease financial strain and improve family welfare. To enhance cancer treatment and aid for Malaysian families with children, we must understand their financial difficulty (Fnu et al., 2022).

There is little research on Malaysian paediatric cancer parents' financial stress. Most research emphasises on psychological and physical aspects of the illness. By investigating financial implications, we may get valuable insights that might help us create better support systems and policies. Hence, the objective of this research is to ascertain the elements that contribute to the financial strain experienced by parents of children with cancer throughout the provision of care and treatment.

Significant of the Study

Paediatric cancer patients have a different experience than adults with cancer since the entire family especially the parents and, in some circumstances, the grandparents is engaged in the child's condition (Okumu et al., 2017). Family members are understandably stressed by the disease's psychological, sociological, and economical implications (Cardinali et al., 2019). These difficulties have been studied little, especially from the viewpoint of cancer families.

Parents of Malaysian paediatric cancer patients have a tremendous financial burden that requires attention. Paediatric cancer may strain a family's finances due to medical treatment, missed earnings, and other expenditures (Roser et al., 2019). These financial issues may be particularly difficult in Malaysia, where families must negotiate a convoluted healthcare system to get their children the treatment they need (Chuah et al., 2019). Financial stress is one of the biggest issues for cancer families (Mitterer et al., 2021). Medical and nonmedical costs exist (Mitterer et al., 2021). Medical prices include diagnostics, physician fees, treatments, and inpatient and outpatient expenditures at the cancer centre or in the patients' communities (Iragorri et al., 2021). Nonmedical out-of-pocket expenditures are expenses connected to the child's cancer that would not have been spent otherwise but are not directly related to diagnosis or treatment (Ritter et al., 2023).

In Malaysia, parents of paediatric cancer patients reported that their child's diagnostic and treatment expenditures sometimes exceeded their monthly income (Aminuddin et al., 2023). This study showed the need for more support and resources to reduce these families' financial stress, which can lead to emotional and psychological distress, strained family relationships, and even the child's treatment.

In conclusion, Malaysian paediatric cancer parents' financial hardship needs more attention and help. These families may struggle financially due to medical bills, missed

earnings, and other difficulties (Friedline et al., 2021). To help families navigate this difficult journey, policy changes, increased funding for support services, and greater collaboration between healthcare providers, policymakers, and the community are needed.

Research Methodology

This research uses the Design and Developmental Research (DDR) approach, which contains three phases: requirements analysis, model design and development, and model assessment.

In the first step, needs analysis, semi-structured interviews were utilised to identify financial difficulties and research requirements of child cancer parents. This study collected as much data as possible using semi-structured interviews to learn about cancer parents' financial problems. The researcher questioned nine child cancer parents during this phase. Purposive sampling was used to choose study participants with certain characteristics based on expertise and research goals (Pomizi Resources, 2018). After recording conversations with cancer patients' parents, the researcher transcribed each question. Lichtman's 2006 3C approach was used to analyse and evaluate each data point from interview transcripts with child cancer patients' parents.

Design and development is the second and most important step for this study's results. In this step, the researcher conducted structured interviews with chosen respondents. Seven counsellors and two counselling instructors were selected for this round. After reviewing child cancer patient parent interviews, the researcher met with all the specialists to discuss the findings. The researcher used ISM to analyse the data. In this step, the experts polished the researcher's components and were allowed to make adjustments if they had other experts' approval. After the debate, experts voted on the selected items. The researcher employed the Concept Star approach to organise items by expert vote.

This study's Design and Developmental Research (DDR) strategy concludes with evaluation. Four counsellors and three counselling instructors were chosen by the researcher. The researcher utilised a Fuzzy Delphi-analyzed questionnaire instrument for this study to gather exact data for this assessment. Before the surveys were issued, respondents saw the prototype components to better understand all the financial parts. All experts were encouraged to offer questions throughout the lecture. Once everyone was happy and understood the researcher's prototype, the experts received their surveys. This step sought validation from all specialists on element usability. Selected professional groups evaluated each financial explanation aspect. This study's element creation process is shown in Figure 1.

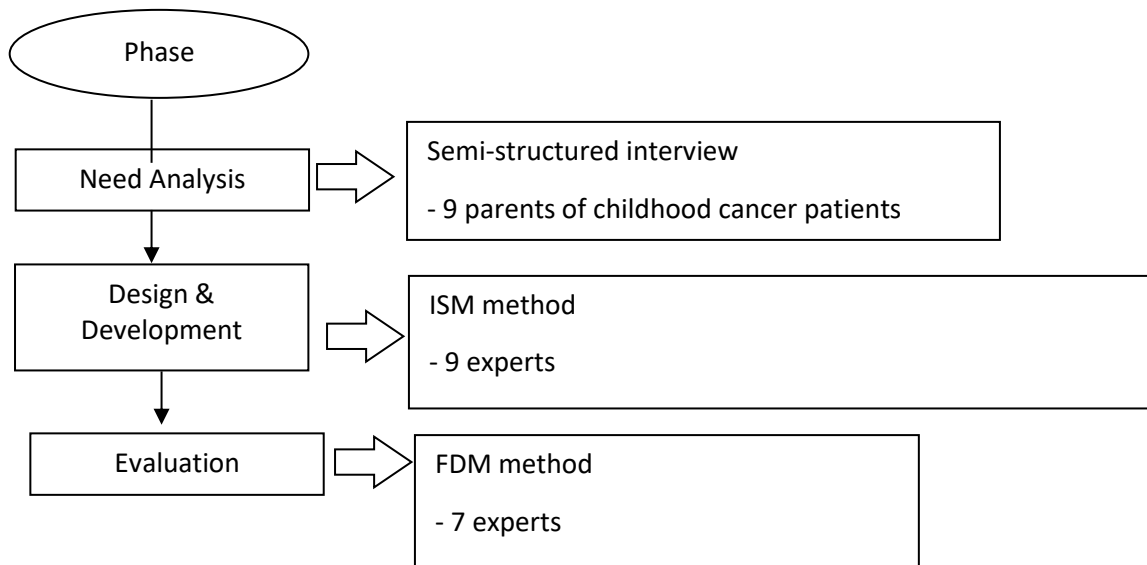


Figure 1. Element creation process.

Findings

Phase 1: Needs Analysis

According to the 3Cs approach (Codes, Categories, and Concepts) Lichtman (2006), there are 13 main elements related to the financial burden: external parties provide financial assistance, the government helps with all child treatment costs, external parties help with children's equipment and needs, family members help financially, transportation costs while managing and caring for the child, and meeting the child's requests. Nine parents of children cancer patients in Malaysia were interviewed about their experiences and challenges caring for cancer kids. Researchers categorised 13 primary components. The researcher transcribed, analysed, and evaluated all data. The data must be improved by professionals in the study's design and development phase. Thus, the majority of respondents suggested a financial guide for parents of children with cancer so they may plan and understand their financial experiences. Table 1 shows the demographic profile of this study's respondents and table 2 shows its financial burden study needs.

Table 1

Demographics of respondents.

Respondents	Sex	Occupation	Monthly Income	Status of marriage	Relationship with patients	Length of care for the patient.
Parents 1 (IB 1)	F	Assistant Engineer	RM 2800	Married	Mother	7
Parents 2 (IB 2)	F	Religious School Teacher	RM 2 000	Married	Mother	11
Parents 3 (IB 3)	F	Bank Officer	RM 3 700	Married	Mother	6
Parents 4 (IB 4)	F	Cashier	RM 700	Married	Mother	5
Parents 5 (IB 5)	F	Medical Laboratory Technologist	RM 2 500	Married	Mother	3
Parents 6 (IB 6)	F	Community Development Assistant	RM 2 300	Married	Mother	8
Parents 7 (IB 7)	F	Car Salesman	RM 1 900	Married	Mother	5
Parents 8 (IB 8)	M	Technician	RM 3 800	Married	Father	9
Parents 9 (IB 9)	F	Clerk	RM 1 800	Married	Mother	14

Table 2

Financial Burden Study Needs

Respondent	Model Development Needs	Transcript of Respondents
Parents 1 (IB 1)	Necessary	<i>"Yes, it's necessary, if it's a good thing it's okay. Whatever is good is okay, if we don't try it we don't know if it works or not."</i>
Parents 2 (IB 2)	Necessary	<i>"There needs to be a guide. If it's for good, it's necessary. Can help parents in terms of management and preparations from a financial aspect."</i>
Parents 3 (IB 3)	Necessary	<i>"There needs to be and that guidance is important because most parents experience financial problems when their children are diagnosed with cancer."</i>
Parents 4 (IB 4)	Necessary	<i>"It is very necessary and important. Add more for me as a parent who has no experience in taking care of a child with cancer. I don't know how much it costs to take care of this cancer child and so on."</i>
Parents 5 (IB 5)	Necessary	<i>"It is necessary and important to have financial preparations for parents of children with cancer."</i>

Parents 6 (IB 6)	Necessary	<i>"It's really good, it's necessary to follow it, it's actually very necessary... because sometimes things like that, what is it... people say it's not in google."</i>
Parents 7 (IB 7)	Necessary	<i>"Haa. financial preparation for parents really needs to be emphasized, it's really important and it's necessary."</i>
Parents 8 (IB 8)	Necessary	<i>"It is very necessary hmm when parents know about the financial problems, they will experience then parents will start making financial plans."</i>
Parents 9 (IB 9)	Necessary	<i>"I agree and there needs to be a financial model to help us parents who have children with cancer, it's very good for us."</i>

Phase 2: Design & Development

The Concept Star approach was used to analyse the data again using Interpretive Structural Modelling (ISM) software after expert talks. All experts agree to limit the components to seven. Some components were eliminated, consolidated, and renamed. All the experts agreed the adjustments, and then the researcher used the Concept Star approach to frame the pieces so they could see the financial consequences of the framework. Figure 2 depicts the components that explain the financial burden of Malaysian parents of children cancer patients and their priority ranking based on research experts' comments.

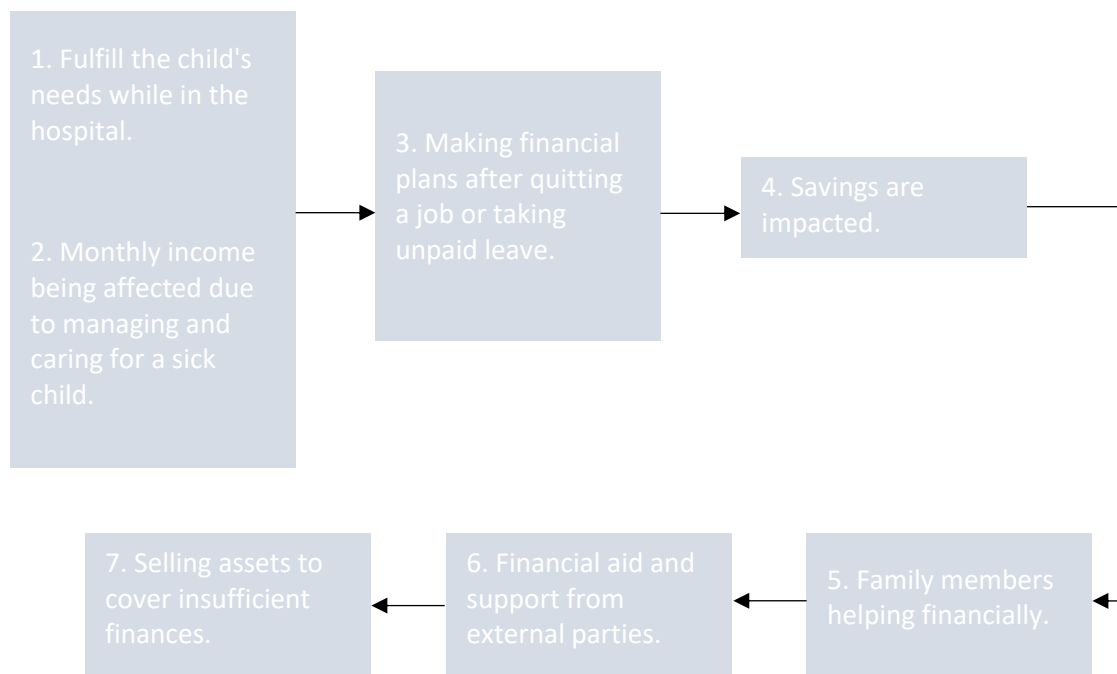


Figure 2: Depicts The Components Financial Burden.

Phase 3: Evaluation

The third phase involves applying the Fuzzy Delphi method to evaluate every single component. The study employed five counsellors and two lecturers as study respondents to deliver the questionnaire instrument that was produced based on the third phase. Prior to that, a pilot study was conducted to guarantee the reliability and validity of every

questionnaire item. Fuzzy Delphi was used to analyse the data and determine the value of each component. Using this approach, researchers must have expert consensus and ensure that the percentage value is at least 75% (Chu & Hwang, 2008). The Fuzzy Delphi procedure must be repeated for the second round until it reaches the predetermined percentage if this percentage figure is not obtained. Therefore, the findings of this study show that the value of agreement between experts has been reached where the percentage value of expert agreement is more than 75 percent as shown in Table 3.

Table 3
Value of Financial Elements Through Fuzzy Delphi Method

Statistics	Financial aid and support from external parties	Monthly income being affected due to managing and caring for a sick child	Fulfill the child's needs while in the hospital	Making financial plans after quitting a job or taking unpaid leave	Selling assets to cover insufficient finances	Savings are impacted	Family members helping financially.
Assess each item	0.07541	0.02828	0	0.02828	0.09426	0.04713	0.05656
Construct value							0.04713
Item < 0.2	7	7	7	7	7	7	7
% item < 0.2	100%	100%	100%	100%	100%	100%	100%
Average % consensus							100
Defuzzification	0.68571	0.77143	0.8	0.77143	0.65714	0.74286	0.71429
Rank	5	2	1	2	6	3	4
Status	Accept	Accept	Accept	Accept	Accept	Accept	Accept

The experts have unanimously endorsed the elements created by the researchers, deeming them suitable for elucidating the financial strain experienced by parents of children with cancer. Figure 3 displays the financial burden model developed by the researcher and assessed by experts to assist parents of children cancer patients in Malaysia.

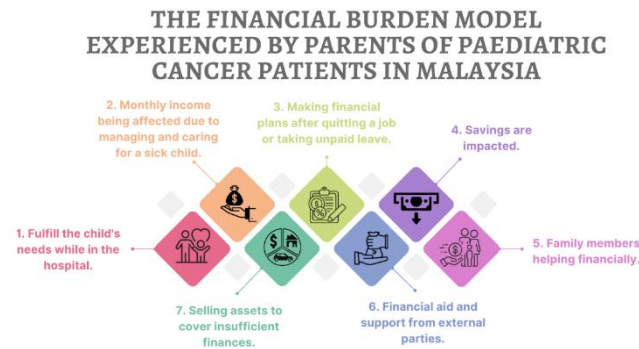


Figure 3: Model of Financial Burden of Parents of Childhood Cancer Patients in Malaysia.

The study's results diverge from Nightingale et al (2022), findings. They identify seven themes that elucidate the financial strain experienced by parents of adolescent and early adult cancer patients. These themes include the impact of socioeconomic status during diagnosis and treatment on the intensity of the financial burden, as well as the specific burden faced by mothers. Parents bear both direct and indirect expenses associated with cancer or cancer treatment. They shield adolescents and young adults from financial hardships. Parents actively seek and may receive financial assistance from social networks and healthcare institutions. They aim to assist their children in navigating the healthcare system and locating financial resources. Parents employ strategies to anticipate and adapt to the costs associated with cancer. Additionally, parents express concerns about the medical and financial prospects of their children during adolescence and early adulthood. This study identified seven key factors that contribute to the financial strain faced by parents of children with cancer. These factors include a decrease in monthly income due to the time and effort required to manage and care for their children, a depletion of savings, reliance on financial assistance and support from external sources, the need to sell assets to make ends meet, financial contributions from family members, the need to make financial plans after quitting work or taking unpaid leave, and the expenses incurred while the child is hospitalized. Nevertheless, both studies share the same number of themes, namely seven, to define the financial stress. Interviews with respondents identified these topics, but the selection of respondents varied throughout the studies.

Discussion

The study results collected from the Design and Developmental study technique identify seven characteristics that elucidate the causes contributing to the financial burden experienced by parents of children cancer patients in Malaysia. A qualitative research conducted by Granek and Rosenberg (2014), has examined the economic difficulties and obstacles experienced by parents after the diagnosis of their child with cancer. This research also investigated the parameters linked to the financial strain experienced by parents of children with cancer. Subsequently, researchers have investigated the impact of this responsibility on the welfare of parents as their children undergo treatment for paediatric cancer. Diagnosing paediatric cancer is a very distressing event that not only affects the kid but also imposes a substantial economic strain on their family. In Malaysia, the healthcare system comprises both public and private providers, creating a significant financial burden for parents of children diagnosed with cancer. The expenses related to the provision of medical treatment for paediatric cancer might be overwhelmingly high. The reference is from (Lansky

et al., 1983). A prior investigation revealed that non-medical expenses paid directly by individuals accounted for 26% of a family's weekly budget. The reference is from Lansky et al., in 1983. The monthly medical expenses might vary from \$100 to \$1,800, depending on the child's diagnosis and treatment plan. The reference is from (Lansky et al., 1983). Despite the presence of public healthcare, families often encounter substantial out-of-pocket costs, which expose them to the possibility of financial adversity. (Nipp et al., 2017). Research has shown that the financial burden experienced by cancer survivors has a detrimental effect on their ability to seek healthcare and their overall quality of life. (Nipp et al., 2017) A cross-sectional study conducted in Malaysia among caregivers of paediatric cancer patients revealed that families reported a significant financial hardship, with ratings ranging from 0 to 100. The reference is from(Warner et al., 2015). Variables linked to higher financial burden included duration of diagnosis, socioeconomic standing, and healthcare use. The reference is from Warner et al. in 2015. The economic impact of juvenile cancer may be significant, as families face difficulties in managing increasing medical expenditures, missed income, and additional financial obligations. Zaidi et al (2012), There is an urgent need for supplementary assistance programs, either provided by the government or other social groups, to mitigate the financial burden on families confronting this catastrophic diagnosis. It is essential to tackle the financial challenges associated with paediatric cancer in order to provide fair access to high-quality healthcare and enhance the well-being of these vulnerable kids and their families. Ensure that individuals may get necessary medical treatment, irrespective of their family's economic situation.

Conclusion

A cancer diagnosis not only affects parents' emotions, but the financial elements also significantly influence the overall well-being of parents with children diagnosed with cancer. The financial strain experienced by parents of children diagnosed with cancer is a notable issue, especially in developing nations such as Malaysia. The expense of cancer treatment may be exorbitant, resulting in significant financial burden on families. A comprehensive analysis revealed that families with low income were the most susceptible to perceiving financial hardship as a result of cancer. This load may lead to serious repercussions, such as the termination of treatment and the worsening of poverty.

Research conducted in Malaysia on caretakers of paediatric cancer patients revealed that the perceived financial burden was significant and had several contributing factors (Warner et al., 2015). Variables such as the duration of illness, socioeconomic position, and the extent of healthcare consumption all had a role in determining the degree of financial strain faced by families. The cumulative expenses associated with medical care, transportation, and missed wages due to parental leave may rapidly amass and become burdensome (Zaidi et al., 2012). It is essential to tackle the economic hardship associated with paediatric cancer in Malaysia in order to guarantee that children get necessary treatment and families do not fall into destitution. Azzani et al (2015), suggest that mitigating the cost may be achieved by identifying high-risk individuals and implementing targeted financial assistance programs. Government and social agencies should intervene to alleviate the significant financial burden on these susceptible households.

Acknowledgement

We express our gratitude to the parents of childhood cancer patients, counsellors, lecturers, and all individuals or groups who have contributed to our study whether via direct or indirect means. Nur Shuhana Binti Mohd Sansuddin received funding for her study as part of the Master of Education, Counselling and Guidance Programme at Sultan Idris Education University. Additionally, assistance was provided by Dr. Nurul Hasyimah Binti Mat Rani, a senior lecturer in the Counselling and Guidance Department of the Faculty of Human Development at Sultan Idris Education University. The Ministry of Higher Education provides fundings via the Fundamental Research Grant Scheme (FRGS/1/2021/SS0/UPSI/03/4). The research has received ethical approval from the Research Management Innovation Centre at Sultan Idris Education University with the reference number 2022-0653-01. Hence, we express our gratitude to the Research Management Innovation Centre, Sultan Idris Education University as well as the Guidance and Counselling Department of the Faculty Human Development, Sultan Idris Education University for their invaluable assistance and facilitation during the data collection process.

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