

# ปัจจัยที่มีอิทธิพลต่อความทุกข์ทรมาน ของบิดามารดาที่มีบุตรเป็นโรคมะเร็ง

## Factors Influencing Suffering of Parents who had Children with Cancer

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### บทคัดย่อ

การวิจัยเชิงพรรณนาหาความสัมพันธ์นี้มีวัตถุประสงค์เพื่อศึกษาปัจจัยที่มีอิทธิพลต่อความทุกข์ทรมานของบิดามารดาที่มีบุตรเป็นโรคมะเร็ง กลุ่มตัวอย่างคือบิดามารดาที่มีบุตรป่วยด้วยโรคมะเร็งและได้รับการรักษาด้วยเคมีบำบัด ณ โรงพยาบาลศูนย์สังกัดกระทรวงสาธารณสุข จำนวน 231 ราย เลือกกลุ่มตัวอย่างโดยวิธีการสุ่มแบบแบ่งกลุ่ม เครื่องมือวิจัยได้แก่ แบบบันทึกข้อมูลส่วนบุคคล แบบวัดความทุกข์ทรมานของบิดามารดา แบบสำรวจความเชื่อเกี่ยวกับการเจ็บป่วยของครอบครัว แบบวัดการรับรู้ความทุกข์ทรมานทางกายของบุตร แบบวัดแรงสนับสนุนทางสังคม และแบบวัดความผาสุกทางจิตวิญญาณ วิเคราะห์ข้อมูลด้วยสถิติพรรณนาและการวิเคราะห์การถดถอยพหุคูณ

ผลการวิจัยพบว่าการรับรู้ความทุกข์ทรมานทางกายของบุตรและความเชื่อเกี่ยวกับการเจ็บป่วยมีอิทธิพลต่อความทุกข์ทรมานของบิดามารดาอย่างมีนัยสำคัญทางสถิติ ( $\beta = .38$  และ  $\beta = .20$ ,  $p < .001$ ) และสามารถร่วมกันทำนายความทุกข์ทรมานของบิดามารดาได้ร้อยละ 23 ( $R^2 = .23$ ,  $p < .001$ ). ผลการวิจัยนี้แสดงให้เห็นว่าการรับรู้ความทุกข์ทรมานทางกายของบุตรและความเชื่อเกี่ยวกับการเจ็บป่วยจะทำให้บิดามารดาเกิดความทุกข์ทรมานได้ ดังนั้นพยาบาลควรตระหนักและทำความเข้าใจเกี่ยวกับการรับรู้ความทุกข์ทรมานทางกายของบุตรและความเชื่อเกี่ยวกับการเจ็บป่วย เพื่อพัฒนาคุณภาพการพยาบาลโดยโปรแกรมการลดความทุกข์ทรมานของบิดามารดาได้อย่างเหมาะสม

**คำสำคัญ:** ความทุกข์ทรมานของบิดามารดา ความเชื่อเกี่ยวกับการเจ็บป่วย การรับรู้ความทุกข์ทรมานทางกายของบุตร แรงสนับสนุนทางสังคม ความผาสุกทางจิตวิญญาณ เด็กโรคมะเร็ง

### Abstract

This research examined the effect of parents' perceptions of a child's physical suffering, parents' beliefs about illness, social support and spirituality on parents' own suffering. The sample was selected by a cluster random sampling technique. Participants included 231 parents of children with cancer from six regional hospitals in Thailand. Data were collected by using a demographic data record form and self-report questionnaires about the perceptions of a child's physical suffering scale, Family Illness Beliefs Inventory, Social Support Questionnaire, Spiritual Well-Being Scale and Suffering Scale. Data were analyzed by using descriptive statistics and multiple regression.

Results showed that the parents' beliefs about illness and parents' perceptions of their child's physical suffering were significantly influence on the parents' suffering ( $\beta = .38, p < .001$  and  $\beta = .20, p < .001$ ). These predictors combined could explain 23% of variance in parents' suffering ( $R^2 = .23, p < .001$ ). Results indicated that the parents' perception of child's physical suffering and their beliefs about illness affected their own suffering. Nurses who care for children with cancer should be aware not only of their patients' distress but also the suffering of the parents. They should develop quality of nursing interventions to reduce suffering and burden of parents in appropriate method.

**Keywords:** parents' suffering, beliefs about illness, perception of child's physical suffering, social support, spirituality, children with cancer

## Introduction

Suffering frequently occurs in an illness of a family member, especially suffering in parents of children with cancer. Cancer is a major health problem for children worldwide. It is also the leading cause of child mortality. Childhood cancer is a potentially life-threatening illness that has a sudden onset and usually requires lengthy treatment. Cancer affects not only the child, but also the parents. Parents are required to adapt to a new situation that involves long hospital stays, changes in parental roles and family relationships, and altered routines.<sup>1</sup>

The treatment of childhood cancer may require parents to leave their jobs and give priority to treatment.<sup>2,3</sup> A child's diagnosis of cancer impacts parents emotionally in the form of shock, disbelief, depression, hopelessness, sadness, anger, guilt and loss of control with fear and anxiety about relapse and uncertainty about the progression of the disease and treatments. Furthermore, parents have difficulties in dealing with feelings of powerlessness in protecting their child from painful and invasive procedures.<sup>1</sup> Thus, parents who cannot manage their tasks and cope with their own emotions can lead to suffering.<sup>1,4</sup>

Based on a review of literature, there are factors related to parents' suffering, such as the perception of child's physical distress, beliefs about illness of the parent, social support and spirituality.

Perception of a child's physical distress occurs when the child is suffering from physical symptoms and pain. The parents' suffering is often related to their inability to eradicate the child's suffering.<sup>5,6</sup> Caregivers manifest high levels of suffering because they witness the physical symptoms and pain in the patients under their care.<sup>4</sup> Patient suffering has a significant association with family caregiver suffering.<sup>7,8</sup>

Beliefs about illness also serve as a source of family suffering and lie at the heart of family healing. The beliefs of parents are often reconstructed after an experience with illness, which both influences and shapes the processes and outcomes of illness in the form of suffering.<sup>9,10</sup> Previous studies have found that beliefs about illness can influence how parents adapt, manage, and cope with illness,<sup>9</sup> possibly fostering their own distress. Parents who have found the cancer experience to be particularly difficult, or believe that their child will die during treatment, have elevated post-traumatic stress symptoms. High levels of parental anxiety and hopelessness are associated with strong parental beliefs that their child will suffer from cancer and treatment and eventually die.<sup>11</sup>

Social support influences the vulnerability of parents.<sup>1</sup> Social support can protect people against suffering.<sup>12</sup> People who perceived social support may facilitate or block the adjustment process that will influence alleviation of suffering.<sup>13,4</sup> Spirituality affects

to human values and the search for purpose and meaning.<sup>14</sup> Spirituality helps people in difficult decisions that might be used to assistance parents fulfill good parental roles. It is negatively correlated with hopelessness, depression and suffering. Spirituality has been found to protect people from suffering and foster well-being.<sup>12</sup>

Therefore, studies of parents' suffering and contributing factors are important. Results may help nurses understand and recognize ways to ease the suffering of parents. If their suffering declines, they can care for children with cancer more effectively. Recognizing the factors contributing to parents' suffering may improve the family survivorship experiences following childhood cancer.

**Conceptual Framework for the Study**

In addition to a synthesis of research evidence from the published literature, the conceptual framework for this study was the illness beliefs model developed by Wright and Bell.<sup>10</sup> Beliefs about illness of the parent are a factor that can either create or heal the suffering of parents.

Parents have beliefs that lead to either facilitate or constrain illness suffering and healing. Facilitating beliefs decrease illness suffering and invite healing. Constraining beliefs refer to beliefs that enhance illness suffering.<sup>15</sup> For example, parents who believe that their child will die during treatment and they will demonstrate symptoms of elevated post-traumatic stress.<sup>11</sup> Beliefs among mothers and fathers of children with cancer may foster distress that leads to suffering. Parents who witness their child's distress are significantly influenced by the mutuality of this relationship.<sup>5</sup> The family's perception of a child's physical distress will be experienced by both the child and parents; thus, it is a shared suffering experience for the family.<sup>16</sup> Social support might encourage the expression of emotions and resolution of distress. It is known to have a mitigating effect on the experience of stress and is linked to lower prevalence of distress.<sup>17</sup> Spirituality appears to be a way for parents that provide well-being, hope and take meaning out of their suffering.<sup>4</sup> A conceptual framework of the study is illustrated in figure 1.

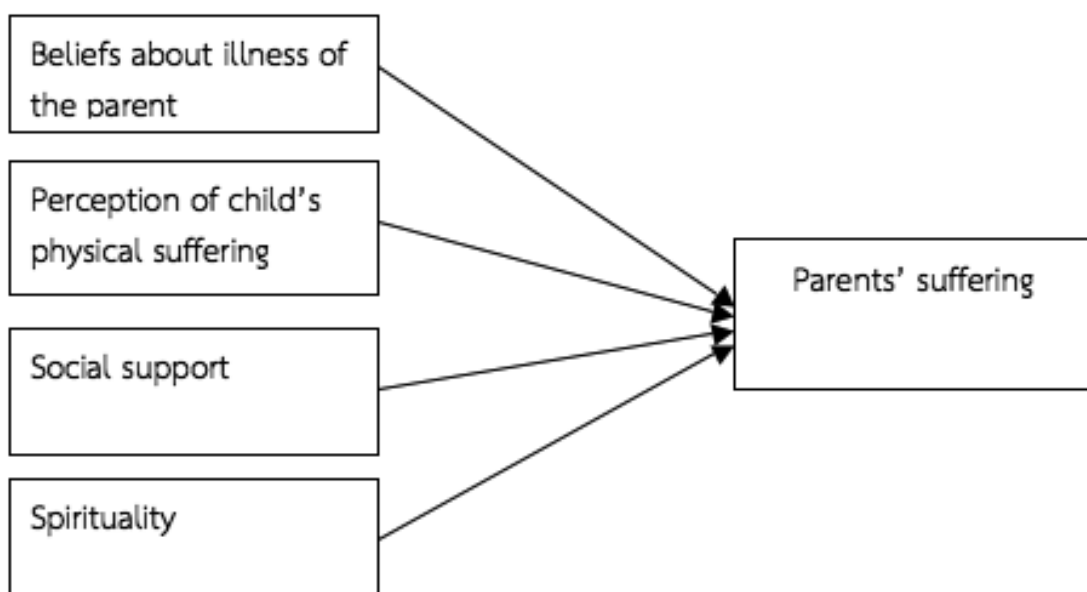


Figure 1 A conceptual framework model

## Research objective

The aim of this study was to examine the effect of beliefs about illness of the parent, perception of child's physical suffering, social support and spirituality on suffering in parents who had children with cancer.

## Design

A descriptive correlational, cross-sectional design was used in this study.

## Methods

### Population and sample

Participants were parents of children with cancer who visited the inpatient or outpatient clinics at a pediatrics department in six regional hospitals in Thailand. Participants were recruited with the following inclusion criteria: 1) Aged more than 18 years; 2) having children aged 1-15 years diagnosed with cancer; 3) children undergoing chemotherapy and who have received cancer treatment within six months, and 4) ability to communicate, read, and write in the Thai language. The data were collected from 231 cases. Exclusion criteria are children diagnosed with end of life care.

### Sampling technique

A cluster random sampling technique was employed to select parents of children with cancer in six regional hospitals. First, the regional hospitals in Thailand were divided into four clusters: Northern region (4 hospitals), North Eastern region (4 hospitals), Eastern region (2 hospitals) and Southern region (2 hospitals). Second, hospitals were randomly sampled from all regions by proportion of number of hospitals 2:1. Therefore, the randomly selected regional hospitals were five hospitals including the Buddhachinnaraj Hospital, Lumpang Hospital, Udonthani Hospital, Sappasitthiprasong Hospital, Chon Buri Hospital, and Suratthani Hospital. Then,

eligible participants who met the inclusion criteria from each hospital were recruited until the number of participants was reached.

Research instruments: There were six research instruments using in the study.

1. The demographic record form was used to collect information about parents and children with cancer.

2. The perceptions of child's physical suffering scale was used to measure the perception of the child's physical suffering. Parents were asked to indicate the extent of the child's suffering from cancer and treatment. The instrument was a modification of a single item, 11-point pain scale, with 0 representing no suffering and 10 representing the worst suffering. A higher score represented the greater the degree of perceived physical suffering of the child.

3. The Family Illness Beliefs Inventory (FIBI) was used to measure parents' beliefs about illness. The FIBI was developed by Kazak et al.<sup>11</sup> and translated into Thai by the researcher using a forward and backward translation procedure. The 41-item inventory reflects both growth-promoting and growth-inhibiting beliefs. It consists of five dimensions: treatment-related suffering, death and devastation, caregiver competence, connection, and finding meaning. It is the 4-point response scale (1 = not at all true for me, and 4 = very true for me). Higher scores indicated stronger beliefs that cancer had a negative meaningful effect. The Cronbach's alpha coefficient of FIBI for this study was .84.

4. The Suffering Scale was used to measure parents' suffering. The suffering scale was developed by Schulz et al.<sup>18</sup> and translated similarly as the FIBI. It is rating scale including three domains of physical symptoms, psychological symptoms and existential suffering. The subscale for physical symptoms and psychological symptoms were ranged from not at all

(0) to very often (3). The existential suffering subscale was ranged from 0 (not at all) to 4 (very much). A higher total score indicated greater suffering. Cronbach's alpha coefficients of the physical symptoms, psychological symptoms and existential suffering were .88, .88, and .73, respectively.

5. The Social Support Questionnaire (SSQ) was used to measured social support. The SSQ was developed by Schaefer, Coyne, and Lazarus<sup>19</sup> and translated into Thai by Hanucharunkul, et al.<sup>20</sup> It is a 21-item questionnaire including three types of support: informational, emotional, and tangible support. The SSQ is a 5-point rating scale from 0 (no support) to 4 (a great deal of support). A higher score indicates higher perceived social support. Cronbach's alpha coefficients were .93

6. The Spiritual Well-Being Scale (SWBS) was used to measure spirituality. The SWBS was developed by Paloutzian and Ellison<sup>21</sup> and translated into a Thai version by Get-Kong.<sup>22</sup> A 20-item instrument designed to capture two components of spirituality comprising religious well-being (10 items) and existential well-being (10 items). It is a 6-point Likert scale from strongly agree to strongly disagree. The greater the scores represent the higher the degree of spiritual well-being. Cronbach's alpha coefficients were .82

#### **Protection of human subjects:**

This study was approved by the Institutional Review Board of the Faculty of Nursing, Burapha University (IRB #03-09-2559) and by each of the six hospitals. After being informed about the study's objectives, risks, and benefits, and their right to withdraw from the study at any time, the participants signed a consent form. Code numbers were used to replace names to ensure confidentiality of participants.

#### **Data collection procedures:**

Following the IRB approval, the researcher contacted the head nurse of each hospital to inform them about the details of the study. The researcher and research assistants contacted the parents of children with cancer who were willing to participate. They introduced themselves; informed them of the objectives, risks, and benefits of this study; and their right to withdraw from the study at any time. All participants formally consented in writing to join the study. The average time for participants to complete the self-administered questionnaires was about 40-50 minutes.

#### **Data analysis:**

Descriptive statistics were used to assess demographic data and perceptions of child's physical suffering, beliefs about illness and parents' suffering. Pearson's correlation was used to describe bivariate relationships. The multiple regressions analysis was conducted to examine the effect of contributing factors to parents' suffering. The significance level was set at .05.

#### **Results**

A total of 231 parents who had a child with cancer participated in the study. A large majority (90.48%) of participants were mothers whose ages ranged from 19 to 56 years ( $M = 34.28$ ,  $SD = 7.09$ ). A majority of the participants was Buddhist (93.51%) and married (84.85%). Less than half (48.92%) of the participants had completed secondary school, while 25.97% had only completed primary school. There were 36.36 % of employees; while equal percent of them (19.48 %) were housewife and agriculture, 15.15% of them were merchants.

The average monthly family income was 18,483 Baht (SD = 27,189), ranging from 2,000 to 200,000 Baht. Nearly half (47.19 %) the participants had family incomes less than 10,000 Baht per month. Nearly two-thirds (64.50 %) spent 17-24 hours per day caring for their child.

Less than two-thirds (62.34 %) of the children with cancer were male with an average age of 7.13 years (SD = 3.59), ranging from 1 to 15 years. Nearly half (47.62%) were in the 6 to 12 years age group

and 28.57% were in 3 to 6 years age group. A large majority (93.07%) were Buddhist. About two-fifths (42.42%) of the children were in primary school, while 25.11% were at the kindergarten level. Most of children had been diagnosed with leukemia (80.09%) and solid or brain tumors (13.85%). The children had been diagnosed with cancer between 2-12 months (45.02%) and 13-24 months (23.81%). Chemotherapy was the only treatment for 93.07% of the children.

**Table 1** Descriptive statistics of the study variables (n = 231)

Variable	Possible range	Actual range	Mean	SD
Perceptions of child's physical suffering	0-10	0-10	6.64	2.72
Beliefs about illness of parent	41-164	73-136	110.3	12.11
Social support	0-84	20-84	60.38	13.32
Spirituality	20-120	66-120	92.86	13.47
Parents' suffering	0-99	1-62	25.22	11.84

The perceptions of a child's physical suffering ranged from 0 to 10 (M = 6.64, SD = 2.72); beliefs about illness of the parent ranged from 73 to 136 (M = 110.3, SD = 12.11); parents' suffering ranged from 1 to 62 (M = 25.22, SD = 11.84); Social support ranged from 20 to 84 (M = 60.38, SD = 13.32); and Spirituality ranged from 66 to 120 (M = 99.86, SD = 13.47)

The result of variables reported perceptions of child's physical suffering, beliefs about illness, social support and spirituality with a mean of each variable higher than one-half of the possible range. The mean score of parents' suffering was 25.22, lower than half the possible range.

**Table 2** Correlation Matrix of the Study Variables (n = 231)

Variable	Perceptions of child's physical suffering	Beliefs about illness of the parent	Social support	Spirituality	Parents' suffering
1. Perceptions of child's physical suffering	1.00				
2. Beliefs about illness of the parent	.35**	1.00			
3. Social support	-.05	-.25**	1.00		
4. Spirituality	-.05	-.44**	.34**	1.00	
5. Parents' suffering	.32**	.44**	-.11	-.23**	1.00

\*\* p<.01

Table 2 shows Pearson correlation coefficients between each of the three variables. Perceptions of the child's physical suffering and beliefs about illness were positively significant with parents' suffering ( $r = .32$  and  $.44$ ,  $p < .01$  respectively). Spirituality was negatively significant with parents' suffering ( $r = -.23$ ,  $p < .01$ ).

Table 3 presents the beta weight of factors that influence parents' suffering at level of statistical significant .001. The beliefs about illness of the parents and perceptions of a child's physical suffering ( $\beta = .38$ ,  $p < .001$  and  $\beta = .20$ ,  $p < .001$  respectively). Moreover, beliefs about illness of the parent and perceptions of a child's physical suffering accounted for 23% ( $R^2 = .23$ ) of the variance in parents' suffering.

**Table 3** Multiple Regression Analysis

Variables	b	Beta	t	p-value
Beliefs about illness of the parent	.41	.38	6.11	.000
Perceptions of a child's physical suffering	.88	.20	3.27	.000
Constant	-17.004			-2.995

$R = .479$ ,  $R^2 = .23$ ,  $F = 33.959$   $p$ -value  $< .001$

## Discussion

The findings provide the significant predictors that influenced suffering in parents who had children with cancer. The results show that beliefs about illness of the parent and their perceptions of the physical suffering of children with cancer influence parents' suffering. The parents' beliefs about their child's cancer are the most important factor that influenced their own suffering. A family's suffering arises from their beliefs about illness more than the illness itself.<sup>15</sup> There are two types of beliefs including constraining beliefs and facilitating beliefs. Constraining beliefs refer to those that decrease the possibilities for discovering solutions and often enhance illness suffering. On the other hand, facilitating beliefs increase solution possibilities, decrease illness suffering, and invite healing.<sup>10</sup> Beliefs about the child's treatment implies that parents believe their child would suffer from the illness and treatment. Beliefs about possible death and devastation refer to the

parents' beliefs that the child could die, bringing emotional devastation to the parents. If parents have doubts about the competence of the health care team in providing good care and understanding the family, those beliefs contribute to the parents' suffering. If parents question whether they can connect with another person, that belief increases personal suffering. Moreover, if parents can find meaning of the illness, those beliefs influence suffering. Results show that parents have increased suffering when they believe and have doubts about any aspect related to their child's illness and treatment across the five dimensions.

In addition, parents' perceptions of their child's suffering affected their own suffering. As parents perceive their children suffer physically, they also suffer. The parents of children with cancer reported that their child's pain and suffer during procedures produced their sorrow.<sup>23</sup> A serious illness in the family with medical treatments impacts the family

system.<sup>10</sup> Suffering within the family is the shared involvement with the child and parents' responses to the illness and treatment.<sup>16</sup> Perceptions of a child's physical suffering occurs when the child is suffering from physical symptoms and pain. Pain is the most frequent and severe for cancer patients.<sup>24</sup> Parents have difficulty dealing with the inability to prevent their child from experiencing painful and invasive procedures.<sup>1, 5, 6, 25, 26, 27</sup> Furthermore, parents of children with cancer reported that their suffering was caused by their child's suffering, especially from painful procedures, side effects of treatment, and infection. Children cry and often ask for help from parents. Parents experiencing their child's suffering also suffer.<sup>28</sup> Velez et al<sup>4</sup> has revealed that even professional caregivers manifest high levels of suffering as they observe the physical symptoms and pain of their patients. Rosenberg et al<sup>25</sup> has also found that parents of children with advanced cancer, and who believe their child suffers greatly, display high psychological distress.

In conclusion, the perception of a child's physical suffering and a parent's beliefs about illness has a significant influence the parents' own suffering. To be effective in providing care for children with cancer, nurses should be aware not only the patients' distress but also the suffering of the parents. A parent who suffers may be unable to care for the child in supportive ways that the child needs. Understanding parents' suffering is useful for nurses to guide and to help them in their struggles.

### Implications and Recommendations

The study results could be utilized to guide nursing practice in the care of children with cancer and their parents. The results provide empirical knowledge important to nursing care. It helps nurses realized that parents are dealing with childhood cancer and are deeply affected. Suffering depends on

how the parents perceive about illness of their children and their child's physical suffering. Nurses should develop and evaluate appropriate interventions to ease the burden of parents who suffer with their children. Nursing interventions should integrate beliefs about illness and perceptions of child's physical suffering. Parents also should be given appropriate information about cancer and its treatment and how children would be affected. Parents need to be reassured that care for their children with cancer will strive to minimize physical suffering. Nurses also need to be aware that parents need to feel comfort and secure as they observe that their children are receiving competent care. In addition, implication to nursing education should contain knowledge about parents' suffering in nursing curriculum related to childhood cancer care. Nursing students should understand beliefs about illness and perceptions of child's physical suffering among the parents who have children with cancer. Recommendations for future studies, the suffering in parents of children with cancer and related factors should be studied at different times of the stages of cancer and treatment because parents' suffering changes over time of the duration of cancer and treatments.

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