Original Article



Anxiety, Depression and Health Profile in Mothers with Children in the Pediatric Intensive Care Unit

Pediatrik Yoğun Bakım Ünitesindeki Annelerde Anksiyete, Depresyon ve Sağlık Profili

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ABSTRACT

Objective: The aim of this study was to investigate, anxiety, depression and health profile among mothers of patients at pediatric intensive care unit (PICU) and pediatric inpatient service (PIS).

Methods: The sample consisted of a total of 40 mothers, including mothers with children in a PICU (group I) and PIS (group II). The mothers' quality of life was measured with the Nottingham Health Profile (NHP), anxiety was measured with the State- Trait Anxiety Inventory (STAI), and depression levels were measured with the Beck Depression Inventory (Beck-D) for the all mothers.

Results: The mean age of the mothers was 31.5 years for group I and 31.25 years for group II. The mean total NHP score of the mothers was 279.0 for group I and 113.33 for group II. The mean total STAI-S score of mothers was 37.1 for group I and 36.65 for group II. The mean total of STAI-T score of mothers was 46.9 for group I and 47.75 for group II. The mean total Beck-D score was 39.7 for group I and 18.5 for group II. There was a statistically significant differences in the levels of anxiety, depression and health profile between the mothers with children in the PICU and those with children in the PIS (p<0.001).

Conclusion: This study showed that having a critically ill child at a PICU unit has negative 17 effect on mothers' depression levels, state anxiety levels and health profile.

Keywords: Critical illness, health profile, intensive care, parents, stress

ÖΖ

Amaç: Bu çalışmanın amacı, pediatrik yoğun bakım ünitesinde (PYBÜ) ve pediyatrik yatılı servisteki (PYS) hastaların anneleri arasında anksiyete, depresyon ve sağlık profilini araştırmaktır.

Yöntemler: Örneklem, PYBÜ (grup I) ve PYS'de (grup II) çocuğu olan anneler dahil olmak üzere toplam 40 anneden oluşmuştur. Annelerin yaşam kalitesi Nottingham Sağlık Profili (NHP) ile, anksiyete Durum-Sürekli Kaygı Envanteri (STAI) ile, depresyon düzeyleri ise tüm anneler için Beck Depresyon Envanteri (Beck-D) ile ölçülmüştür.

Bulgular: Annelerin yaş ortalaması grup I için 31,5, grup II için 31,25 idi. Annelerinortalama toplam NHP skoru grup I için 279,0, grup II için 113,33 idi. Annelerin ortalama

toplam STAI-S skoru grup I için 37,1 ve grup II için 36,65 idi. Ortalama STAI-T puanortalaması, grup I için 46,9, grup II için 47,75 idi. Ortalama Beck-D skoru grup I için 39,7, grup II için 18,5 idi. PICU'lu çocukları olan anneler ile PIS'li çocukları olan anksiyete, depresyon ve sağlık profili düzeyleri arasında istatistiksel olarak anlamlı bir fark vardı (p<0,001).

Sonuç: Bu çalışma, PYBÜ'de kritik hasta bir çocuğa sahip olmanın annelerin depresyon düzeyleri, durumluk kaygı düzeyleri ve sağlık profili üzerinde olumsuz etkisi olduğunu göstermiştir.

Anahtar Sözcükler: Kritik hastalık, sağlık profili, yoğun bakım, ebeveyn, stres

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Introduction

Acceptance of the child to the pediatric intensive care unit (PICU) is among one of the most stressful parenting experiences. Families of children with chronic or severe illnesses sometimes face difficulties that have never been considered before. The result for the child is unknown, procedures and treatments may be invasive and uncomfortable for the patient, and the environment may include tensions that may affect the level of stress of the parents (1).Intensive care units are a complex and stressful environment for patients. It may also haveimportant physical, cognitive, psychological and functional consequences for patient relatives. Various treatment and care methods are applied by multidisciplinary staff for the patients that have an acute-chronic disease or disease predicted to develop (2). Hospitalization of a family member in critical care units causes overwhelming stress and distress (3).

PICU support children who are admitted with life-threatening medical conditions, as well as being intended for treating children with traumatic, surgical, internal, acute and chronic pediatric diseases with mostly complex approaches. Innovations in pediatric surgery, hematology/oncology and state-of-theart advanced life support techniques have expandedtreatment options for critically ill infants and children. Mortality rates in childhood critical illness and injury have plummeted, and death rates in PICUs are uniformly low even fortertiary units at 1.5% to 8% (4). Additionally, since the technological environment, equipment and operation at the PICU are different from the other departments of hospitals, being treated at the PICU is a very troubling and stressful experience for both patients and their parents (5). Dramatic oscillations in the orbit of the disease may vary both to deterioration and recovery. This is a source of distress not only for the child in PICU but for the whole family (6).

A disease of the child causes important changes in the life of a family. Accordingly, everything will become different in comparison to before the child's disease, the life of the family will change completely, material costs will increase, and spiritual losses will be experienced. The sick child, the parents, siblings, even close relatives will be affected negatively because of stress created by illness and treatment.

Mothers get under stress for their children due to the uncertain results of short- or long-term conditions and possibilities like disability and death. Having a sick child increases the anxietyof mothers whether children are at the PICU or the inpatient hospital service.

Moreover, desperation of not being able to intervene in case of need increases anxiety and stress (7). Images that come from monitors, alarms of machines and different types of equipment, thesound of the staff, bright lights, smells, insomnia, witnessing the invasive interventions ontheir own children or other children constitute sources of stress for people who fall under the responsibility of looking after patients (8). It is shown in studies that lack of daylight, usingtechnologically complex machines, visiting at fixed times or being completely forbidden fromvisiting at certain hours cause stress and anxiety for patients and their families at these units (9). Depression is among the many psychological disorders that occur in all societies, and it may depend on many reasons. It is clear that a child's health status will affect the psychological well-being and quality of life of the family. Family members want to support, comfort, get close to and have the feeling of touching the patient as in normal times. Similarly, the patients that are at ICU need to be supported by their family members (10).

The purpose of our study was to evaluate the anxiety, depression and health profile among mothers at PICUs and PIS.

Methods

Study Design and Setting

This cross-sectional, single-center study was conducted with mothers of children who were hospitalized at Children's Health and Diseases Departments.

Subjects

The sample consisted of 40 children and their mothers. The children were recruited consecutively from amongst the patients who were hospitalized at the pediatric intensive care unit or the pediatric inpatient service at first time within the 6-month period from July 2016 to October 2016.

The inclusion criteria for mothers were as follows: hospitalized a child at PICU or PIS (Children's Health and Diseases Department); staying in PICU and PIS minimum 24 hours-3 months at first time; smaller than 12 years old for the children; absence of a severe or chronic medical condition (i.e., diabetes mellitus, musculoskeletal disorders); absence of a patient or a disabled person for whom the mother is responsible; absence of an application to an patient and/or outpatient clinic for kind of medical support within the last 3-months period prior to the study, being an adult and volunteering to participate in the study. Mothers of children who had cognitive or mental impairment as reported in their medical history and chronic psychobiological disorders were excluded. Group I (n=20) was defined as the mothers of children at the PICU, and the mothers of children at the pediatric inpatient service was in group II (n=20). The characteristics of the mothers and their children are listed in Table 1.

Approval of the local Ethics Committee was obtained for this study. Clinical Research Ethics committee decision no:1/15-24.06.2016. Written informed consent was obtained from each participant. The study was conducted in accordance with the principles of the Declaration of Helsinki.

Data Collection

Data including age, sex, gestation week, birth type, birth weight, height and weight, diagnosis and time of diagnosis, frequency of hospitalization, cost of treatment, accompanying diseases, presence of intubation, surgeries, medication and doses, analgesics use, time of hospitalization, nutrition type of the children were collected and recorded in the Child Clinical Data Form. Data including age, number of live and dead births, the age of becoming a mother for the first time, duration of education, working situation, previous psychiatric treatments and previous traumatic events, presence of disease of the mothers, financial situation of the families, the parents' expectation for the future of the child and daily hours of care were also collected and recorded in the Parent Clinical Data Form.

The risk of depression and depressive symptoms were assessed in the subject using the BeckDepression Inventory (Beck-D). It is a very reliable and well-validated scale that is easy to apply (11,12). This self-assessment scale that was developed by Beck as a 4-point Likert-type to measure pessimism, sense of failure, lack of satisfaction, feelings of guilt, restlessness, depressive symptoms such as fatigue, appetite, indecision, sleep disturbance, social withdrawal is made of 21 items. Each item has a 4-point scale self-assessment scoring whichidentifies depressive symptoms. The total score is between 0 points and 63 points.

The State-Trait Anxiety Inventory (STAI) is a 40-item inventory that is used to measurelevels of state and trait anxiety (13,14). The questionnaire has two parts: the SATI-S (20 questions) score, which provides the level of state anxiety at the time of completing theinventory, and the STAI-T (20 questions) score, which measures the inherent trait anxiety level of the subjects. There are four options for each expression in the STAI. These are; Not at all (1), Somewhat (2), Moderately so (3) and Very much so (4). In the inventory, the items 1, 2, 5, 8, 10, 11, 15, 16, 19

Table 1. Participant characteristics (n=40) participants 373							
	Group I (n=20)	Mean ± SD or n (%) Group II (n=20)					
Maternal characteristics	Maternal characteristics						
Age at delivery (years)	31.5±3.76	31.25±4.86					
Educational level	ducational level						
Primary school	5 (25)	14 (70)					
High school	14 (70)	4 (20)					
University	1 (5)	2 (10)					
Employed	5 (25)	2 (10)					
Housewife	15 (75)	18 (90)					
Infant characteristics	fant characteristics						
Gender	ender						
Boys	8 (40)	10 (50)					
Girls	12 (60)	10 (50)					
Birthweight (g)	3002.7±405.3	3113.67±259.1					
Diagnosis							
Neurologic disorders	5 (25)	5 (25)					
Surgery	6 (30)	5 (25)					
Respiratory failure	9 (45)	10 (50)					
SD: Standard deviation							

and 20 are the items that are inversely scored. In the assessment, the state anxiety point is calculated by extracting the result from the total point of direct assessments to opposite expressions and adding 50 points. There are responses as Never (1), Seldom (2), Often (3), Always (4) in the Trait Anxiety Scale. In this section, the inverselyscored expressions are the 21, 26, 27, 30, 33, 36 and 39th items. The trait anxiety point is calculated extracting the result from total point of direct assessments and adding 35 points. Both levels of anxiety are intended to be determined because state anxiety level rises in people who have a high level of anxiety. In general, if the scores of state and trait anxiety levels are high, the general anxiety level is high, and a person who has 60 points or more, they should receive professional help.

The Nottingham Health Profile (NHP) that was developed by Hunt and McEwen is used to determine the relationship between health problems and common daily activities (15). The validity and reliability of the Turkish version of NHP have been well established through scientific adaptation procedures (16). This survey includes 38 items and assesses 6 dimensions about life status like energy (3 items), pain (8 items), emotional reactions (9 items), sleep (5 items), social isolation (5 items) and physical activities (8 items). The questions are answered by Yes/ No statements. Each section is scored between 0 and 100. Ascore of 0 is the best possible health status, and a score of 100 is the worst possible health status. In this study, the sub-scores and total scores of NHP were assessed. The total score was obtained by combining the sub-scores of NHP.

Questionnaires, which took approximately 30 minutes to complete, were given to the participants by the same researcher, in a private room at the hospital in face-to-faceinterviews.

Statistical Analysis

Statistical analysis was carried out by using the SPSS software (version 21; the Statistical Package for the Social Sciences, Chicago, IL, USA). Descriptive characteristics are presented as mean ± standard deviation or n (%). Student's t-test and Kruskal-Wallis test were used to test the differences in the BECK-D, STAI and NHP scores between the two groups. The anxiety, depression and health profile measurements of the mothers of children in different disease groups were compared with one-way analysis of variance (ANOVA) in independent groups. The level of statistical significance was accepted as p<0.05.

Results

The mean age of mothers in the sample (n=40) was 31.37 ± 4.31 years. The proportions ofprimary school, high school and university graduates were 47.5%, 45% and 7.5%, respectively. The mean age of the mothers in group I (n=20) was 31.5 ± 3.76 years (Table 1). Among the mothers in this group, 25% were employed, and 75% were housewives. The proportions of primary school, high school and university graduates were 25%, 70% and 5%, respectively. The mean age of the mothers in group II (n=20) was 31.25 ± 4.86 years. Among mothers in this group, 10% were employed, and 90% were housewives. The proportions of primary school, high school and university graduates were 25%.

graduates were 70%, 20% and 10%, respectively. There was a significant difference in the educational statuses between the groups (p=0.01), but there was no significant difference between the groups regarding the mothers' age (p=0.84) or occupational status (p=0.21). There was no statistically significant difference in the demographic characteristics of the mothers in the two groups (p>0.05). The children at the PICU were diagnosed with 5 (25%) neurological diseases, 6 (30%) postoperative surgeries and 9 (45%) respiratory failures, and they all received mechanical ventilator support. Children who were hospitalized included 5 (25%) with neurological diseases, 5 (25%) with postoperative surgery and 10 (50%) with respiratory failure. 1

Among the Beck-D Total Scores the mothers in group I, the minimum score was 18, the maximum score was 56, and the mean score was 39.7 ± 9.71 . The minimum score in the mothers of group II was 5, maximum score was 31 and the mean was 18.5 ± 7.94 (Table 2). There was a statistically significant difference between the groups (p<0.001).

The mothers' state/trait anxiety scores are shown in Table 2. The mothers in Group I had significantly higher STAI-S scores than those in group II (36.5 v 31.3; p=0.001). Their mean STAI-T scores were 47.75 and 46.9, respectively. There were no significant differences between the groups in terms of their STAI-T anxiety scores (p=0.461).

Table 2. The Mean Values For Beck Depression Inventory and STAI Form Scores in Group I 398 and Group II (n=40 participants)

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	Group I (n=20)	Group II (n=20)	р		
	Mean ± SD	Mean ± SD			
BECK-D	39.7±9.71	18.5±7.94	0.001		
STAI-S	36.5±3.48	31.3±4.6	0.001		
STAI-T	47.75±4.07	46.9±6.01	0.461		

BECK-D: Beck Depression Inventory Total score, STAI-S: The Anxiety Inventory-State, STAI-T: The State-Trait Anxiety Inventory-Trait, SD: Standard deviation

Table 3. The Mean Values For Nottingham Health Profile
Subscale Scores in Group I and 415 Group II

	Group I (n=20)	Group II (n=20)	Р				
	Mean ± SD	Mean ± SD					
Nottingham health profile							
Nel	74.12±29.8	27.5±34.88	0.001				
Np	21.65±24.9	9.99±22.5	0.30				
Ner	75.2±23.8	36.16±28.39	0.001				
Ns	34.7±26.9	15.6±22.9	0.008				
Nsi	58.5±24.9	19.14±21.9	0.001				
Npa	14.7±15.8	4.8±9.12	0.076				
Nottingham total	279.0±83.1	113.33±76.97	0.001				

Nel: Energy level, Np: Pain, Ner: Emotional reaction, Ns: Sleep, Nsi: Social isolation, Npa: Physical activity, SD: Standard deviation

The NHP scores of mothers are shown in Table 3. There were highly significant differences in the energy level, emotional reactions, sleep, social isolation and total scores of NHP between the groups (p<0.001). Group I had worse health profile. PICU group of children were divided into three subgroups as neurological (n=5), surgical (n=6) and respiratory failure (n=9)patients. When the anxiety, depression and quality of life levels of the mothers of children in different disease groups were compared, there was no statistically significant differenceamong the disease groups in terms of anxiety, depression or health profile levels (p>0.05). The children at the PIS were divided into three subgroups as neurological (n=5), surgical (n=5) and respiratory failure (n=10) groups for reasons of hospitalization. When the anxiety, depression and health profile measurements of the mothers of children in different disease groups were compared in independent groups, no statistically significant difference was found among the disease groups in terms of anxiety, depression or health profile (p>0.05).

Discussion

The results of this study showed that having a critically ill child at PICU has negative effect on mothers' depression levels, state anxiety levels and health profile status.

In particular, parents at PICU experience traumatic and negative emotions in a wide range. This is because they usually must make complex decisions about the critical illness of their children. These decisions could include some big and important operations and surgical procedures like brain operations, tracheostomy and gastrostomy intubation. Although these invasive operations are life-saving for children, they may cause depression, anxiety, social isolation and anger in their lives (3). Parents experience the stress of having a sick or injured child at the PICU, and they must be provided with continuous information so that they can absorb and process information (17). Carlson et al. (18) stated that frequent visits of the family members to the intensive care unit could provide more information about the medical condition of the patient, the families are more comfortable in dealing with the stress of their situation, and the communication with the medical team is easier. In this study, the primary caregivers were mothers, and although the anxiety and depression levels of the mothers were affected, the fact that they accompanied their children for 16 hours to participate in the nursing process and that medical information was accessed more frequently increased the adaptation of the mothers to the process. It facilitated their acceptance of the disease. Thus, they might need support and encouragement.

In addition to the severity of the status and disease variables, parental anxiety increased, and quality of life was reduced. A worried parent is more likely to perceive a higher risk for his child and misinterpret information about his child's condition. In a study with parents of children admitted to PICU, parents had a high level of anxiety within the first 24 hours (19). The authors hypothesized that higher parental anxiety would affect medical information 2adversely. The initial concern after being admitted to the PICU is usually reduced over time, which makes it easier for parents to be informed (20). Mothers' anxiety levels, family dynamics and hospitalizations of the child may be affected by factors other than children's

illnesses. In our study, the reason that the mothers had more trait anxiety scores at the PICU than those who were at the PIS may be the anxiety that their children may change momentarily at the intensive care unit.

In our study, the reason why mothers at the PICU had higher state anxiety scores than thechildren at the PIS might be that the mothers of these children were concerned that their children's condition may change fast at the intensive care unit. Actually, the mothers were staying with their children for about 16 hours. Medical staff provided information continuously. We believe that this anxiety depends on the condition of the child and their dependence on the mechanical ventilator.

Parents may need to apply for support by others like physicians, other children's healthcareteams or other family members. Emotional overload and reactions could be reasons for this guidance. Parents who are worried about their children have to be informed in an appropriate and clear manner, to provide them with support and specific advice (21). Similarly, in ourstudy, the Nsi (social isolation) NHP score was higher than in Group I than Group II.Moreover, Group I had significantly higher scores of NSP than those in Group II (emotional reactions). We believe that this is due to the fact that these children's situation is more critical like the environment they are in.

Studies on children at PICUs usually focused on diseases and patient care, and the parent side has been relatively neglected. Our literature review revealed a limited number of studies that examined the quality of life mothers of children at PICUs.

According to the report published by WHO in 2004 on prevention of mental problems, stressful life events, physical discomfort and disruption of family order affect mental health risk factors. If these conditions persist for a long time, problems such as risk of cardiovascular disease and cancer increase (22). In our study, we believe that Group I had higher NHP Nel (energy) and Np (pain) scores than Group II, and these mothers felt more tired, which may cause some physical disturbances in the longrun. Although the N (p) scores were high in bothgroups, there was no significant difference between the groups. We believe that the physical conditions and care load of the mothers should be reviewed. Accompanying times may beshared with other family members. Recommendations may be made to attendants aboutprotection of their posture and musculoskeletal systems while putting the child on their lap, breastfeeding and sitting.

There are many studies in the literature that measured the quality of life of parents in negative situations. In 2010, Yılmaz et al. (23) carried out a study with 40 children with diagnoses of neuromuscular diseases. The health related quality of life levels of the mothers were assessed with the Turkish version of the NHP and Beck-D, while the Wee-Functional Independence Measure (Wee-FIM) was used to determine of functional independence levels of the children. They found that the functional levels of

children affect the quality life of mothers. There was a moderate correlation between the total NHP scores of the mothers and the total FIM score and sphincter control of the child, while it was weakly correlated with the locomotion of the child (p<0.001). In any case of illness of children, including neuromuscular diseases, cancer and cerebral palsy, the illness was found to negatively impact maternal health related quality of life. In 2015, Erdogan et al. (24) applied Beck-D to the parents of 25 children in at a PICU to assess the depression levels of parents, compare these levels based on whether there is a difference between mothers and fathers. The depression rates were significantly higher in both the mother and father of the children at the PICU than those in the normal population. The study revealed the necessity of providing psychological counseling and psychiatric support to the parents of children. Adanir et al. (25) investigated the psychopathology in pediatric BMT (bone marrow transplantation) survivors and their mothers in comparison to healthy controls in 2017. The researchers used the Symptom Checklist-90-Revised (SCL-90-R) tool to assess psychopathology in mothers. Accordingly, clinicians should be aware of psychiatric symptoms or disease of the mothers whose children were operated or have experienced life- threatening conditions. Moreover, psychosocial support with medical treatment is very important.

Limitations of this study include its small sample size and assessment of only mothers. Additionally, the single-center methodology is another limitation of this study. Despite limitations, these findings suggest that mothers who have a child at PICU may have more stress, anxiety, depression, and so, low health profile.

Conclusion

The PICU should include managing not only a sick or injured child, but also the problems of the rest of the family members. In addition to the technical aspects of care, emotional support is also needed. Future research should not only focus on critically ill children at PICUs but also psychological support for their mothers. Healthcare professionals should consider and be aware of the psychological status and the health profile of the mothers.

Ethics

Ethics Committee Approval: Approval of the local Ethics Committee was obtained for this study. Clinical Research Ethics committee decision no:1/15-24.06.2016.

Informed Consent: Written informed consent was obtained from each participant.

Peer-review: Internally peer reviewed.

Authorship Contributions

Concept: B.Ç., A.K., Design: B.Ç., A.K., Data Collection or Processing: B.Ç., A.K., Analysis or Interpretation: B.Ç., A.K., Literature Search: B.Ç., A.K., Writing: B.Ç., A.K.

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