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암환아 어머니의 고통과 외상 후 성장

김미영
을지대학교 간호대학

Posttraumatic Growth Characteristics and Distress in Mothers of Children with Cancer

Kim, Mi Young
College of Nursing, Eulji University, Seongnam, Korea

Purpose: The aim of this study was to understand distress and posttraumatic growth (PTG) in mothers of children with cancer. **Methods:** The data were collected through self-reported questionnaires completed by 222 mothers of children with cancer who had visited the hospital between 9th August and 17th September 2013. **Results:** The results showed high distress both currently and at diagnosis in the majority of respondents. Analysis of the effects of general characteristics on PTG revealed that religious respondents, or those with considerable religious influence, had higher PTG. PTG was also higher in participants with 2 or more children, and for whom the patient was the second-born or later. There were no significant differences in PTG according to either the mother's characteristics (age, level of education, employment status, and burden of medical care costs) or the patient's characteristics (age, gender, birth order, diagnosis, duration of disease, and recurrence). **Conclusion:** The results of this study allowed a balanced observation of both positive and negative psychological states, such as distress and PTG, in mothers of children with cancer. These study findings may be useful foundation data for development of interventions to promote PTG.

Key Words: *Child, Neoplasms, Mothers, Posttraumatic, Growth*

INTRODUCTION

Cancer is the leading cause of disease-related death among children in South Korea. In 2012, cancer was diagnosed in 148.5 per million children in South Korea, and the number of cases has been increasing each year.[1] Due to technological advances in treatment that have reduced mortality, pediatric cancer is often a chronic illness that can cause lifetime physical and psychological issues. Pediatric cancer affects not only the patients themselves, but also impacts their families, including their quality of life, physical and mental health, daily activities, family dynamics, and parent and sibling roles.[2] Within the family, mothers, as the primary caretakers, often experience guilt, anxiety about the treatment process and prognosis, fear about responsibility for the future, despair, powerlessness, and high levels of psychological distress,[3] as well as symptoms of emotional disability, depression, and posttraumatic stress disorder (PTSD).[4] These psychological problems are important, since they affect more than just the mother. Shin and Shim[5] reported that child-raising stress among mothers of children with cancer affects the social competence of their children, and Sawyer et al.[6] reported that psychological coping of mothers during the treatment period affected the psychological coping of patients 2 years after completing treatment.

However, not all of these individuals live in despair. Positive changes have been associated with the process of overcoming disease, including changes in oneself, relations with others, future plans,[7] recognizing new possibilities and personal strengths, permanent changes, and increased gratitude for life.[8] Tedeschi and Calhoun[9] described these positive changes, beyond previous levels, in the course of overcoming adversity

주요어: 암, 환아, 어머니, 외상 후, 성장
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Address reprint requests to: Kim, Mi Young
College of Nursing, Eulji University, 553 Sanseong-daero, Sujeong-gu, Seongnam 13135, Korea
Tel: +82-31-740-7398 Fax: +82-31-740-7359 E-mail: kimmy@eulji.ac.kr

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as posttraumatic growth (PTG).[9]

PTG is a complex, multidimensional concept,[10] whose characteristics require further understanding. Hence, the present study investigated PTG in mothers to determine the effects of general and disease-related characteristics of the mother and the patient on PTG. Understanding distress and PTG in mothers of children with cancer is fundamental for understanding individuals receiving nursing care when faced with adversity. Moreover, it provides data that enables alleviation of negative aspects and positive changes when faced with adversity.

This study aimed to determine the extent of distress and PTG in mothers of children with cancer, and investigate the relationship between PTG and the general and disease-related characteristics of mothers and patients.

METHODS

1. Study design

A descriptive cross-sectional design was employed. The data were collected through self-reported questionnaires completed by mothers of children with cancer who had visited the hospital.

2. Sample

The subjects included mothers of children with cancer who visited a university hospital in Seoul, South Korea. The selection criteria included having a child who had been diagnosed with cancer over 3 months before the study or, in cases where children were being followed up and monitored after treatment completion, had discontinued treatment within the previous 5 years.

3. Instruments

In the present study, PTG was measured using the Korean version of the Posttraumatic Growth Inventory (K-PTGI), which was adapted from the PTGI[9] and has been validated in South Korea.[11] K-PTGI was verified with validity in a research involving cancer care givers in the country.[12] Also whether it is suitable to use the instrument on the mothers of children with cancer was approved by 4 professors in Adult Nursing and 1 in Pediatric Nursing. The K-PTGI uses a 6-point Likert scale and consists of 16 items in 4 subdomains: changes in self-awareness, increased depth of interpersonal relationships, discovery of new possibilities, and increased religious/spiritual interest. The 6-point Likert scale ranges from 0 (strongly disagree) to 5 (strongly agree), with a total score ranging from 0 to 80 points, and where higher scores are indicative of greater growth. The reliability of this instrument at the time of development was based on a Cronbach's α = .92, and was also .92 in the current study.

Distress was also measured in the mothers of children with cancer at the time of diagnosis and at current status. The measurements were made on a 7-point scale with reference to a previous study that measured traumatic shock on a 7-point scale.[11] The general characteristics of the mother and patient as well as the disease-related characteristics of the patient were also investigated.

4. Data collection and ethical considerations

This study was approved by the hospital's institutional review board (IRB No. H-1307-064-503) and the guidelines of the Declaration of Helsinki were followed. The data collection process was as follows. The researcher explained the study objectives to each mother and distributed questionnaires only to those who provided written consent to participate. During the research, 230 questionnaires were collected among which 8 were exclude due to unsuitability for analysis, data from 222 subjects were used in the final analysis. Eight questionnaires unfit for analysis were excluded; thus, 222 questionnaires were included in the final analysis. The number of subjects, which turned out to be 200, was thought to be satisfactory given the fact that using the setting of G*Power 3.1[13] with effect size .4, power .8 and α .05. The consent form for participation guaranteed subjects' anonymity and confidentiality and stated that participation could be discontinued at any time during questionnaire completion.

5. Data analysis

IBM SPSS Statistics for Windows, version 20.0 was used for data analysis. Descriptive statistics were used for analysis of general characteristics and PTG, and Cronbach's α was used to assess the reliability of the measurements. T-tests and analysis of variance were used to verify differences in PTG according to general and disease-related characteristics, and Scheffe's multiple comparison method was used for post-hoc testing. The correlation between distress of mothers of children with cancer and PTG was analyzed with Spearman's correlation.

RESULTS

1. Differences in PTG according to the general characteristics of the sample

The mean age of the mothers was 39.3 years, 134 (60.4%) had an edu-

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cational level of university graduate or higher, and 40 (18.0%) were employed. With regard to the burden of medical care costs, 71 and 51 mothers (32.0% and 23.0%) responded that they were 'a large burden' and 'an extremely large burden', respectively. There were no statistically significant differences in PTG according to the mothers' age, education level, employment status, or burden of medical costs.

Among respondents, 150 mothers (67.6%) were religious; 57 (25.7%) and 85 (38.3%) responded that religion was "influential" and "greatly influential", respectively. PTG was significantly higher among mothers who were religious or heavily influenced by religion than non-religious mothers (t = - 4.50, $p < .001$ and F = 17.15, $p < .001$, respectively). Among subdomains, there were differences in "change in self-perception", "increase in interpersonal depth", and "increase in spiritual interest".

Meanwhile, the mean age of the children was 8.4 years, 126 were male (56.8%), and 105 (47.3%) were the first or only child. PTG in the mothers was significantly higher for second- or later-born children, rather than first or only children (t = - 2.13, $p = .034$). Among subdomains, there were differences in "increased interpersonal depth" (t = - 2.00, $p = .047$) and "increased spiritual interest" (t = - 2.47, $p = .014$). There were no differences in PTG according to child age or sex (Table 1).

2. Differences in PTG according to patient's disease-related characteristics

The mean age of the patients at the time of diagnosis was 5.3 years, and the mean length of disease was 2.7 years. In terms of diagnosis, leukemia was most common (86 children, 38.7%), followed by brain tumors (36 children, 16.2%), and neuroblastomas (24 children, 10.8%). There were no differences in PTG according to age at the time of diagnosis, length of disease, or diagnosis.

Among patients, 82 (36.9%) completed treatment; of these, the PTG of their mothers in the domain of "change in self-perception" was higher than among mothers of patients still undergoing treatment (t = - 2.09, $p = .038$). Relapse occurred in 49 patients (22.1%), but relapse did not result in significant differences in PTG (Table 2).

Table 1. Differences in PTG according to the General Characteristics of the Mother and Patient (*N* = 222)

Variables	Categories	n (%) or M±SD	Change of self-perception		Increase of interpersonal depth		Finding new possibilities		Increase of spiritual interest		Posttraumatic growth	
			M±SD	t or F (*p*)	M±SD	t or F (*p*)	M±SD	t or F (*p*)	M±SD	t or F (*p*)	M±SD	t or F (*p*)
Age (year)	20~29	8 (3.6)	17.5±3.66	0.97	12.0±3.70	1.88	9.9±2.23	1.54	2.5±2.83	2.11	41.9±7.55	1.60
	30~39	109 (49.1)	21.0±6.10	(.406)	16.2±5.37	(.134)	11.1±2.88	(.206)	5.2±3.33	(.099)	53.5±14.33	(.192)
	40~49	90 (40.5)	21.1±5.81		15.5±5.55		10.3±2.89		5.6±3.44		52.6±14.59	
	≥50	15 (6.8)	21.5±6.31		17.3±6.60		9.9±3.67		4.9±3.29		53.5±18.05	
	M±SD	39.3±5.97										
Level of education	≤High school	88 (39.6)	21.4±5.68	1.07	16.5±5.78	1.52	10.6±2.95	-0.17	4.8±3.33	-1.60	53.4±14.72	0.61
	≥College	134 (60.4)	20.6±6.08	(.284)	15.4±5.31	(.130)	10.7±2.86	(.869)	5.5±3.40	(.112)	52.2±14.56	(.545)
Employment	Employed	40 (18.0)	21.3±5.32	-0.35	16.1±5.11	-0.26	10.1±2.98	1.461	4.9±3.62	0.73	52.3±14.44	0.21
	Not employed	182 (82.0)	20.9±6.07	(.725)	15.8±5.62	(.793)	10.8±2.86	(.145)	5.3±3.34	(.469)	52.8±14.67	(.831)
Burden of medical care costs	Not at all	15 (6.7)	24.7±5.06	2.08	17.7±6.61	1.74	11.5±3.14	0.60	5.9±3.90	0.33	59.9±16.33	1.36
	Hardly	24 (10.8)	19.9±5.86	(.084)	13.5±6.40	(.143)	10.4±3.23	(.661)	5.1±3.53	(.861)	48.8±16.44	(.249)
	Moderately	61 (27.5)	20.4±6.68		16.4±5.74		10.8±2.74		5.1±3.55		52.6±15.97	
	Very	71 (32.0)	20.6±5.99		16.0±5.08		10.7±2.93		5.5±3.36		52.8±13.59	
	Extremely	51 (23.0)	21.5±4.78		15.5±4.86		10.3±2.25		5.0±3.06		52.4±12.47	
Religion	Have	150 (67.6)	21.7±5.31	-2.40	16.4±5.23	-2.30	10.9±2.66	-1.86	6.6±2.82	-10.77	55.6±13.18	-4.50
	Not have	72 (32.4)	19.5±6.68	(.018)	14.6±5.93	(.022)	10.1±3.27	(.066)	2.4±2.58	(<.001)	46.6±15.59	(<.001)
Influence of religion	No religion or not at all[a]	80 (36.0)	19.4±6.72	5.89	14.6±5.97	4.22	10.3±3.26	3.46	2.5±2.48	130.98	46.7±15.45	17.15
	Influential[b]	57 (25.7)	20.8±5.21	(.003)	15.7±4.85	(.016)	10.3±2.76	(.066)	4.8±2.30	(<.001)	51.6±12.25	(<.001)
	Greatly influential[c]	85 (38.3)	22.5±5.21	a<c	17.1±5.29	a<c	11.3±2.51		8.2±2.10	a<b<c	59.1±12.67	a<c
Child's age (year)	0~2	36 (16.2)	21.4±5.34	0.17	17.1±5.34	0.77	11.3±3.12	2.29	4.8±3.25	1.06	54.6±14.00	0.33
	3~6	58 (26.1)	20.6±5.72	(.953)	15.8±5.22	(.547)	10.4±2.93	(.061)	5.0±3.39	(.376)	51.9±14.18	(.858)
	7~12	67 (30.2)	20.7±6.39		15.1±5.62		11.1±2.32		5.9±3.21		52.8±14.36	
	13~17	51 (23.0)	21.3±6.14		16.0±5.75		10.2±3.07		5.1±3.69		52.8±15.70	
	≥18	10 (4.5)	21.0±5.93		15.3±6.17		8.8±3.58		4.3±3.30		49.3±17.00	
	M±SD	8.4±5.42										
Child's gender	Male	126 (56.8)	21.5±6.03	1.63	16.3±5.68	1.57	11.0±2.75	2.26	5.4±3.41	0.97	54.3±14.55	1.93
	Female	96 (43.2)	20.2±5.73	(.104)	15.2±5.26	(.117)	10.2±3.01	(.025)	5.0±3.35	(.334)	50.5±14.46	(.055)
Child's birth order	1st or only child	105 (47.3)	20.4±6.13	-1.36	15.1±5.52	-2.00	10.4±2.90	-1.24	4.7±3.21	-2.47	50.5±14.53	-2.13
	≥2nd	117 (52.7)	21.5±5.71	(.176)	16.5±5.44	(.047)	10.9±2.87	(.217)	5.8±3.46	(.014)	54.7±14.44	(.034)

3. Differences in PTG according to mothers' distress and perceptions of growth

On average, the mothers' distress at the time of diagnosis was 6.7 points (on a scale of 1~7 points), and 221 mothers (99.5%) reported feeling higher than ordinary distress (≥4 points). The average current distress scored 4.5 points (on a scale of 1~7 points), and 170 mothers (76.6%) reported feeling higher than ordinary distress. There were no differences in PTG according to distress at the time of the diagnosis. However, when lower current distress was associated with higher PTG (r=-.137, p=.041). Forty mothers (18.0%) showed no decrease in distress, and there was no difference in PTG according to the decrease in distress.

The majority of subjects (97.3%) reported PTG, which occurred an average of 8.2 months after diagnosis. However, there were no differences in the extent of PTG depending on whether PTG was reported and the time that PTG started (Table 3).

Table 2. Differences in PTG according to Patient Disease-Related Characteristics (*N*=222)

Variables	Categories	n (%) or M±SD	Posttraumatic growth	
			M±SD	t or F (*p*)
Child's age at diagnosis (year)	0~2	85 (38.3)	53.1±14.81	0.04
	3~6	56 (25.2)	52.2±14.21	(.988)
	7~12	63 (28.4)	52.7±14.96	
	13~17	18 (8.1)	52.4±14.70	
	M±SD	5.3±4.60		
Duration of illness (year)	3 month~1 yr	72 (32.4)	52.1±14.58	1.29
	1~3	75 (33.8)	54.7±14.44	(.275)
	3~5	47 (21.2)	49.2±14.70	
	5~10	21 (9.5)	55.6±12.63	
	>10	7 (3.1)	51.6±19.89	
	M±SD	2.7±2.8		
Child's diagnosis	Leukemia	86 (38.7)	53.7±14.30	0.56
	Brain tumor	36 (16.2)	53.3±14.88	(.728)
	Neuroblastoma	24 (10.8)	50.5±13.65	
	Malignant lymphoma	20 (9.0)	54.8±15.92	
		13 (5.9)	54.1±12.69	
	Retinoblastoma	43 (19.4)	50.1±15.68	
	Others			
Treatment	On treatment	140 (63.1)	52.4±15.04	-0.37
	Treatment terminated	82 (36.9)	53.2±13.90	(.713)
Relapse	Yes	49 (22.1)	55.2±15.26	-1.38
	No	173 (77.9)	52.0±14.37	(.171)

DISCUSSION

In the present study, as subjects scored an average 6.7, which is a severe level of distress compared to distress for various types of trauma in typical individuals (5.64~5.89 points).[14] Distress caused by a child's disease was even higher than the greatest types of distress among traumas, such as "abuse in childhood", "loss of employment", "failure to find employment", "sexual harassment or abuse", and "becoming the victim of crime" [15]. Korean parents generally have a high level of attachment to their children, and feel sorrow, compassion, and gratitude towards their children, forming a relationship based on the monistic view of parent and child as one entity.[15] Therefore, the nature of the parent-child relationship in Korean culture likely amplifies distress in mothers of children with cancer. Current distress decreased in 82% of subjects compared to distress at the time of diagnosis, consistent with a report that the level of current stress is lower than the stress at the time of an experience.[16] However, the high level of distress persisted, with 76.6% of moth-

Table 3. Differences in PTG according to Mothers' Distress and Perceptions of Growth (*N*=222)

Variables	Categories	n (%)or M±SD	Posttraumatic growth	
			M±SD	t or F or r (*p*)
Mother's distress (at diagnosis) (7-point likert scale)	Less than usual distress (≤3)	1 (0.5)	71.0	-.099*
	More than usual distress (≥4)	221 (99.5)	52.6±14.60	(.141)
	M±SD	6.7±0.76		
Mother's distress (current) (7-point likert scale)	Less than usual distress (≤3)	52 (23.4)	55.5±14.99	-.137*
	More than usual distress (≥4)	170 (76.6)	51.8±14.41	(.041)
	M±SD	4.5±1.60		
Mother's alleviation of distress	Not alleviated	40 (18.0)	49.4±17.13	-1.61
	Alleviated	182 (82.0)	53.4±13.93	(.109)
Experienced psychological growth	Yes	216 (97.3)	53.0±14.43	-1.71
	No	6 (2.7)	42.7±18.54	(.088)
The point at which psychological growth began (year)	≤1	184 (82.9)	53.1±14.49	0.87
	≥2	29 (13.1)	51.8±14.70	(.485)
	Don't know	3 (1.3)	50.5±12.02	
	Not yet	6 (2.7)	42.7±18.54	
	M±SD (month)	8.2±7.86		

*Spearman's correlation.

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ers reporting a higher than usual level of distress. It is very difficult for mothers of children with cancer to see their child in distress, and it is very distressing to know that they cannot take their place.[17] This means that, following the initial shock of diagnosis, each treatment stage brings new stresses and continued distress.

In addition, there were no differences in PTG according to distress at the time of diagnosis or the subsequent reduction in distress, consistent with the results of another study that reported no association between PTG and PTSD before and after bone marrow transplantation.[18] The lack of association between PTG and distress at the time of diagnosis suggests that PTG is determined not by the distress itself, but rather by the way individuals acknowledge and handle distress resulting from trauma. The lack of association between PTG and the reduction in distress is consistent with a previous study reporting no association between adversarial growth and variables associated with psychological distress (e.g., depression, anxiety, PTSD).[19] These findings indicate that PTG does not mean an immediate escape from distress. In the present study, although the majority of subjects (97.3%) reported growth, 76.6% still felt a higher than normal level of distress, a finding that supports the idea that stress and growth can co-exist.[20,21] Therefore, it is important to understand that distress may still be high in those who report PTG and to continue with interventions for that distress.

When PTG of mothers was measured, it is discovered that the average for each questionnaire was 3.3 (range 0~5). This result, when compared to the average of college students and ordinary persons who experienced traumatic events (2.6)[11] was found to be higher. Considering the result from aspect of child's disease, the result was higher than those for mothers of children with type 1 diabetes (2.7)[8] and similar to those of mothers of children with cancer (3.2).[8] This findings show that psychological state of mothers of children with cancer is not the same as those of people who were the subjects of traumatic events or cancer patients themselves. The fact that their children are suffering from fatal illnesses[22] differentiate them from mothers of children with other types of diseases. From the findings, it can be concluded that it is required to carry out in-depth researches for the psychological stats of the mothers.

On the other hand, because the PTGI does not suggest a cut-off threshold for PTG, when subjects were asked, in a single question whether they felt that they had grown, the majority (97.3%) responded that they had experienced growth. This level is similar to that of a previous study in which the majority of parents of pediatric cancer patients showed growth in life goals, interpersonal relationships, and self-relationships in a semi-structured interview,[7] as well as studies in which 83~100% of breast cancer patients, rape victims, and HIV/AIDS patients showed growth.[23-25] Thus, mothers of children with cancer also show PTG through adversity.

The passage of time is considered an essential element for growth,[10] but investigation of PTG according to the length of disease, which signified the passage of time since cancer diagnosis, showed no significant differences in PTG. This finding is consistent with a systematic literature review on long-term, positive and negative psychological effects in parents of pediatric cancer survivors,[26] which did not find any consistent association between time since diagnosis and coping. A previous study that investigated trauma with different characteristics revealed that long-term, repeated, interpersonal trauma such as child abuse, domestic abuse, and living as a refugee, resulted in different psychological sequelae from one-time traumas such as road traffic accidents, burglary, or rape.[27] Cancer does not end with the diagnosis, and continues to present new difficulties during the course of treatment, and therefore has different characteristics from one-time traumatic incidents. Therefore, the time following cancer diagnosis should be considered a continuous incident, which makes it difficult to observe time-dependent effects.

The lack of association between PTG and time means that the passing of time does not guarantee that growth will occur. Problems and emotions are often thought to resolve with time, hence the phrase "time heals all". However, this result suggests that the passage of time does not always result in a resolution or positive improvement. Among the subjective responses in this study, while one mother responded, "As soon as I heard the diagnosis, I thought about the positives", another said, "I still feel angry and unfairly treated, even after 10 years". In other words, the diversity of human responses to shocking incidents needs to be understood, and the idea that these problems naturally resolve with time should be avoided. The subjects' psychological state should be more carefully considered, with an understanding that even when a long time has passed since diagnosis, subjects may still be psychologically frail.

In the present study, analysis of differences in PTG according to the mother's general characteristics revealed higher PTG among religious individuals and those who were highly influenced by religion. This observation is consistent with previous studies in breast cancer survivors, unaffected individuals, and hematopoietic stem cell transplant recipients who were religious or more often engaged in religious activities showed higher PTG.[9,28] In terms of subdomains, there were differences in "change in self-perception", "increased interpersonal depth", and "increased spiritual interest", while there was no difference in "finding new

possibilities". Religious practices are reportedly useful in life-threatening situations with low personal control, such as a child's illness, but problem-based measures are more useful in controllable situations such as medicating children and alleviating adverse effects.[26] Hence, the reason that "finding new possibilities" was unrelated to religion may be because it is more closely related to control. Since religion affects other subdomains, in addition to directly related domains such as "increased spiritual interest", religion fundamentally influences systems of thought, which suggests the importance of spiritual care.

Investigation of PTG according to the patients' general characteristics revealed reduced growth in "increased interpersonal depth" among mothers whose first-born child was diagnosed with cancer. This may be because these mothers had encountered the crisis when they were still not fully accomplished in their roles as parents, and may have lacked spouse or family support. Therefore, social support, particular family support systems, must be considered when applying interventions.

The present study investigated distress and PTG in mothers of children with cancer, offering a better understanding of PTG, and a foundation to improve PTG in mothers of children with cancer. The overall results of the present are of significance because not only did the study focus on the agony and difficulties experienced by mothers of children with cancer, but it also furthered the understanding of positive aspects and provided a balanced perspective. However, it is found that the limitations are as follows. First, due to the fact that only 1 sentence was used to determine distress levels, it is rather restricted to obtain in-depth outcomes not to mention that the outcomes were difficult to be generalized. Second, since this study was conducted on mothers of children with cancer who visited the outpatient department of a single university hospital, care should be taken when generalizing the results.

CONCLUSION

The present study examined distress and PTG characteristics in mothers of children with cancer, and investigated the association between PTG and general and disease-related characteristics in mothers and patients. The results showed that a high level of distress in mothers of children with cancer, and that the passage of time did not necessarily lead to a natural reduction in distress or occurrence of PTG. Based on these findings, the psychological state of subjects should be closely observed not only initially, but long after, and appropriate interventions should be applied. Nursing care to reduce distress and interventions to improve PTG needs to be performed continually, irrespective of the time since diagnosis.

In addition, among the general and disease-related characteristics of mothers and patients, religious status and the influence of religion affected the majority of PTG subdomains, highlighting the need for an environment and conditions that can provide appropriate spiritual care. Nurses are typically thought to fulfill an important role of improving PTG and caring for mothers of children with cancer, based on the nurses' understanding of the mothers' psychological states.

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