

Development of a counselling-based self-wellbeing model for informal caregivers of childhood cancer patients in Malaysia

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ABSTRACT

Cancer is a chronic disease that causes patients and their caregivers to face various challenges throughout treatment and care. This study aimed to develop a counselling-based self-wellbeing model for informal caregivers of childhood cancer patients in Malaysia. This study employed the design and development research (DDR). The first phase involved needs analysis using a systematic literature review and semi-structured interviews of nine caregivers of childhood cancer. The second phase involved two methods: nominal group technique (NGT) and interpretive structural modeling (ISM). The third phase involved evaluating the usability of the model through the Fuzzy Delphi method (FDM) with the agreement of seven experts. This study successfully developed a counselling-based self-wellbeing model for informal caregivers of childhood cancer patients in Malaysia. This model has 12 components consisting of: i) financial; ii) career; iii) knowledge related to management and care of child cancer patients; iv) emotional management and care; v) spiritual; vi) cognitive and rationalization; vii) social relationships; viii) roles of counsellors in helping parents; ix) spouse and family relationships; x) physical; xi) communication; and xii) facilities. This model is proposed to be used by counsellors, especially who serve in health institutions to help parents who have children with cancer.

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1. INTRODUCTION

Pediatric hematological cancers such as leukemia and lymphoma are the most common types of cancer in children in Malaysia and around the world, with leukemia contributing to 25.1% of cancers in children aged 0-19 years in 2020, non-Hodgkin's lymphoma reporting for 4.5%, and Hodgkin's lymphoma reporting for 0.9% [1]. According to previous studies [2], [3], cancer not only has a great impact on patients, but also on informal caregivers responsible for treating or managing cancer patients. In previous study by Cai *et al.* [4], it was found that the quality of life of informal caregivers of cancer patients is usually lower than those who care for patients with other chronic diseases. Informal caregivers often face financial,

social [5], physical [2], psychological, and personal problems [6] so they often ignore their own interests [7]. The caregiving experience during this process not only affects the emotional, physical, psychological, social, financial, and personal caregivers, but also affects the functionality of their lives.

Informal caregivers who are responsible for the care and treatment of childhood cancer patients experience a significant burden and bear a considerable responsibility. Cancer not only impacts the patients but also the informal caregivers (parents) who are responsible for caring for or managing the patient [8]. Cancer also affects patients' quality of life, especially in terms of cognitive function [9], daily life role [10], social activities [11], self-functioning [12], and physical ability [13]. The study of Marín-Maicas *et al.* [14] shows that the disability of cancer patients cause them to depend on informal caregivers such as family members to cope with cancer, which then affects their family dynamics and experiences. Caregivers often face financial, social [15], physical, psychological, and personal problems [16] that cause them to neglect their own physical and emotional needs [17]. Some studies also reported that caregivers of cancer patients experience anxiety, stress, and feeling burdened when providing health care to patients, especially at home [18]. This overwhelming care experience affects the caregivers' emotional, physical, psychological, social, financial, and personal needs, and their functionality in life.

Effective interventions and appropriate support can help informal caregivers face the aforementioned challenges and improve the quality of care they provide to patients. In this context, the role of a counsellor is essential in providing emotional and psychological support to informal caregivers. Psychological support provided by counsellors can help informal caregivers make the best decisions to treat their children and provide the necessary support. A lot of previous studies focus on cancer patients but not on the informal caregivers of childhood cancer patients [19]. Previous models emphasize wellbeing but are not related to counselling, which overlooked the counsellor's role in supporting the needs of informal caregivers of childhood cancer patients [20], [21]. To bridge the research gap, this objective of this study is to develop a counselling-based self-wellbeing model for informal caregivers of childhood cancer patients in Malaysia. The lack of a preexisting model that guides counsellors in their support of informal caregiver coping with cancer in children makes this study all the more urgent. Furthermore, current research and models do not adequately address the many facets of informal caregiver personal wellness.

2. METHOD

The design and development research (DDR) based on Richey and Klein [22] was used in this study and encompasses three phases. The first phase was needs analysis, in which the researchers conducted a systematic literature review and semi-structured interviews to identify the needs of model development. A semi-structured interview method was used to obtain views from informal caregivers of childhood cancer patients in Malaysia. Applying a purposive sampling technique, nine informal caregivers were selected as respondents. The data were analyzed using the thematic analysis technique [23]. Thematic analysis is an approach to analyzing qualitative data. Finding and reporting patterns in data sets and then deducing their meaning from those patterns is what it entails.

The second phase was the design and development phase of the model. In this phase, two main methods were used: nominal group technique (NGT) and interpretive structural modeling (ISM). The NGT facilitates expert verification of component and element designs and determines element priority for each study model component. The NGT was used to encourage the contribution of ideas and validate the components and elements of the planned model. The role of the expert involved was to contribute ideas and evaluate the importance of each component and element of the model. After expert discussion, NGT was also used to set each element's priority order in the model through a voting system.

After the NGT process, the ISM approach was used. ISM helps researcher to create a framework or structure to describe each element's interaction based on the context. In this approach, the elements that have been prioritized were used to form the structure of the well-being model. ISM enables the analysis of the relationship between these elements and forms a hierarchical structure which describes the relationship between them. This process allows for a deep understanding of the dynamics and interactions occurring between the components of the well-being model that has been formed. The combination of NGT and ISM ensures the formation of a relevant, comprehensive, and effective model in improving the well-being of informal caregivers of childhood cancer patients in Malaysia.

Model evaluation was the last phase in this study, in which, the researchers evaluated the appropriateness of the model that has been developed. This phase was conducted to collect information related to the interaction between the product (model) and the user, as well as the contribution of the specific properties of the model in achieving an optimal level of usability. In the evaluation phase, the evaluation aspects were divided into four main aspects: suitability of components, suitability of elements, suitability of arrangement of elements in components, and suitability of the model as a whole. The evaluation was conducted using a questionnaire-shaped instrument, and the research sample consisted of counsellors who

had experience in conducting counselling sessions with informal caregivers of childhood cancer patients, as well as academic lecturers in the field of counselling and personal well-being. The questionnaire data was analyzed using the Fuzzy Delphi method (FDM) technique to obtain accurate data in evaluating the model's usability.

3. RESULTS

3.1. Phase 1: needs analysis

There were nine respondents participated in the first phase (needs analysis). Two wellbeing models namely Hettler's six-dimensional wellbeing model [20] and Ryff's psychological wellbeing model [21] were referred to when conducting this phase. Based on the findings from the literature review and semi-structured interviews of informal caregivers of childhood cancer patients in Malaysia, 30 components were coded by the researchers. For the need for the model, the majority of respondents who are informal caregivers of childhood cancer patients agreed that a self-wellness model based on counselling is needed to guide and help caregivers in managing their wellbeing along the process of care and treatment of childhood cancer patients. Table 1 displays the examples of the research findings in verbatim form. Based on findings in Table 1, it is clear that caregivers of cancer children require a well-being model to assist them.

Table 1. Examples of verbatim for model development needs

Respondent	Needs analysis for model	Respondent transcript
Informal caregiver (TF 4)	Agree	<i>"It is very necessary and important. I strongly agree with whatever leads to goodness, and it is very necessary and important."</i>
Informal caregiver 5 (TF 5)	Agree	<i>"It is indeed necessary and important to have emotional preparation."</i>
Informal caregiver 6 (TF 6)	Agree	<i>"It's actually very good, yes its good, it's really very good... because sometimes things like that, well, people say it's not available on Google."</i>

3.2. Phase 2: design and development

For the first part of the design and development phase, the four main components adapted from Hettler's six-dimensional wellbeing model [20] and Ryff's psychological wellbeing model [21], combined with eight new main components coded by researchers through semi-structured interviews with informal caregivers of childhood cancer patients, were used in the design and development of the model. All 12 components are: i) financial; ii) career; iii) knowledge related to management and care of child cancer patients; iv) emotional management and care; v) spiritual; vi) cognitive and rationalization; vii) social relationship; viii) roles of counsellor in helping parents; ix) spouse and family relationship; x) physical; xi) communication; and xii) facilities. The second part of the self-wellbeing model design and development phase was model development analysis, in which the ISM approach was used as a tool to develop the model. Figure 1 shows the self-wellbeing model developed for informal caregivers of childhood cancer patients based on counselling in Malaysia.

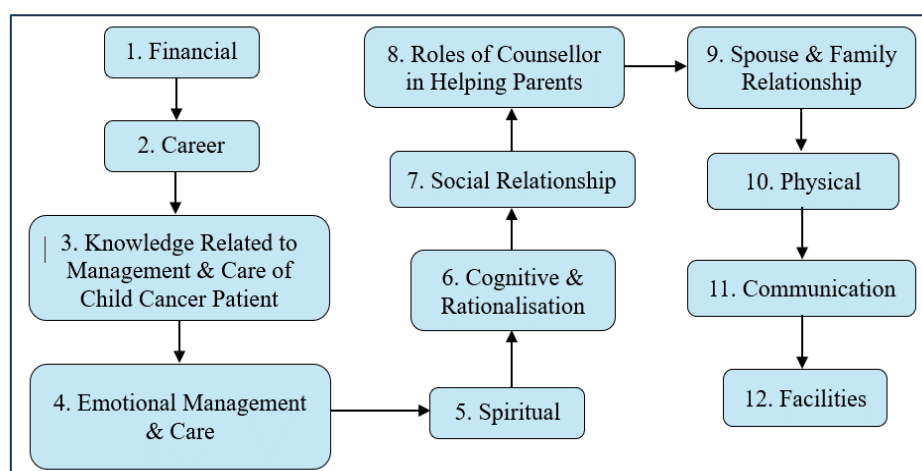


Figure 1. Self-wellbeing model framework based on counselling for informal caregivers of childhood cancer patients in Malaysia

3.3. Phase 3: evaluation of model

Table 2 shows the details of the Fuzzy Delphi analysis of the suitability of the model components based on the data provided by the respondents. Requirements for the Fuzzy Delphi analysis are i) threshold value ($d \leq 0.2$) and ii) percentage of expert agreement $\geq 75.0\%$ and defuzzification with Fuzzy score (A) $\geq \alpha$ -cut value = 0.5. Table 2 indicated that the suitability of all 12 components recorded a very encouraging result. All experts, unanimously, with a percentage value of more than 90%, agreed that all components recorded a Fuzzy score value (A) exceeding the minimum requirement of 0.6. Overall, all items of this component suitability section received a suitable assessment status. Table 3 displays the details of the FDM analysis of the overall fit of the self-wellness model.

Based on the findings in Table 3, the overall suitability status of this model recorded a very encouraging result. All experts, unanimously, with a percentage of agreement reaching 100%, agreed with each statement regarding the suitability of the entire model as presented in Table 3. As for the Fuzzy assessment, all experts recorded a value of Fuzzy score (A) exceeding the minimum requirement, with all of them recording a value above 0.6. In conclusion, all items in the overall fit section of the model received a fit rating status.

Table 2. Details of Fuzzy Delphi analysis for each of suitability according to components flow in the wellbeing model

No.	Item	d value in each	Percentage for each $d \leq 0.2$ (%)	Average of Fuzzy number	Status
1	Financial	0.04	100	0.74	Suitable
2	Career	0.09	100	0.68	Suitable
3	Knowledge related to management and care of cancer child patient	0.04	100	0.74	Suitable
4	Emotional management and care	0	100	0.8	Suitable
5	Spiritual	0.02	100	0.77	Suitable
6	Cognitive and rationalization	0.05	100	0.74	Suitable
7	Social relationship	0.05	100	0.74	Suitable
8	Role of counselors in helping parents	0.04	100	0.74	Suitable
9	Spouse and family relationship	0.047	100	0.74	Suitable
10	Physical	0.07	100	0.65	Suitable
11	Communication	0.05	100	0.71	Suitable
12	Facilities	0.07	100	0.71	Suitable

Table 3. Details of the Delphi Fuzzy analysis for the overall fit of the self-wellbeing model

No.	Item	d value for each item	Percentage for each $d \leq 0.2$ (%)	Average of Fuzzy number	Status
1	This model is very practical to be used by counsellors or counselling lecturers in helping and applying self-wellness elements based on counselling to parents of children with cancer.	0.05	100	0.71	Suitable
2	This model is able to be a guide for counsellors and counselling lecturers in planning self-wellness programs based on counselling and the application of elements to parents of childhood cancer patients.	0.05	100	0.71	Suitable
3	This model clearly shows counsellors and counselling lecturers about the objective of personal well-being based on counselling according to priority to parents of children with cancer.	0.04	100	0.65	Suitable
4	This model clearly shows counsellors and counselling lecturers about the content of self-wellness-based counselling according to priority to parents of children with cancer.	0.02	100	0.62	Suitable
5	This model clearly shows counsellors and counselling lecturers about self-wellness aids based on counseling according to priority for parents of child cancer patients.	0.02	100	0.62	Suitable
6	This model clearly shows counsellors and counselling lecturers about strategies in achieving personal well-being based on counselling according to priorities for parents of children with cancer.	0.04	100	0.65	Suitable
7	This model clearly shows counsellors and counselling lecturers about self-wellness assessment based on counselling according to priority to parents of children with cancer.	0.05	100	0.71	Suitable

4. DISCUSSION

In conclusion, the results of this study are in line with the findings of previous studies [24], [25], which showed that informal caregivers of children with cancer face personal, family, and sociocultural challenges. The findings are also supported by other studies [24], [26], [27], which states that such care of cancer patients affects the caregiver profile, quality of life, social-cultural, and mental health of informal caregivers or families who treat and manage children with cancer. Childhood cancer not only changes

children's lives but also affects families and their surrounding environment. The results of the study showed that all informal caregivers agreed with the development of this model, reaching a 100% agreement rate. Compared to previous models [28], [29], this study produces a new holistic and comprehensive model that includes 12 components of self-wellbeing based on counselling for informal caregivers.

This lack of counselling-focused guidance has been discussed by Asma'u *et al.* [30]. With the result of this study, the outcome of this study was to develop a new solution and guidance in the form of a well-being model based on counseling that can be used by counselling practitioners, especially counsellors who serve in health institutions and will handle clients consisting of informal caregivers of childhood cancer patients. Counsellors can help parents of children with cancer enhance their emotional well-being, overcome challenges, and build personal development plans [31]. Additionally, parents as informal caregivers can use this model as a preliminary step to maintain their wellbeing during the care and treatment of a child battling cancer. This newly developed model focuses on a holistic view of the childhood cancer community, especially for the informal caregivers (parents and family). It aims to support and enhance their wellbeing as they navigate the critical challenges of having a child battling cancer. For future studies, researchers can improve this model by providing a comprehensive module that can be accessed by counselors and caregivers that can explain this model in more detail. In addition, future researchers can develop a new holistic model for well-being of caregivers that can focus on the caregivers of other patients such as adult cancer patients or other critical patients.

5. CONCLUSION

This study underscores the pressing need for a structured self-wellbeing model to support informal caregivers of childhood cancer patients in Malaysia. The model was conceptualized, designed, and evaluated through a rigorous three-phase research process. Phase 1 established the foundation by identifying 30 components from literature reviews and caregiver interviews, highlighting the critical need for a counseling-based wellness framework. Phase 2 saw the thoughtful integration of Hettler's six-dimensional well-being model and Ryff's psychological well-being model with new components identified during the study, resulting in a comprehensive 12-component model addressing multifaceted caregiver needs. Finally, phase 3 confirmed the robustness and relevance of the model, with unanimous expert agreement and Fuzzy assessment scores exceeding the minimum threshold. These results affirm the model's potential to provide practical guidance for informal caregivers, helping them manage their well-being while supporting childhood cancer patients. This innovative approach bridges a crucial gap in caregiver support, offering a meaningful contribution to counseling and healthcare.

The findings of this study have significant implications for the counsellor and caregiver support. The development and validation of a self-wellbeing model specifically tailored for informal caregivers of childhood cancer patients address a critical gap in existing support systems. By incorporating multidimensional components derived from both established well-being models and empirical data, this framework provides a holistic approach to managing caregiver well-being. For counseling practitioners, this model serves as a structured tool to guide interventions aimed at enhancing the physical, emotional, and psychological resilience of caregivers. Counsellors also can adopt the model to design support programs that complement medical treatments, fostering a more comprehensive caregiving ecosystem. Moreover, the study underscores the value of using participatory and empirical approaches, such as semi-structured interviews and ISM, in developing practical and context-specific frameworks. Future research could expand on this work by adapting the model to other caregiving contexts or exploring its long-term impact on caregiver and patient well-being.

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AUTHOR CONTRIBUTIONS STATEMENT

This journal uses the Contributor Roles Taxonomy (CRediT) to recognize individual author contributions, reduce authorship disputes, and facilitate collaboration.

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C : Conceptualization

M : Methodology

So : Software

Va : Validation

Fo : Formal analysis

I : Investigation

R : Resources

D : Data Curation

O : Writing - Original Draft

E : Writing - Review & Editing

Vi : Visualization

Su : Supervision

P : Project administration

Fu : Funding acquisition

CONFLICT OF INTEREST STATEMENT

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. All authors affirm that there are no political, religious, ideological, academic, or intellectual conflicts of interest associated with the content or findings of this manuscript.

INFORMED CONSENT

All participants involved in this study were fully informed about the purpose, procedures, and voluntary nature of their participation. Written informed consent was obtained prior to data collection, including for interviews, expert validation, and model evaluation activities. Participants were assured of confidentiality and anonymity of their responses, and their right to withdraw from the study at any time without penalty.

ETHICS APPROVAL

For ethics approval, this research has obtained ethical approval from the Research Management Innovation Centre, Sultan Idris University of Education with reference number 2022-0653-01.

DATA AVAILABILITY




The data that supports the findings of this study are available from the corresponding author [NHMR], upon reasonable request.

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