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A Comprehensive Model for Understanding the Emotional Strain on Caregivers of Children with Cancer in Malaysia

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Abstract

Parents of children with cancer face significant emotional challenges that impact their well-being. This study examines the emotional difficulties experienced by parents during their child's cancer treatment using a Design and Development Research approach. Semi-structured interviews with nine parents identified 44 emotional factors which were systematically refined into a final model consisting of 28 components through expert review by Interpretive Structural Modelling and the Fuzzy Delphi Method. The findings highlight the need for structured emotional support, counseling interventions and effective communication from healthcare providers. The study provides an evidence-based framework for psychosocial support services in pediatric oncology setting.

Keywords: Counselling, Emotional challenges, Caregivers, Pediatric Cancer

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1.0 Introduction

The diagnosis and treatment of pediatric cancer can be a highly challenging and emotionally draining experience for families (Omer, 2024). Childhood cancer significantly affects the daily lives and emotional well-being of all family members (Lewandowska, 2022). In Malaysia, parents of children with cancer often face emotional challenges that deeply impact their ability to support their child during treatment (Tan, Sambhi & Shorey, 2024). Research on parental stress in pediatric oncology shows that while stress may be temporary for most parents, it can still significantly affect both the parents and children, requiring therapeutic help (Hajal & Paley, 2020). One of the biggest emotional challenges for these parents is the uncertainty and fear about their child's prognosis and the unpredictable nature

of the disease (Polakova et al., 2024). This anxiety can be overwhelming, leading to post-traumatic stress and strained parent-child relationships (May et al., 2023).

2.0 Literature Review

A study in Jakarta, Indonesia, found that parents of children with cancer faced many issues, including stress, the need for specialized care, and lack of psychological, financial, and social support (Efendi et al., 2022). Additionally, the medical treatments for pediatric cancer can be deeply upsetting for both the child and the parents, increasing anxiety and emotional vulnerability (Atkins & Padgett., 2024). Parents often struggle with the emotional pain of seeing their child suffer, feeling helpless, ashamed, or guilty (Pollack, 2024). A cross-sectional study involving 124 caregivers revealed that 37.9% experienced abnormal anxiety levels while 44.4% showed signs of borderline depression (Karimi Moghaddam et al., 2023). Caregiver emotional strain stems from multiple interconnected factors including the gradual deterioration of the child's health, heightened awareness of mortality risk, fear of death, anxiety about treatment outcomes, financial pressures and disruptions to family roles and responsibilities (Amin et al., 2024; Joshi Poonam et al., 2025).

Effective communication and support from healthcare professionals are crucial to help parents cope with these emotional challenges (Ng, Dudeney & Jaaniste, 2023). Healthcare teams can help parents process their emotions, adjust to new responsibilities, and be more involved in their child's care by offering open communication and providing clear, age-appropriate information to both the patient and family members (Ashcraft et al., 2019). Support services like counseling and peer groups are vital for helping parents in Malaysia manage the unique emotional challenges of caring for a child with cancer (Blazin et al., 2018). Parental emotional health is influenced by factors such as demographics, medical issues, coping skills, social support, and family dynamics. These emotional factors are important because they can be addressed in interventions. This research aims to explore the emotional challenges faced by Malaysian parents of children with cancer, providing healthcare professionals with insights into the needs of these families. This may help with early detection of emotional distress and referrals to appropriate support services, as well as identify areas where current caregiver support initiatives could be improved.

3.0 Methodology

The methodology is strengthened by the structured Design and Developmental Research approach, incorporating need analysis, expert validation, and model assessment. The application of Interpretive Structural Modelling and the Fuzzy Delphi Method guarantees methodological rigour, expert consensus, and practical relevance. This research followed the Design and Developmental Research (DDR) approach, which consists of three phases: (i) phase 1-need analysis, (ii) phase 2-design and development, and (iii) phase 3-assessment. DDR is defined as the process of designing, developing, and evaluating instructional and non-instructional products or technologies to create or improve models (Richey & Klein, 2007).

During the initial phase, semi-structured interviews were conducted to gain a deeper understanding of the emotional challenges faced by Malaysian parents of cancer patients. Purposive sampling was employed to select nine parents of children aged one to eighteen who were currently receiving or had previously undergone cancer treatment in hospitals throughout Malaysia. Interviews were carried out from June to December 2022, with participants supplying informed consent.

The interview questions covered demographic and emotional aspects, and the interviewer allowed participants to freely express their experiences, using prompting questions if necessary. After the interviews, the researcher transcribed the responses and applied the Lichtman 3C's technique to identify key comments for study.

The second phase focused on the design and development of the model. Seven counsellors and two counselling lecturers were interviewed to assess the findings from the parents' interviews. The researcher used Interpretive Structural Modelling (ISM) to analyse the data, and the experts worked together to refine the components through discussion and voting. This step was vital in ensuring that the model was relevant to the target audience.

In the final phase, the effectiveness of the model was assessed. Four counsellors and three counselling lecturers participated in the evaluation. The Fuzzy Delphi method, developed by Kaufman and Gupota (1998) and enhanced by Noh JY et al. (2020), was used to facilitate expert consensus. This method combines fuzzy set theory with the traditional Delphi technique, allowing for precise measurement and resolution of issues. The experts reviewed the components and elements of the emotional model to ensure it met the needs of parents of children with cancer in Malaysia. Overall, this research aimed to create a comprehensive emotional model that addresses the needs of Malaysian parents of children with cancer, guided by expert feedback and analysis.

4.0 Findings

4.1 Phase 1: Need Analysis

Lichtman's (2006) 3 C (Codes, Categories, and Concepts) method identified 44 key emotional challenges faced by parents of children with cancer. Nine parents of childhood cancer patients in Malaysia were interviewed to discuss their emotional experiences. The researcher transcribed the interviews and analysed the data by coding key themes. The findings from phase 1 require approval and evaluation from experts in phase 2, which focuses on the design and development of the model. All participating parents emphasized the need for an emotional challenge model to help them prepare and guide them through their caregiving journey. Table 1 presents the demographics of the participants, and Table 2 highlights the need for further research on the emotional difficulties faced by parents of

childhood cancer patients in Malaysia (Lichtman, 2006).

Table 1: Demographics of respondents.

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

Table 2: Emotional Challenges Study Needs

Respondent	Model Development Needs	Transcript of Respondents
Parents 1 (IB 1)	Necessary	"There needs to be and that guidance is important because most parents experience emotional problems when their children are diagnosed with cancer."
Parents 2 (IB 2)	Necessary	"There needs to be a guide. If it's for good, it's necessary. Can help parents in terms of management and preparations from an emotion aspect."
Parents 3 (IB 3)	Necessary	"Yes, it's necessary if it's a good thing."
Parents 4 (IB 4)	Necessary	"It is very necessary and important. Especially for me as a parent who has no experience in taking care of a child with cancer. I don't know how to manage my emotion during take care of this cancer child and so on."
Parents 5 (IB 5)	Necessary	"It is necessary and important to have a good emotion."
Parents 6 (IB 6)	Necessary	"It's really good, it's necessary to follow it, it's actually very necessary... because sometimes things like that, people say it's not in google."
Parents 7 (IB 7)	Necessary	"Haa. Emotional management for parents really needs to be emphasized, it's really important and it's necessary."
Parents 8 (IB 8)	Necessary	"It is very necessary."
Parents 9 (IB 9)	Necessary	"I agree and there needs to be an emotional model to help us parents who have children with cancer, it's very good for us."

4.2 Phase 2: Design & Development Model

The researcher used the Interpretive Structural Modelling (ISM) approach with Concept Star software to analyze the findings. Experts agreed to reduce the number of components to 28 by combining, removing, and renaming some elements. Based on expert feedback, the emotional challenge model was revised using Concept Star software. Figure 1 illustrates the revised model showing the emotional challenges faced by parents of childhood cancer patients in Malaysia, with priorities determined by expert votes.

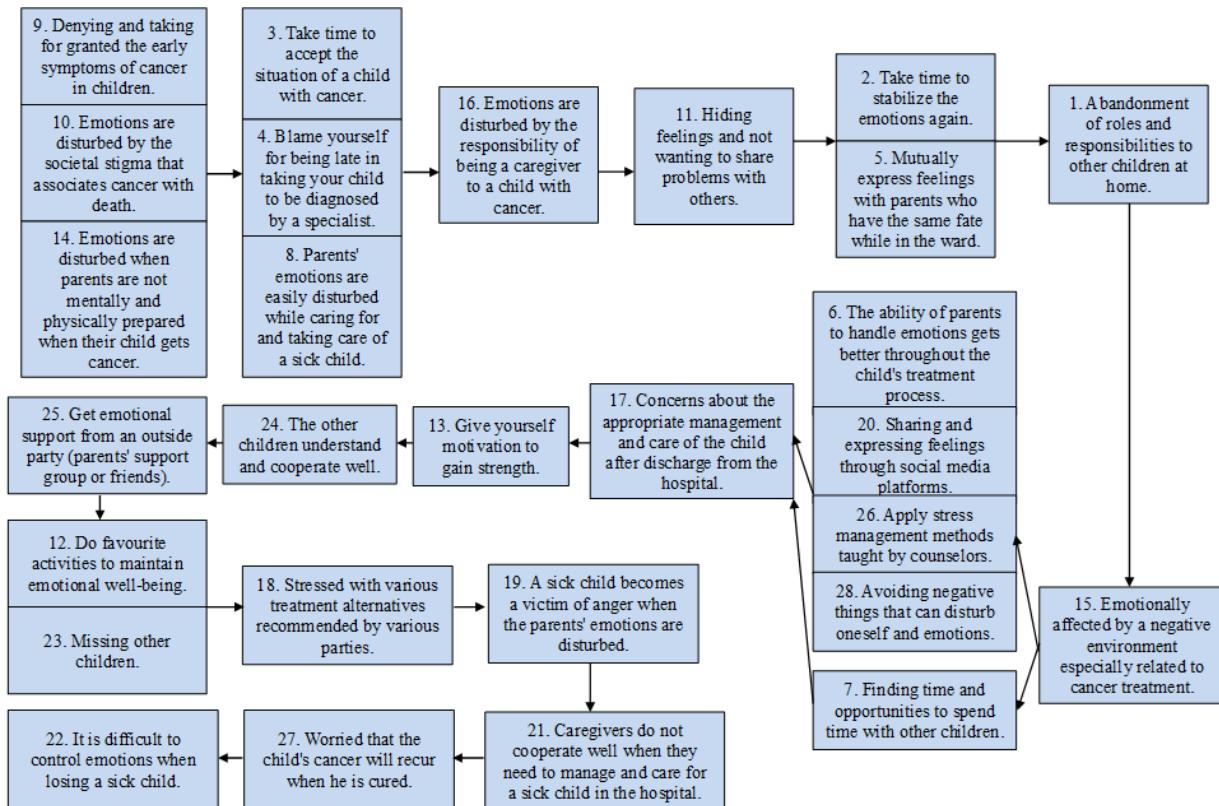


Figure 1: An overview of the emotional challenges model via Concept Star

4.3 Phase 3: Evaluation

In the final phase, the researcher utilised the Fuzzy Delphi method to systematically analyse expert evaluations of each of the 28 components.

Five counsellors and two lecturers participated as experts to assess the components from the study model. Before distributing the questionnaire, the researcher presented the model framework from the second phase to ensure the experts understood it. The Fuzzy Delphi method was used to analyze the data and determine the value of each component. To ensure reliability, researchers must obtain expert consensus with a minimum of 75% agreement (Chu & Hwang, 2008). The findings show that expert consensus was achieved, with agreement exceeding 75%, as shown in Table 3.

Table 3: Value of Emotional Challenges Components Via Fuzzy Delphi Method

Statistics	Component t1	Component t2	Component t3	Component t4	Component t5	Component t6	Component t7	Component t8	Component t9	Component t10
Value of the item	0.0707	0	0.02828	0.02828	0.05656	0.02828	0.02828	0.5656	0.02828	0.02828
Item < 0.2	7	7	7	7	7	7	7	7	7	7
% of item < 0.2	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%
Defuzzification	0.71429	0.8	0.77143	0.77143	0.74286	0.77143	0.77143	0.71429	0.77143	0.77143
Ranking	4	1	2	2	3	2	2	4	2	2
Status	Accept									

Table 3: Value of Emotional Challenges Components Via Fuzzy Delphi Method

Statistics	Component t11	Component t12	Component t13	Component t14	Component t15	Component t16	Component t17	Component t18	Component t19	Component t20
Value of the item	0.04713	0.02828	0.02828	0.13432	0.04713	0.02828	0.02828	0.04713	0.04713	0.02828
Item < 0.2	7	7	7	5	7	7	7	7	7	7
% of item < 0.2	100%	100%	100%	71%	100%	100%	100%	100%	100%	100%
Defuzzification	0.74286	0.77143	0.77143	0.55714	0.74286	0.77143	0.77143	0.74286	0.74286	0.77143
Ranking	3	2	2	7	3	2	2	3	3	2
Status	Accept									

Table 3: Value of Emotional Challenges Components Via Fuzzy Delphi Method

Statistics	Component 21	Component 22	Component 23	Component 24	Component 25	Component 26	Component 27	Component 28
Value of the item	0.02828	0.02828	0.05656	0.02828	0.08484	0.05656	0.02828	0.08484
Item < 0.2	7	7	7	7	6	7	7	6
% of item < 0.2	100%	100%	100%	71%	85%	100%	100%	85%
Defuzzification	0.77143	0.77143	0.71429	0.77143	0.62857	0.68571	0.77143	0.71429
Ranking	2	2	4	2	6	5	2	4
Status	Accept							



Figure 2: Model of Emotional Challenges Experiences by Parents of Childhood Cancer Patients in Malaysia.

5.0 Discussion

Experts have reached a consensus supporting the components formulated by researchers, deeming them appropriate for elucidating the emotional challenges faced by parents of childhood cancer patients in Malaysia. Figure 2 presents a model of emotional challenges created by researchers and assessed by experts to assist parents of childhood cancer patients in Malaysia. Northern, southern, central, and east coast Malaysian parents of cancer-afflicted children were involved in the study. This study used qualitative in-depth interviews to understand Malaysian paediatric cancer parents' perspectives. The researchers synthesized and drew conclusions from data using themes and sub-themes. The study contradicts (Anwar, Asiya & Afzal, 2024). The researchers found eight elements that explain the misery and emotional burden child cancer parents face, along with 24 associated issues. One of the themes include cancer parents' economic burdens.

This study examines how the parent-child connection impacts parents' stress, emotional state, and caregiving for children with cancer. It highlights the importance of understanding the emotional and parental perspectives when supporting parents of children with life-threatening diseases like cancer. The findings show that parents play a significant role in their child's cancer treatment and management. This emphasizes the need to understand parents' relationships with medical professionals and specialists. Other studies (Ahmadnia et al., 2021; Cheung et al., 2021; Polanco et al., 2022) support this view.

The study also explored parents' views on their essential role in caring for their children during treatment. They are committed to improving their child's health, and stress related to illness and treatment often increases the child's need for assistance. Previous research has shown that parents, especially mothers, emphasized the importance of being with their child to improve emotional well-being and leadership. Sick children feel better when they are close to their parents, with clear differences between hospital and home care. Due to various pressures and responsibilities, parents may spend excessive time caring for their children before a diagnosis. Many parents spent evenings in hospital parking lots to manage their emotions. Some felt overwhelmed with their hospitalized child. Mothers, in particular, often slept on camp blankets beside their children or in communal hospital wards, highlighting the difficult conditions and their concerns for their children's privacy. These findings align with previous studies (Dawson et al., 2020; Bodryzlova et al., 2023). The

study offers a conceptual understanding of the emotional challenges faced by Malaysian parents of cancer patients and examines their unique perspectives on parenting.

6.0 Conclusion and Recommendations

The findings give an evidence-based framework for counsellors and healthcare providers to assess emotional needs, detect early indicators of distress, and carry out specialised counselling interventions. Methodologically, the merging of qualitative inquiry, Interpretive Structural Modelling, and the Fuzzy Delphi Method enhances rigour in counselling research. The emotional challenges faced by parents of childhood cancer patients in Malaysia are complex and deeply influenced by cultural, societal, and personal factors. This study highlights the significant psychological impact of a childhood cancer diagnosis, including fear, anxiety, helplessness, and emotional exhaustion. It emphasizes the need for targeted interventions, such as counselling, support groups, and culturally sensitive programs tailored to the Malaysian context. Understanding the emotional experiences of these parents is essential for counsellors, healthcare professionals, and support organizations who aim to provide holistic care. Creating a supportive environment that focuses on emotional resilience can ease the burden on parents and improve the quality of care for the affected children.

Future research should focus on developing frameworks that combine emotional support with medical treatment to better assist families facing the challenges of childhood cancer in Malaysia. This article offers valuable insights into the emotional struggles of parents of children with cancer in Malaysia, helping counsellors understand cultural and emotional factors. It also encourages caregivers to seek support and practice self-care, while promoting the integration of culturally sensitive psychosocial programs to reduce caregiver burnout and improve paediatric oncology care. Overall, the article advocates for a compassionate and supportive care ecosystem in Malaysia that addresses both emotional and medical needs.

This research has significant limitations. First, the small sample size of nine parents limits the findings' potential for generalization. Second, the method of semi-structured interviews may be subject to interviewer and social desirability biases, and the flexible questions may limit data comparability. The study's findings are also limited to Malaysian parents and may not be applicable to other cultures or healthcare settings. Finally, this study only records emotional experiences at precise moments in time, perhaps ignoring how they evolve during treatment. To improve research outcomes and increase the generalisability and cultural relevance of the emotional difficulties model for caregivers of children with cancer, future studies should incorporate more diverse samples from various regions within Malaysia. Furthermore, cross-cultural studies involving carers from diverse Southeast Asian or developing nations could provide valuable insights into the environmental and cultural factors influencing emotional stress.

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