

Effect of Family Nursing Intervention on Suffering Parents of Children with Cancer: A Quasi-Experimental Study

Abstract

Background: Childhood cancers often lead to significant distress for parents. This study aimed to evaluate the effects of a Family Nursing Intervention (FNI) on the suffering of parents of children with cancer. **Materials and Methods:** This study employed a quasi-experimental design with a sample of 42 parents of children with cancer. The experimental group participated in a four-week FNI program with weekly 90-minute sessions, while the control group received only routine care. Data were collected using a parenting suffering scale at baseline and after the intervention and analyzed using descriptive statistics and *t*-tests. **Results:** This study showed that, at post-test, the parents who participated in the FNI had significantly lower suffering scores compared to those in the control group ($t_{37,60} = -3.45$, $P = 0.001$). **Conclusions:** These findings suggest that FNI could alleviate parents' suffering in similar contexts in the future.

Keywords: Cancer, children, family nursing, suffering

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Introduction

Cancer is a chronic and life-threatening illness and a leading cause of mortality in children. The incidence of childhood cancer is increasing, and the most common type is leukemia.^[1] Advances in treatments and family support have considerably improved survival rates, with approximately 80% of affected children recovering.^[2] However, child survivors and their parents face unique challenges while transitioning to the survivorship phase.^[3] Cancer causes suffering for both children and their parents. Being confronted with the initial diagnosis, parents often experience shock, stress, fear, uncertainty, depression, guilt, feelings of insecurity, and profound changes in their worldview.^[4] Parents' suffering intensifies as they gain insight into the intensive treatments, healthcare needs, and prognosis of their child's cancer. This leads to difficulties in supporting their child through the adverse effects of chemotherapy.^[5] Parents' suffering encompasses physical, psychological, social, and spiritual dimensions, beginning at the time of diagnosis and persisting throughout the treatment phase.^[6] Each stage of the illness changes the family dynamics, impacting behavior, communication, and relationships.

These challenges often result in somatic problems and role reversals within the family.^[7] Mothers, in particular, experience a significant psychological impact due to their child's cancer and associated treatment modalities.^[8] Parental suffering is closely linked to the family's and child's beliefs and anticipations regarding cancer symptom and their experiences.^[9] Witnessing children's symptoms and suffering following painful procedures could impede the parent's ability to make decisions effectively.^[10] Hence, parents require substantial support to fulfill their psychological, informational, and emotional needs during the illness and treatment phases.^[7] For instance, one study implemented a brief FNI based on the Calgary models to evaluate family health and functioning outcomes.^[11] Additionally, combining social support with structural interventions, such as rehabilitation programs, can help affected families feel reintegrated and supported following treatment.^[12] However, parents from different contexts, cultures, or religious beliefs might cope with and alleviate suffering in distinct ways. In Thai culture, family plays a central role in decision-making and providing support during illness. Religious practices often aid families cope with the challenges of diagnosing and treating childhood cancer.

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For instance, unique cancer incidence rates were observed in Southern Thailand, where certain religious groups exhibited lower prevalence rates of cancer.^[13] Moreover, religion, population demographics, and cultural factors affected the occurrence rates. In Thai society, cancer is often perceived negatively, with stigma associated with fear, shame, and death. Despite these challenges, childhood cancer survival rates have shown improvement in Thailand. A Thai Pediatric Oncology group was established to provide standardized treatments for childhood cancers. Additionally, following healthcare reforms, the provision of universal healthcare schemes and increased access to various healthcare facilities have enabled individuals from low socioeconomic backgrounds to afford treatment and achieve better outcomes.^[14] Cancer brings about various complications, including emotional distress, social isolation, loss of income, financial strain, disruptions in family dynamics, and insufficient psychosocial support, all of which can make it more difficult for families to care for their children.^[15] Considering these wide-range impacts, family-based nursing interventions are crucial. Thus, this study developed family-based interventions designed to provide culturally sensitive care, update information, reduce stress, offer psychosocial support, and enhance caregiving abilities. This study aimed to evaluate the effects of a Family Nursing Intervention (FNI) on the suffering of parents of children with cancer.

Materials and Methods

This study used a prospective, quasi-experimental design to evaluate the preliminary effects of the intervention among the parents of children with cancer from the inpatient pediatric and chemotherapy units of a regional public hospital in eastern Thailand in 2021. Using a power of 0.80, a significance level of 0.05, and an effect size of 0.8 from the pilot study, the estimated sample size was 42. A total of 21 participants were randomly assigned per group (experimental and control). The inclusion criteria were as follows: (1) parents who were taking care of their children during the chemotherapy, (2) ability to communicate in Thai, (3) no history of a neuropsychiatric disorder, and (4) willingness to participate. Participants were excluded from the study if their children died during the intervention period. The FNI program was developed based on components of the illness belief model, the family empowerment program, and the context of alleviating suffering among parents of children with cancer. The experimental group received the FNI, a four-week program for 90 minutes per session at the inpatient pediatric or chemotherapy unit. The doctoral-prepared researcher provided all sessions to the parents in a private room. There were four training sessions with one week apart from each session. This is an individual-based intervention. It comprised five steps as follows: (i) creating a trusting relationship, (ii) understanding the reality of suffering while caring for a child, (iii) changing beliefs and practicing methods to alleviate suffering, (iv) strengthening

the parents' confidence, and (v) reflecting and concluding. All the participants in the experimental group completed the intervention program [Table 1]. Demographic data of parents and children were collected. The suffering scale^[16] was used to assess the suffering level in the past 7 days. It had four domains, namely physical symptoms (6 items), spiritual suffering (9 items), psychological symptoms (11 items), and social and functioning distress (10 items). Both father and mother completed demographic data and the suffering scale. Responses were rated on a four-point scale (0 = not at all to 3 = very often). A higher score indicated greater suffering. The Cronbach's alpha for this study was 0.86. Descriptive statistics, the Chi-square test, Fisher's exact test, and *t*-tests were performed using SPSS (version 27; IBM Corp.).

Ethical considerations

This study obtained ethical approval from the institutional review boards of the researcher affiliation (IRB# 49/2558) and the study hospital (IRB # 044/58/0/q). All the participants provided their consent to be involved in this study.

Results

Among the study participants, two parents in the control group were excluded since they missed the last session and post-test. Three-fourths (75%) of the parents were mothers of children with cancer. All the parents were Buddhist. Family income in the control group was significantly higher than in the experimental group ($P < 0.05$). The predominant disease of children was acute lymphoblastic leukemia (ALL), and all received chemotherapy. Further, the change in parents' average suffering score ($\bar{D}$) was significant in the experimental group. After receiving the FNI program, the parents' average suffering scores decreased significantly, whereas the scores in the control group did not change significantly [Table 2].

Discussion

The results indicated that the FNI effectively alleviated the suffering of parents of children with cancer. The experimental group experienced a significant reduction in suffering compared to the control group, with effects similar to those achieved through other interventions, such as antineoplastic therapy administration,^[17] self-help interventions,^[18] and cognitive-emotional interventions.^[19] These interventions focused on cognitive processing and emotional communication and also helped alleviate traumatic stress and adjustment difficulties, particularly in mothers of children with cancer. The FNI program was delivered within a context of non-judgmental support and a trusting relationship between the researchers and parents. It provided valuable insights into the reality of parents' suffering and offered critical information to aid parents explore options for alleviating suffering and changing constraining beliefs. Furthermore, parents' psychological well-being is essential to a child's recovery process. Parents in the experimental group practiced mindfulness meditation,

Table 1: Intervention

Steps	Activities (Individual parent)
Step 1. Creating a trusting relationship	1.1 Introducing one another, explaining the study objectives, family genogram, and family attachment. 1.2 Encouraging the parent to ask questions related to parental suffering.
Step 2. Understanding the reality of suffering when caring for a child	2.1 Inviting the parents to tell stories about beliefs regarding illness and expectations in caring for their child. 2.2 Discussing beliefs regarding illness and experiences of alleviated suffering, holistic needs of parents, and finding the meaning of life and having hope. 2.3 Commending the parents' strength and devotion to their child
Step 3. Changing beliefs and practicing methods to alleviate suffering.	3.1 Asking questions that reflect on the impact of caring for their child. 3.2 Training the parents to improve communication in challenging situations and to practice mindfulness every hour. 3.3 Providing updated information for other options or beliefs in caring for their child. 3.4 Providing affirmation of the parents' strength of being a good parent and providing moral support for the parents. 3.5 Encouraging the parents to plan ways to reduce their suffering.
Step 4. Strengthening the parents' confidence	4.1 Exploring changes by inviting the parents to explain and confirm changes in their suffering. 4.2 Maintaining childcare ability, advocating for the child, and practicing family routines. 4.3 Reducing psychological distress by making parents practice deep breathing exercises for five to 15 minutes every session.
Step 5. Reflecting and concluding	5.1 Assessing their suffering and reflecting on changes in family care and the parents' confidence. 5.2 Offering reflections regarding observed changes and discussing additional plans related to childcare practices.

Table 2: Comparison discrepancy of mean pre- and post-test suffering scores between the experimental and control groups of the participants

Group	<i>n</i>	Mean (SD)	$\bar{D}$ (SD)	<i>t</i>	df	<i>p</i>	Effect size
Experimental group	21		23.90 (17.14)				
Pre-test		94.50 (15.80)					
Post-test		70.60 (17.70)		3.45***	37.60	<0.001	0.396
Control group	19		5.16 (17.13)				
Pre-test		83.20 (18.70)					
Post-test		78.00 (19.60)					

*** $p < 0.001$, n =number of samples, SD=standard deviation, $\bar{D}$ =mean score difference between pre- and post-test, t = t -value, df=degree of freedom

which significantly reduced their psychological distress. This finding aligns with a previous study, which indicated psychosocial individualized interventions can reduce emotional distress and positively affect hope among patients and caregivers.^[20] Along with healthcare professionals' support, parents also contribute to their children's recovery by staying close to them, engaging in various activities, fulfilling their needs, and motivating them to fight through the pain.^[8] Symptom distress is a crucial factor that requires attention. Both children and their families believed that enduring symptoms of suffering were vital to defeat cancer, leading them to adapt and live with it. They employed strategies such as getting adequate rest and using a trial-and-error approach to manage symptoms effectively.^[9] Moreover, this study highlighted the challenges encountered while caring for a child with cancer, including disruptions in family dynamics and difficulties with self-care. Providing body-mind therapy could ease cancer-related complications, acting as an adjuvant to oncologic care. It promotes serenity and encourages parents to openly discuss various aspects of the disease and treatment, helping them manage emotional challenges.^[21] In the context

of this study, Thai Buddhist parents practiced praying and merit-making as coping mechanisms for dealing with the diagnosis and treatment of cancer. These practices reaffirmed their belief that performing good deeds brings happiness and alleviates suffering. Nevertheless, it is essential to recognize that each family needs a unique approach, tailored to their understanding and psychosocial needs.^[22] In addition, nurses must receive proper training to overcome their distress, as they often face physical and psychological exhaustion while delivering oncologic care. This training is crucial not only for their well-being but also to better support parents in reducing their burden^[23] and enhancing their caregiving abilities. The limitation of this study is that, at the baseline, the parents in the experimental group had significantly higher suffering scores than those in the control group, which may impact the generalizability of the findings.

Conclusion

A unique contribution of the FNI program was its holistic approach, offering psychosocial, spiritual, and educational

support to parents of children with cancer. By alleviating suffering within the family, the program helps normalize and improve the quality of life. One of the strengths of the FNI program is its ability to create a healing context by maintaining a trusting relationship between the implementer and the family throughout the program. The FNI involves discussing illness beliefs and alleviating suffering with compassion, respect, and acceptance. Through reflecting on suffering, parents are trained in mindfulness meditation to reduce distress. The FNI program also has the potential to raise awareness among nurses and other healthcare professionals about the importance of alleviating suffering in parents of children with cancer. Ideally, nurses could implement the FNI program as part of routine care for pediatric cancer patients and their families, offering sustained support to those facing similar challenges.

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Conflicts of interest

Nothing to declare.

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